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**UNDERSTANDING ADOLESCENT ADJUSTMENT TO
MATERNAL CANCER:
A STUDY OF PERSONAL EXPERIENCES AND PSYCHOSOCIAL
FACTORS THAT PROMOTE ADJUSTMENT.**

**Leonor Rodríguez
BA, M.Psych.Sc**

Thesis submitted to the National University of Ireland Galway, in fulfilment
of the requirements for the Degree of Doctor in Philosophy (Psychology)

School of Psychology
National University of Ireland Galway



Primary Supervisor: Dr. AnnMarie Groarke, School of Psychology,
National University of Ireland, Galway

Co-Supervisor: Professor Pat Dolan. Child and Family Research Centre,
National University of Ireland, Galway

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Dedicated to all of those whose life has been changed by cancer ...

*When you're weary, feeling small
When tears are in your eyes, I'll dry them all
I'm on your side when times get rough
And friends just can't be found
Like a bridge over troubled water
I will lay me down
When you're down and out
When you're on the street
When evening falls so hard
I will comfort you
I'll take your part when darkness comes
And pain is all around
Like a bridge over troubled water
I will lay me down
Simon and Garfunkel- Bridge over Troubled Water*

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ABSTRACT

Parental cancer is a stressful situation that can have a strong impact on adolescents lives (Su & Ryan-Wenger, 2007; Giesbers et al., 2010; Sieh et al., 2010; Helseth & Ulfsaet, 2003).

Objectives

The objectives of this research were to (a) explore the subjective experience of adolescents' psychological adjustment to maternal cancer with particular focus on perceived social support (b) explore mothers' perceptions of their adolescent's adjustment to maternal cancer (c) design and pilot an online intervention to enhance adolescent adjustment to maternal cancer (e) examine the role and relative impact of perceived stress, coping, perceived social support, maternal attachment and self -efficacy on adolescent adjustment (mood and wellbeing) (f) explore the mediating and moderating effects of social support in the relationship between perceived stress, coping and adjustment.

Method

Participants in this study were 40 male and female adolescents (mean age =16.78) whose mothers had been diagnosed with cancer within the previous two years. A subsample of these (N=14) and a group of 10 mothers with cancer (mean age = 48) completed semistructured interviews. All Adolescents completed an online survey assessing perceived stress, coping, perceived social support, attachment, self-efficacy, positive affect, negative affect, satisfaction with life, anxiety and depression. A Pilot study examined the usefulness of an eight week online life skills programme designed to enhance adjustment in adolescents (N= 14).

The study has a mixed method approach; specifically a fully mixed concurrent equal status design. The qualitative phases consisted of three studies: Meta-ethnography, Thematic Analysis and Interpretative Phenomenological Analysis. The quantitative phase included a multivariate analysis of predictors of adolescent adjustment and the design and piloting of the eight week life skills programme for adolescents.

Results

The meta-ethnography identified three themes: (i)An individual journey from diagnosis to the future, (ii) My family and me: Our shared

experience and (iii) Coping and dealing with the unexpected. The thematic analysis of adolescent interviews identified three themes: (i)The challenge of maternal cancer, (ii)building back my broken world and (iii) my vision of the future. The Interpretative Phenomenological analysis reported two themes: (i)Becoming my mother's mum and (ii) A family experience. The analysis of maternal interviews revealed two themes: (i) Facing the fear of the unexpected and (ii) I wanted to be a good mother, no matter what. The quantitative analysis described the impact of individual differences in adolescent adjustment. Perceived stress and coping explained 23 % of variance in positive affect ($\beta=-0.31$, $p<0.05$), ($\beta=0.44$, $p<0.05$), 21% of variance in negative affect ($\beta=0.44$, $p<0.05$) and 14% of variance in life satisfaction ($\beta=-0.4$, $p>0.05$), ($\beta=0.2$, $p>0.05$). Perceived social support and attachment explained 14% of variance in life satisfaction ($\beta=0.33$, $p<0.05$). Perceived self-efficacy explained 6% ($\beta=0.31$, $p<0.05$) of variance in life satisfaction and 12% of variance in positive affect ($\beta=0.41$, $p<0.05$).The study identified a moderating effect of perceived social support in the relationship between perceived stress and positive affect.

The AMC Programme improved adolescent knowledge, coping skills and social supports.

Conclusions

Adjustment needs to be understood as a process rather than as an outcome since maternal cancer is a succession of phases that impose different demands on adolescents. Factual information about cancer and to normalize their emotions.were the main needs of Adolescents

Adjustment needs to be approached in a holistic manner to understand the influence of environmental factors in adolescent's experiences particularly family structure and characteristics.

Individual differences in perceived stress, coping skills, social support, attachment and self efficacy can have an impact on adolescents adjustment experiences and adolescents with higher levels of social support experience more positive outcomes.

Adolescent experiences are influenced by developmental factors, that is age, and gender and this should be taken into consideration when examining the needs of adolescents who experience maternal cancer.

Generally adolescents can identify positive experiences from what is a very difficult experience in their lives.

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GENERAL INTRODUCTION

ADOLESCENT ADJUSTMENT TO MATERNAL CANCER

The World Health Organisation (2015) determined that cancer is among the leading causes of morbidity and mortality around the world, in 2012 there were 14 million new cases and 8.2 million cancer related deaths. The National Cancer Registry of Ireland (2015) reported that there were 9312 new cases of female cancers per year, of which 44% were deceased. The most common types of female cancers were breast cancer (30.2%), colorectal (11.2%) and lung cancer (10.4%). According to the World Health Organisation (2013) breast cancer is among the ten most common causes of death in women worldwide.

Many of the women diagnosed with cancer are mothers. Parental cancer is a stressful situation as there may be changes in the parent- child interaction as well as the threat of possible parental death due to the disease (Su & Ryan-Wenger, 2007). Adolescents dealing with parental cancer have shown more psychosocial problems than those who have healthy parents (Giesbers et al., 2010). They may have to face more caregiver tasks while dealing with their own developmental needs such as identity formation and puberty (Sieh et al., 2010).

Helseth and Ulfsaet (2003) examined the effect of having a parent with cancer on the well-being of their children. Children's strategies to maintain well-being were sufficient to a certain point, if the load became too heavy well-being decreased.

Pedersen and Revenson (2005) identified that adolescents can turn a negative event into a way of enhancing their skills and psychological resources. Individual and contextual characteristics will determine if a challenging experience such as parental disease becomes an opportunity for growth or not, social support may be one of these contextual factors.

Adolescent adjustment to maternal cancer can determine the impact of this experience on adolescent well-being. Adjustment is a complex concept. In this study adjustment has been operationalized as life satisfaction and mood (depression, anxiety, positive affect and negative affect) (Nelson & While, 2002). Previous research has suggested that youth

facing parental cancer have difficulties adjusting and can experience anxiety or depressed mood (Brown et al., 2007). Weinstein and Mermelstein (2007) suggest adolescence is a time of high risk for the emergence of mood disorders, mostly in girls.

Adjustment experiences can be supported or limited by individual differences in perceived stress, coping, perceived social support, maternal attachment and self-efficacy.

Stress occurs when an event or situation, or combination of them, are perceived by the adolescent as exceeding his or her ability to respond comfortably to them (Smith & Carlson, 1997). Coping refers to the behavioural and cognitive measures a person uses to tolerate or handle external and internal demands and conflicts (Visser et al., 2007). The transactional model of stress and coping (Lazarus & Folkman, 1984; 1987) suggests that combined variation in cognitive appraisal and coping responses account for individual differences in outcome to perceived stressful events. This model provides a useful theoretical framework to understand the response of adolescents faced with a major stressor in their lives.

Previous research has suggested that parental cancer can be described as a stressor in young people's lives (Hymovich, 1995; Dehlin & Reg, 2009; Issel et al., 1990; Welch et al., 1996, Leedham & Meyerowitz, 1999; Faulkner & Davey, 2002; Huzinga et al., 2005; Edwards et al., 2008). In a cancer context, Mireault and Compass (1996) assessed the short term adjustment of young people and adolescents after parental death due to cancer and suggested that the adolescent phase may be a vulnerable time to experience stress, regardless of the stressor causing it. Su and Ryan-Wenger (2007) found that children who appraised parental disease as a stressful situation may appraise it as a challenge, threat, harm or loss the latter resulting in maladaptive behaviours.

Regarding coping, Su and Ryan-Wenger (2007) determined that appraisal of the severity of the disease and perception of stress affect coping. Stressful events appraised as controllable are related to problem focused coping but emotion focused coping is related to less controllable events.. Seigffge-Krenke (1995) suggested that coping is perceived as a

dynamic process in which stress and coping are perceived as interrelated. Appraisal is important as it determines how a person copes. Appraisals are a set of judgments that are continuously changing according to the events which have an impact on a person's well-being. Hampel and Petermann (2006) carried out research with adolescents and found that perceived stress and maladaptive coping were associated with adjustment difficulties, particularly in females.

Previous research has described the impact of social support on adjustment. Haffen and Laursen (2009) conceptualized adolescent adjustment as being directly associated with social support. They consider that close relationships are crucial indicators of adjustment across the life span. Laursen and Mooney (2008) found that close relationships were also related to successful adaptation and were a marker of individual adjustment. Social support has also been linked with mood and life satisfaction (adjustment). Matsuda, Tsuda, Kim and Deng, (2014) described that support from significant others was associated with positive affect and increased life satisfaction. Ammar, Nauffal and Sbeity (2013) found that perceived social support was positively correlated with well-being. Matsuda et al. (2014) suggested that perceived social support was associated with life satisfaction through positive affect and negative affect which suggest a relationship between social support, mood and adjustment.

Social support has been identified as a moderating variable of psychological well being. Chao (2011) and Lakey and Cohen (2000) reported that social support appears to buffer the relationship between perceived stress and psychological well being. Dolan, Pinkerton and Canavan (2006) described that social support has a buffering effect when facing stress, as well as having a positive impact on people's mental health. In a cancer research context, Baron, Cutrona, Hicklin, Russell and Lubaroff (1990) tested the contribution of social support to blood based measures of immune function of individuals exposed to stressful circumstances; in this case it consisted of the treatment of their spouse for urological cancer. The study identified a positive relationship between social support and the immune function under stress. Participants with higher levels of social support had faster proliferation of cells that boost the immune system and

were more effective at destroying tumor cells compared with those that fell below the median level of social support. This finding suggests that social support can provide a powerful psychological benefit for people when under severe levels of stress (Baron et al, 1990).

The impact of parental attachment on adjustment has also been described previously. Cutrona et al. (1994) determined that a positive relationship with parents can contribute to the development of positive self perceptions in young people (e.g. self-efficacy) and beliefs that they can trust others and that others are available for them. Positive parental interactions during times of stress are likely to facilitate adjustment and adaptive coping. Lewis et al. (1993) carried out research with families experiencing maternal cancer and identified that a higher quality of exchange in the mother child relationship lead to higher child functioning. Howes, Hoke, Winterbottom and Delafield (1994) carried out a study to examine the relationship of medical and psychological factors in women with breast cancer compared to their children's psychosocial adjustment, including adolescents up to 16 years of age. They showed that emotional and behavioural problems in children were associated with their mother's psychological adjustment to disease and emotional distress. Mothers who were more distressed also reported more symptoms in their youngsters. Lewis and Darby (2003) and Nelson and While (2002) showed that in families experiencing parental cancer, children with poor adjustment were more likely to have a parent with poor adjustment.

Perceived self-efficacy (Bandura, 2006) consists of people's beliefs in their capability to achieve specific tasks. It is a judgment of a person's capability to execute specific performances. Self -efficacy has been related with adjustment in adolescent populations. Yang et al (2010) described that enhanced self -efficacy can lead to improvement in people's adjustment in the long term. Bandura (1997) explained that young people who enter their adolescence with a sense of inefficacy can experience more stress and dysfunction in their new environmental and biopsychosocial developmental demands. Luszczynska et al. (2005) identified that general self -efficacy seems to be an adaptive construct that is related with active coping strategies such as planning and having a fighting spirit, which contribute to

successful adaptation to stressful situations. Cicognani (2011) identified that adolescents with higher self- efficacy and family support tend to use better coping strategies and report higher levels of well being.

Overview of the Current Study

The current study (AMC study) provides a detailed account of the experiences of adolescents adjusting to maternal cancer. Utilising the framework of the stress-coping model (Lazarus & Folkman, 1984; 1987), the study also examines predictors of adolescent adjustment, specifically examining the role of stress and coping; social support and attachment; and self-efficacy on depression, anxiety, positive affect, negative affect and life satisfaction. The mediating and moderating role of social support in the stress, coping and adjustment relationship is also explored. An online programme to improve adolescent adjustment is developed.

The initial proposed methodology for this study was a randomized controlled trial to evaluate the efficacy of the online intervention for adolescents whose mothers were diagnosed with breast cancer. An a priori power analysis determined that 92 participants were needed but considerable recruitment challenges arose during the intervention phase of the study. Many mothers declined participation for their adolescents. The study was thus extended to adolescents whose mothers had a diagnosis of varied cancers. Recruitment continued to prove difficult, however, and so it was only possible to conduct pilot work on the intervention. Given the barriers encountered, a research objective to examine maternal views of their adolescent's adjustment was incorporated into the study.

Research objectives

1(a). Explore the subjective experience of adolescents' psychological adjustment to maternal cancer with particular focus on perceived social support.

1(b). Explore mothers' perceptions of their adolescent's adjustment to maternal cancer.

2(a). Design and pilot an online intervention to enhance adolescent adjustment to maternal cancer within two years since diagnosis.

2(b). Examine the role and relative impact of perceived stress, coping, perceived social support, maternal attachment and self-efficacy on adjustment (mood and wellbeing).

2 (c). Explore the mediating and moderating effects of social support in the relationship between perceived stress, coping and adjustment.

Chapters 1-3 provide a literature review of current research in the area. Chapter 1 provides a definition of adolescence as a developmental stage and examines the role of perceived stress, coping, perceived social support, parental attachment and self-efficacy as determinants of adjustment in the general population and specifically in adolescent populations. Chapter 2 provides an overview of cancer definitions, statistics, treatments and side effects of the illness and examines the impact of cancer on young people and their families. Chapter 3 presents a meta-ethnography specifically focused on current qualitative research findings on adolescents' adjustment to parental cancer.

Chapter 4 presents the results of data collection. The first study explored the experience of adolescents' psychological adjustment to maternal cancer, particularly identifying the circumstances that may facilitate or challenge adolescent adjustment. The study is a Thematic Analysis of semi structured interviews carried out with 15 adolescents to understand their adjustment and social support needs at the time of maternal cancer. In addition, an Interpretative Phenomenological Analysis of three purposefully selected interviews was conducted to further understand adolescent individual differences in adjustment in the context of maternal cancer (Study 1a).

Study 1 also explores mothers' perceptions of their adolescent's adjustment to maternal cancer using a Thematic Analysis of semi structured interviews carried out with 10 mothers (Study 1b).

Study 2 (a) was focused on the design and piloting of an online intervention to enhance adolescent adjustment to maternal cancer within two years since diagnosis. This is an eight session online intervention to enhance adolescent adjustment to maternal cancer (AMC Programme). In all 40 adolescents agreed to participate in the online programme and completed the baseline assessment. Only 14 of these participants completed all phases, that is the baseline assessment, intervention sessions, post-test and follow-up.

Study 2(b) includes baseline assessments for 40 participants and examines the impact of perceived stress, coping, maternal attachment, perceived social support, self-efficacy on positive affect, negative affect, life satisfaction, anxiety and depression.

Study 2(c) explores the mediating and moderating effects of social support in the relationship between perceived stress, coping and adjustment.

Chapter 5 presents the general discussion, limitations and recommendations for future research.

Mixed methods

The AMC Study has a mixed method approach; it is based on a combination of qualitative and quantitative methods that allow researchers to provide answers for particularly complex research questions (Johnson & Onwuegbuzie, 2004). Mixed methods research is defined by Muncey (2009) as a type of research which “...combines elements of qualitative and quantitative research approaches (...) for the broad purpose of breadth and depth of understanding and corroboration” (p.123).

The proposed methodology of mixed methods for the AMC Study is concurrent, this means that both qualitative and quantitative phases of the research study happened simultaneously. Therefore, the AMC Study has a convergent parallel design (Creswell & Plano Clark, 2011). This design involves concurrent timing to implement the qualitative and quantitative phases of the study, prioritising both methods equally. The mixing phase occurs at the overall interpretation of results, where findings complement each other (Muncey, 2009).

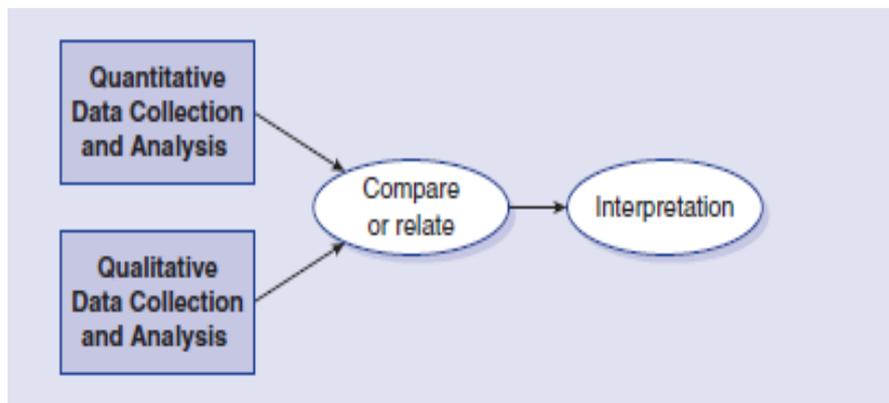


Figure. 1. Convergent parallel design (Creswell & Plano Clark, 2011).

CHAPTER 1

PSYCHOLOGICAL ADJUSTMENT IN ADOLESCENCE

Chapter 1 provides a description of the adolescent developmental stage and adolescent adjustment. It outlines research examining the the role of predictors of adolescent adjustment, specifically perceived stress, coping, perceived social support, parental attachment and self -efficacy.

Defining Adolescence

Lalor, de Roiste and Devlin (2007) defined adolescence as a “formative, transitional period from childhood to adulthood involving biological, cognitive and psychological changes that contribute to young people reappraising themselves and their relationships to their social worlds” (p.19). Adolescence may be a time of vulnerability to social and emotional problems, but most adolescents manage to adjust successfully. Adolescence is also a time of identity formation, individuation and adjustment within themselves and the expectations society has placed on them. Lalor et al. (2007) viewed adolescence as a time of energy, dynamism and potential, but also a time of uncertainty, awkwardness and searching for a place in society, as the fundamental transition from childhood to adulthood takes place.

Cicognani (2011) described adolescence as a transitional stage where young people experience physical, cognitive, psychosocial and normative (age-specific) changes that can be significant sources of stress. Most adolescents, however, have the resources to cope successfully with these demands. Adolescence is a period of successful coping and productive adaptation.

Seigffge-Krenke (1995) defined adolescence as a ‘period of transition characterized by accelerated processes of change in cognitive, social, and psychological functioning, accompanied by marked physical restructuring’ (p.1). Adolescence is a stage in which adolescents are confronted with several changes, however Seigffge-Krenke (1995) suggested that they can adapt in a constructive fashion which may lead to developmental advances.

The international definition of 'child' is a person younger than 18 years. This definition is included in the UN Convention of the Rights of the Child. The twentieth century is known as the 'era of adolescence' which evolved due to social and economic changes brought by industrialisation and capitalism in the United States and Western Europe, however this definition has been questioned over the past years.

Arnone (2014) defined adolescence as a triphasic period of rapid development and physical growth. Adolescents have three tasks in this developmental stage: identity formation, separation from authority to achieve independence and seek conformity from peers. Regarding the specific age range of adolescence, Arnone (2014) argued that there is no general consensus across disciplines but 'it seems now that twenty-five is the new eighteen' (p.48). This extension of adolescence is supported by neuroscience as it has been identified that the density of the neural connections between the amygdala and cortices which deal with emotions and cognitions, have a continued maturation and growth into adulthood (Arnone, 2014; Johnson, Blum & Giedd, 2009).

Adolescence is a complex developmental stage. It is a transitional period between childhood and adulthood that requires specific tasks to be achieved including identity formation, individuation, adjustment, and to acquire socially responsible behaviours and also values and ethical beliefs. It is also a stage of dualities where adolescents can experience energy and dynamism versus uncertainty, awkwardness, loneliness. The concepts of adjustment and adaptation were mentioned by several studies as part of the challenges of adolescence (Lalor et al, 2007; Seigffge-Krenke, 1995 and Cicognani, 2011), yet it is not clear what the psychological definition and implication of adjustment are at this developmental stage and mostly how adolescents live and experience these processes.

Defining Psychological Adjustment

Brennan (2001) explained that the term adjustment originated from the Darwinian concept of 'adaptation' which suggests that the species which is the fittest to adapt to threats in their environment are more likely to survive.

Research seems to provide different definitions of adjustment. Stanton, Revenson and Tennen (2007) described that adjustment is usually defined in research as “the presence or absence of diagnosed psychological disorder, psychological symptoms, or negative mood” (p.368). According to Stanton et al. (2007), more recently research has included positive affect and perceived personal growth as indicators of positive adjustment. Ganai and Mir (2013) defined psychological adjustment as the behavioural processes by which a person maintains equilibrium between their different needs and also between their needs and the obstacles they face in their environments. Simons, Chen, Simons, Brody and Cutrona (2006) carried out research on the impact of parenting practices on child adjustment. Their study used conduct problems as the indicator of child adjustment, as it was described as the outcome that is most commonly used in studies of family structure differences in child adjustment.

Hamburg and Adams (1967, as cited in Stanton et al., 2007) described the basic adaptive tasks that people face in the process of adjustment to life transitions as regulating distress, maintaining personal worth, restoring relations with significant others, recovery of bodily functions and bolstering a personally and socially acceptable situation. Ganai and Mir (2013) identified four components in any adjustment process: A need or motive that is a strong and persistent stimulus, the lack of fulfilment of this need, exploratory and problem solving behaviour and finally a response that removes or reduces the initial stimulus and completes the adjustment. Adjustment, therefore, seems to be a series of processes and not just a single one.

Adjustment, therefore, can be perceived as a complex concept. Stanton et al. (2007) described adjustment as a multifaceted concept that encompasses several components including interpersonal, cognitive, emotional, physical and behavioural domains. These components, however, are interrelated and influence each other. This complexity can be a challenge when measuring adjustment. Seiffge-Kremke (2000) suggested that there is no single and objective measure of adolescent emotional and behavioural problems that could be suggested as a true indicator of maladjustment. Fields and Prinz (1997) found that the variety of indices of adjustment

hindered the possibility of summarizing the findings of research studies on adjustment. This is a significant limitation for research.

Brennan (2001) explained that the concept of adjustment can be vague and misleading as research has focused on adjustment as an ‘end point’ of coping and not as a process of change happening to an individual. Adjustment should be defined as the processes that happen over time through which a person manages, learns and accommodates multiple changes caused by changing circumstances in life.

Predictors of Adjustment

The adolescent phase presents many developmental tasks and many factors influence how adolescents adjust to the challenges presented. Existing research with adults, both healthy and ill groups indicates that the availability of personal resources, such as social support and self-efficacy beliefs can impact on psychological adjustment (Curtis, Groarke & Sullivan 2014; Chao, 2011; Lakey & Cohen, 2000). In addition, consistent findings demonstrate that the manner in which stress is perceived and the type of coping used to manage it has implications for adjustment (Groarke, Curtis & Kerin, 2013; Quine & Pahl, 1991). Similar findings have been reported with adolescent samples (Aldwin, 2011; Hampel & Petermann, 2006) and positive attachment relationships with parents also relate to adjustment in this group (Cutrona, Cole, Colangelo, Assouline & Russell, 1994; Clemmens, 2009).

Perceived Stress and Adjustment

A relationship between stress and adjustment has been identified in previous research with adult and younger populations (Hampel & Petermann, 2006; Moskowitz, 2011). Aldwin (2011) described that that biological response of stress in the body happens when the body releases catecholamines including epinephrine and norepinephrine. The sympathetic nervous system arousal and the hypothalamic- pituitary- adrenocortical axis (HPA) releases corticosteroids including cortisol. Stress as a biological response system has short term protective effects as it prepares the body to meet the demands of stressful situations. On the opposite side, long term activation of these systems can have long term implications for health including suppression of cellular immune function, increase in blood

pressure, increased heart rate, ventricular arrhythmias and neurochemical alterations associated with psychiatric disorders (Aldwin, 2011).

The Transactional Model of stress (Lazarus & Folkman, 1984;1987) describes that there are individual differences in how stress is appraised. Stress arises when environmental demands, mostly those which are personally significant, exceed the person's resources to respond. Perception of stress as a threat elicits negative emotions and maladaptive coping, whereas the perception of stress as a challenge is linked with favourable emotional and coping responses. Stress arises when environmental demands, mostly those which are personally significant, exceed the person's resources to respond. Personal resources such as optimism and social support are also brought to bear in stress transactions (Ayers & Steptoe, 2007).

Quine and Pahl (1991) suggested that coping is a process by which people try to manage the discrepancy they are perceiving between the demands of the stressor and their resources. The nature of the coping strategies used depends on the coping resources available in a person's environment. According to Folkman and Lazarus (1979, cited by Quine & Pahl, 1991) there are five categories of coping resources which include utilitarian resources (socio-economic status, resources), health, energy and morale (pre existing psychiatric or physical illness), social networks (close relationships), general and specific beliefs (self-efficacy, self esteem) and problem solving skills (intellectual skills, intellectual flexibility).

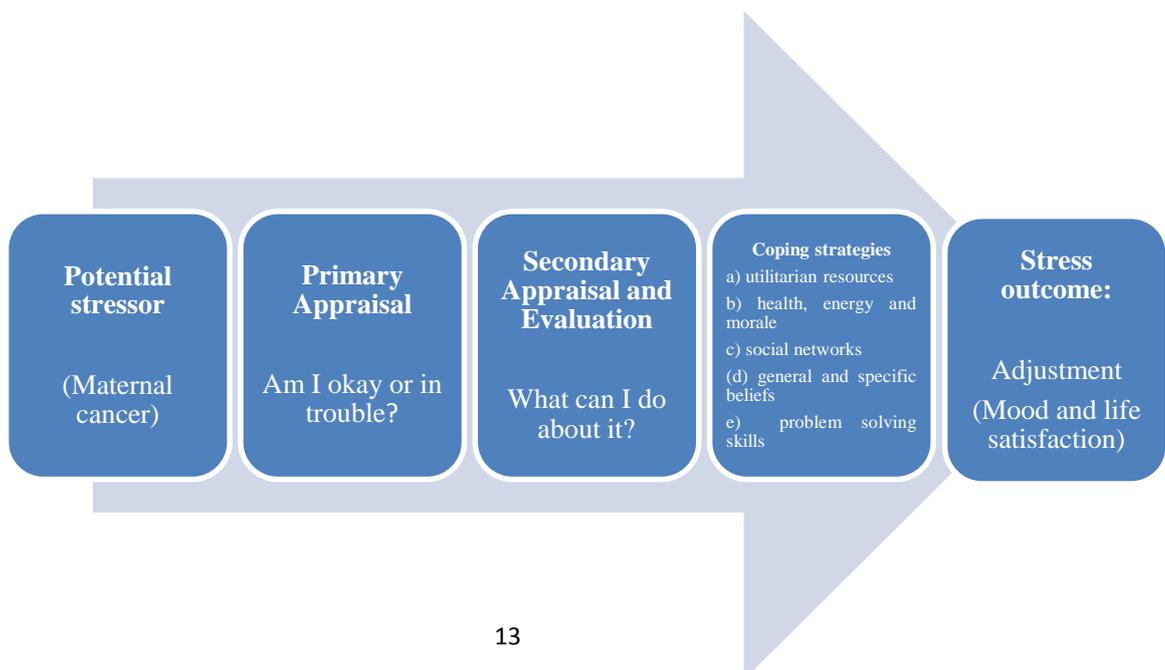


Figure 2. A model of stress and coping. Adapted from Quine and Pahl (1991)

According to Aldwin (2011) coping with stress is a process which changes over time. The initial appraisal of how stressful a situation is may change after an assessment of the coping resources available (secondary appraisal). Appraisal may include both conscious and unconscious processes. Tertiary appraisals occur after a situation has been resolved but it involves long term appraisals of the impact and meaning it had.

Moskowitz (2011) suggested that previous research has identified that stress is associated with negative emotions and this has an impact on psychological and physical health including the immune system, cardiovascular system and respiratory system. It has also been associated with higher mortality rates in people with chronic illness, depression and other forms of psychopathology.

Regarding children and young people specifically, Aldwin (2011) reported that previous research has identified a possible pattern in levels of stress and developmental stages. The number of life events tends to increase from preschool to elementary school. At age 12, however, there seems to be a sharp increase until it reaches peak at 15 and begins to decline thereafter. These developmental differences in exposure to stress vary according to the social context of the children. Older children are usually exposed to a larger variety of social situations which may mean a greater likelihood of exposure to stress.

Hampel and Petermann (2006) found in a sample of 286 adolescents between 10 and 14 years of age, that perceived stress and maladaptive coping was positively associated with adjustment problems. Girls in particular perceived a higher level of interpersonal stress and used more social support than boys. Jones, Beach and Forehand (2001) examined the role of family stress in adolescent adjustment. Family relationship stress, reported both by father and mother, was associated with depressive symptoms in adolescence. Conger, Patterson and Ge (1995) also reported a positive association between parental depression, child adjustment problems (mean age 12 years) and stressful life events. Negative mood in young

people was also associated with more irritability in this group. These findings suggest that parental stresses and strains affect child development.

Coping and Adjustment

According to Aldwin (2011) coping originated from different theoretical traditions. The original psychodynamic theory (Anna Freud) focused on defence mechanisms, defined at the time as unconscious mechanisms used by the ego to deal with the anxiety caused by conflicts between the superego and the id¹. Aldwin (2011) indicates that there is still an ongoing debate as to whether coping is a conscious and voluntary process versus an unconscious and involuntary one. Compas et al. (2001) defined coping as “conscious volitional efforts to regulate emotion, cognition, behaviour, physiology, and the environment in response to stressful events or circumstances” (p. 89). These processes are related to individual differences in biological, cognitive, social and emotional components. Coping refers to the behavioural and cognitive measures a person uses to tolerate or handle external and internal demands and conflicts (Visser, Huizinga, Hoekstr, van der Graaf & Hoekstra, 2007).

Cognitive process approaches emerged from the theory of Lazarus and Folkman (1984). In this framework coping depends on the appraisal of a situation. It includes both problem focused strategies and emotion focused strategies which a person may use to try to regulate their emotional state. Coping is a complex set of different strategies that are usually directed at different facets of a problem and may show change over time (Aldwin, 2011). Thoits (1995) described that certain types of coping may be more beneficial for improving a person’s well- being, although there seems to be no consensus on this in the literature.

Compas, Connor-Smith, Saltzman, Thomsen and Wadsworth (2001) carried out a literature review on the way in which children and adolescents cope with stress in their lives and determined that coping is associated with psychological adjustment and psychological symptoms, and that problem

¹ Id, ego and superego are structures of personality according to Psychodynamic Theories.

focused and engagement coping are associated with better adjustment. On the contrary, emotion focused coping and disengagement coping are associated with poor adjustment, however the causal role of coping in adjustment is not clear.

Aldwin (2011) described a developmental approach to coping. In the early years, self regulation is initially an interpersonal construct and then becomes an independent construct in later childhood, accompanied by an increase in cognitive emotion regulation. Problem focused coping can become increasingly complex as children learn that some coping strategies are more effective than others in specific situations. Previous research, according to Aldwin (2011), has identified that the adolescent phase may enable more complex forms of problem focused coping. Humour may also begin to be used as an important coping strategy. Parents still exert a significant influence in the type of coping strategies adolescents use, although adolescents would usually turn to siblings, romantic partners and friends for support.

Skinner and Zimmer-Gembeck (2011) suggested that during adolescence there is an increase in the use of meta-cognitive strategies to deal with challenges and failures that is, abstract instead of concrete representations, improved working memory capacity, ability to engage in multidimensional thinking and self- reflection. This allows adolescents to reflect on their own emotions, cognitive processes and actions. This has an impact on coping. They can use the information gathered in the long term and apply it to local decisions for strategies to solve problems. It also allows adolescents to imagine future emotional and social consequences of an action. Meta-cognition allows adolescents to coordinate multiple perspectives and pathways to decide on a specific issue. Adolescents are also able to construct advanced and coherent representations of others, securing sources of aid and support for them. They can access sources of support when others are not physically present, improve stress management and increase the focus of their coping actions.

Seigffge-Krenke (1995) examined adolescent coping within the stress –coping framework of Lazarus and Folkman (1984). The study evaluated generalized perceived stress in adolescence and identified that

primary appraisal (first global appraisal of events) was followed by reactions including confusion, preliminary cognitive coping efforts and action impulses. In secondary appraisal, adolescents analyzed their own coping resources, scope of action, and expectations of success and analysis of obstacles. Tertiary appraisal was associated with situational changes.

Ebata and Moos (1991) described that adolescent responses to stress are important in predicting how successfully they can adapt to challenges during adolescence. Their study compared distressed adolescents and healthy ones. The study found that adolescents who use more approach coping and less avoidant coping were better adjusted, that is adolescents who actively make an effort to change, manage or positively reappraise a situation have better long term adjustment. Those adolescents who instead engage in more avoidant coping are at a higher risk of subsequent poor adjustment. Research shows that coping can differ across age and gender in young people. Aldwin (2011) identified that boys may use more aggressive and physical activities, while girls would tend to use humour to cheer themselves. Cicognani (2011) also described that female adolescents use a wider variety of coping strategies than boys. Hampel and Peterman (2006) investigated age and gender effects on perceived interpersonal stress, coping and psychological adjustment in adolescents (10 to 14 years). The study reported that problem focused coping was associated with less adjustment problems. Emotion focused coping was also related with less adjustment problem but this relationship was stronger in females than males.

Social Support and Adjustment

Dolan and Brady (2012) defined social support as “acts we perform in order to give or get help and relates to those which reduce stress and assist coping in life” (p. 31). Social support includes words, actions and feelings that allow support, however it depends on a person’s specific problems and circumstances. Cohen, Gottlieb and Underwood (2000) defined social support as a broad concept which refers to “any process through which social relationships might promote health and well-being” (p. 4). Dolan (2003) suggested that social support is an important feature of people’s lives. It “refers to the acts we perform in order to access from or

supply other people with assistance’’ (p. 36). It also provides sustenance to overcome stress and be able to cope in life, according to Bal et al. (2003), social support has a major impact on mental health.

According to the theoretical definition of social support by Dolan and Brady (2012), tangible (concrete), emotional, advice and esteem support are the main types of social support. Concrete support or ‘tangible’ support are practical forms of help which can be measured as physical acts of helping between a young person and a member of their social network, for example a loan on a book or money or helping a friend tidy up their garage. Emotional support relates to feelings and includes intimate relationships, including ‘being there’ for people, listening to them and providing unconditional love. Advice support is also known as ‘information’ and ‘guidance’ support. It relates to helping someone to make a decision or providing them with information on how to complete a task. Esteem support is how others consider and inform a person about their worth and competency. It is the value others have of a person.

According to this same model (Dolan & Brady, 2012) social support has four main qualities: closeness, reciprocity, admonishment (non criticising) and durability. Closeness relates to the extent that an individual retains feelings of ease, comfort and familiarity with and towards members of their social network. Reciprocity is the extent to which favour provided to other people, is returned. Admonishment (non-criticising) refers to the avoidance of criticism and durability refers to the assurance that people who seek support will actually obtain it. Dolan and Brady (2012) emphasized that all qualities are needed by youth; however, some qualities may be more valuable at specific times.

Laursen and Mooney (2008) described the links between adolescent adjustment and perceived quality of parent, child and friendship relationships. They hypothesized that ‘‘close relationships are a cornerstone of successful adaptation and a reliable marker of individual adjustment’’ (p. 1). Hafen and Laursen (2009) identified an association between adjustment problems and perceived parental support for adolescents between 11 and 13 years of age in a diverse sample. Changes in adjustment problems were related with changes in parental support. Declines in support relationships

were accompanied by a decline in adolescent adjustment. Adolescent adjustment was directly associated with social support and close relationships are crucial indicators of adjustment across the life span.

Mitchell, Billings and Moos (1982) suggested that increasing support in an individual's social environments is a central focus for the prevention of pathology and a way to promote well-being. According to Mitchell et al. (1982) the impact of support on well being may occur in different ways. Social support and well-being may simultaneously be affected by other variables such as social competences, psychological impairment and stress. People who lack support and are socially isolated, however, are more likely to experience distress even if there are no other concomitant stressors.

Chu, Saucier and Hafner (2010) carried out a meta-analysis including 246 studies of the general relationship between social support and well-being in children and adolescents, and reported that perceived social support was associated to well-being. Matsuda, Tsuda, Kim and Deng (2014) in a study with university students showed that perceived social support is associated with life satisfaction directly, and indirectly through positive affect and negative affect. Perceived social support is also associated with subjective well-being (Ammar, Nauffal & Sbeity, 2013).

Greenglass and Fiksenbaum, (2009) found a reciprocal relationship between coping and social support. Social support appears to buffer the relationship between perceived stress and psychological adjustment and this moderating effect is mediated by problem focused coping (Chao, 2011; Lakey & Cohen, 2000). Self confident and optimistic people may receive more social support and may be more effective at mobilizing it when they are under stress (Greenglass & Fiksenbaum, 2009). Social support is a significant factor for the reduction of stress (Lyraeos, 2012).

Gottlieb (1987) described a relationship between coping and social support and suggested social support could be defined as "social mediated coping". Social support has a primary preventive function through ongoing feedback and anticipatory guidance. The social network helps members prevent potential stressors, engage in anticipatory coping with stressors and provides guidance in new situations. According to Hirsch (1980) people

with a helpful natural support system would adapt successfully to stressful situations. Bal, Crombez, Van Oost and Debourdeaudhuij (2003) described how social support affects coping with stressful events: the main effects hypothesis and the stress buffering hypothesis. The main effects describes that there is a direct effect of social support on mental health because social networks provide positive experiences and also provide stable and socially rewarding roles, therefore, people with higher levels of social support would feel more liked and cared for. The stress buffering hypothesis considers that social support has an indirect stress reducing effect acting as a buffer for the negative consequences of stressful events. Bal et al. (2003) investigated the role of social support on well being and coping after a stressful event in a group of non clinical adolescents. The study found evidence for the main-effect hypothesis. Adolescents that perceived low availability of family support had more behavioural and trauma specific symptoms. The buffering hypothesis was not supported but there was a trend suggesting that a higher perception of social support available from family had an influence on support seeking strategies and less avoidant coping in stressed adolescents.

Dolan and Brady (2012) suggested that social support in young people can enhance their self-efficacy and self-esteem. Social support can be a protective shield for youth at risk, as being held in positive esteem by adults and peers is crucial during adolescence. This reinforces a person's positive feelings of worth and if others believe in the skills of a young person, this may increase their chance of success.

Seiffge (2004) found that adolescents deal with stressors by seeking support from parents and friends. Friends in particular become very important. Bokhorst, Sumter and Westenberg (2009) even suggest that adolescents may rely less on their parents or family and instead their friends become increasingly important. However family and friends still make up adolescents' central helping system (Dolan, Pinkerton & Canavan, 2006). Siegler, DeLoache, Eisenberg and Saffran (2014) described that children and adolescents who are able to deal constructively with stressful situations are generally better adjusted than children who lack these skills and avoid stressful situations all together. Constructive skills include negotiating with

others to settle conflicts, planning strategies to resolve upsetting situations and seeking social support.

Dolan and McGrath, (2006) suggested that informal sources of support are key to adolescents' social networks, but they are a very important resource when helping young people facing difficulties. Social support plays a crucial role during adolescence "the importance of perceived social support during this phase of life cannot be underestimated" (Haluska, Jessee & Nagy, 2002, p.1317).

Parental Attachment and Adjustment

Armsden and Greenberg (1987) defined attachment as 'an enduring affectional bond of substantial intensity' (p.428). Attachment theory is concerned with the effects of optimal and non optimal social attachments and their impact on psychological fitness. Emotions such as anxiety, sadness, depression and anger occur at times of threat or actual loss of attachment relationships. Well adjusted people at any age are those that have the confidence in the accessibility and responsiveness of another person they trust.

Guarneri, Ponti and Tani (2010) suggested that from an attachment point of view, adolescents develop their own points of view and separate from their parents which may lead to a modification in the family balance between connectedness and autonomy. This does not mean a disruption of attachment relationships with their parents as adolescent autonomy happens in the context of secure, close and enduring relationships between adolescents and their parents.

Cutrona et al. (1994) described that the rejection of parental ties is not essential for adolescents to achieve a competent adult status; instead, those individuals that continue to have a close relationship with their parents report higher levels of self- confidence and independence. Parental support during times of stress facilitates positive adjustment and adaptive coping in adolescents (Cutrona et al., 1994). Clemmens (2009) reported that adolescents benefit from supportive and sensitive mothers because they explore their own emotions and responses from this secure attachment base; however when mothers are ill. They can be anxious or extremely tired

which would often decrease their awareness of their children's internal states. Adolescents felt misunderstood when they had to cope with the stress on their own. Armsden and Greenberg (1987) examined the affective and cognitive dimensions of attachment to parental and peer figures in undergraduate students. The study identified that adolescents with high security attachments to their parents were very well adjusted, reported higher than average self esteem and enjoyed frequent communication with their families. Those who had low security attachment style instead expressed feelings of resentment and alienation. They were also more emotionally and verbally detached from their parents, which could make them more vulnerable to deterioration in their well being.

Self-efficacy and Adjustment

Self-efficacy consists of people's beliefs in their capability to perform a specific action required to achieve a desired or specific outcome. Bandura (1997) defined perceived self-efficacy as "a judgement of one's ability to organize and execute given types of performances, whereas an outcome expectations is a judgement of the likely consequence such performances will produce" (p. 21).

Bandura (1997) described self- efficacy as a multidimensional set of belief systems which vary across level, generality and strength. Luszczynska, Scholz and Schwarzer (2005) reported that self- efficacy can be generalized or specific. General self-efficacy is a universal construct defined as "belief in one's competence to cope with a broad range of stressful or challenging demands" (p. 440). General self-efficacy may explain a broad range of behaviours and coping outcomes in less specific contexts; for example it might be useful to explain multiple behaviours, well-being in ill patients and adjusting to illness demands. Specific self-efficacy is associated to more specific tasks. Self-efficacy has been associated with people's mood (Bandura, 1997), coping (Cicognani, 2011), social support (Trouillet, Gana, Lourel & Fort, 2009) and well being (Vaezi & Fallah, 2011).

Bandura (1997) suggested that mood can provide affective information to judge personal efficacy. Mood can also have an impact on

how events are interpreted, cognitively organised and retrieved from memory. Mood bias can also influence a person's judgement of their personal efficacy (Bandura, 1997). People use perceived affective reactions to recall information that forms their evaluations; they make positive evaluations when they are feeling in a good mood and negative evaluations when they are in a bad mood. Evaluation judgements can be altered if the information provided by the affective state is also changed.

Cicognani (2011) found that higher self-efficacy positively correlates with active and internal coping and adolescents with higher self-efficacy and family support tended to use less withdrawal (as a coping strategy) and report higher levels of well being. According to Hirsch (1980) a heightened sense of self-efficacy resulting from helpful guidance received can help sustain coping behaviours.

Trouillet et al. (2009) carried out a study on how coping changes with age with a community sample between 22 and 88 years of age. The study found that higher levels of social support satisfaction predicted higher levels of self-efficacy but they did not find a relationship between self-efficacy and coping. Trouillet et al. (2009) suggested self-efficacy (as a coping strategy) is not affected by age and this may mean that self-efficacy may compensate for a decline in social support.

Bandura (1997) specified that self-efficacy follows a developmental pattern. Different developmental periods bring new competency requirements and challenges for coping efficiently. Development is related to an expansion in children's social world and young people who enter their adolescence with low self-efficacy can experience more stress and dysfunction with the new environmental and biopsychosocial demands (Bandura, 1997). Adolescents experience major educational, biological and social transitions, so adolescent self-efficacy beliefs in social and academic contexts can have an impact on their well-being and development. (Bandura,1997).

Previous research with adolescents has described the long term impact of self-efficacy on adolescents' adjustment. Caprara, Barbaranelli, Pastorelli and Cervone (2004) examined the ability of self-efficacy beliefs to predict the psychosocial outcomes of 489 adolescents. Self-efficacy had

a long term impact on developmental outcomes, as adolescents who judged themselves as more capable of self regulating their actions showed lower levels of problem behaviour, achieved higher grades and had greater popularity within their peers. Vecchio et al. (2007) carried out a longitudinal study with 650 adolescents to evaluate the impact of self-efficacy predictors on life satisfaction. The study reported that academic and social self-efficacy were better predictors of life satisfaction than early academic achievement and peer preference, which suggest the relevance of self-efficacy beliefs in life satisfaction.

Summary

Adolescence is a complex developmental stage defined as a transition from childhood to adulthood. This stage is characterized by developmental demands and tasks such as separation from authority, identity formation and acquisition of socially responsible behaviours into adulthood. Some adolescents adjust successfully but others can struggle. Currently there seems to be a lack of congruency in the definition of psychological adjustment. Different research studies have defined the concept in different terms and have used a variety of instruments to measure it, making comparisons difficult. Overall adjustment has been defined as an absence of psychological disorders and symptoms and the presence of positive mood, personal growth. Differences in adjustment success or difficulty can be understood by analysing the different determinants of adjustment including perceived stress, coping, perceived social support, parental attachment and self -efficacy. Initial perceptions of stressful situations can determine how successfully a person copes and it also depends on personal and environmental resources available, including coping skills and self -efficacy. Social support and secure attachment relationships between parents and adolescents can act as a 'buffer' against the detrimental effects of stress and improve psychological adjustment and well being. People with more resources tend to report better adjustment outcomes.

CHAPTER 2

THE NATURE OF CANCER AND ITS IMPACT ON THE FAMILY

This chapter provides general information on cancer including the definitions, statistics, treatments and side effects of the illness. It includes statistics on cancer in Ireland, the United Kingdom and Latin America which are the countries where participants in the current study originate. The psychological impact of parental cancer on young people and their family is outlined.

Cancer worldwide: Definition, Prevalence, Types and Treatments.

According to Cancer Research (UK) a total of 12.66 million people were diagnosed with cancer in 2008; of these, 7.56 million died from the illness. A total of 40% of cancers consisted of lung, colorectal, stomach and female breast cancer. Breast cancer is the most common cancer diagnosed in women worldwide. Breast cancer is also the most common cause of death from cancer in the female population worldwide, for example in 2008 there were 460,000 deaths from breast cancer alone. The World Cancer Research Fund International determined that breast cancer was the most common cancer, representing 25% of all new cancer diagnoses in 2012. Exclusively female cancers, for example, cervical cancer represented 8% of all cancer diagnoses in the same period.

Pecorelli, Favalli, Zigliani and Odicino (2003) suggested that having an accurate account of the incidence, mortality and survival rates of cancer that affect women is a challenge as there is no single world cancer database; accurate data on cancer incidence are very recent and are usually not population-based. More than half of all new cancers occur in less developed countries (2,561,666 cases compared with 2,175,974 cases in the developed world). Breast cancer is the most common type of cancer in women worldwide; it represents more than 1/5 of the global cancer burden. Ferlay et al. (2015) reported that there were 14.1 million new cases and 8.2 million cancer related deaths in 2012. The most common cancers diagnosed worldwide were lung (1.82 million), breast (1.67 million) and colorectal (1.36 million). The largest number of deaths registered were from lung, liver and stomach cancer. Specifically for women, Ferlay et al. (2015) described

that breast cancer is the most common cancer diagnosed, both in more and less developed countries, although more cases occur in less developed regions of the world. Cervical cancer is the second most common type of cancer in less developed countries (445, 000 vs. 83,000 in developed regions). Lung cancer is the leading cause of cancer related deaths in more developed countries, followed by breast cancer.

Cancer can originate in many different parts of the body and would have a different classification depending on where it is located including carcinomas, sarcomas, lymphomas and leukaemia.

Table 1: *Summary of Cancer Types*

Types	Definition
Carcinomas	Cancer originates on the cells that cover external and internal body surfaces, for example, lung, breast and colon.
Sarcomas	Cancer is found in the supporting tissues of the body like bones, cartilage, fat, connective tissue and muscle.
Lymphomas	Cancer originates in the body's immune system like lymph nodes.
Leukaemia	Cancer of the immature blood cells that grow in the bone marrow and accumulate in the blood stream.

According to the National Cancer Institute there are several risk factors associated with cancer including tobacco use, unhealthy diet, physical inactivity, chronic infections from hepatitis B (HBV), hepatitis C virus (HCV) and specific types of Human Papilloma Virus.

Based on the microscopic appearance of cancer cells, physicians can assign a numerical 'grade' to the cancer which is based on the possible behaviour of a tumour in response to treatment. Cancers with higher abnormal cell appearance and greater numbers of dividing cells tend to grow faster and spread more easily. Lower grade numbers (I and II) are cancers with fewer cell abnormalities than those with higher grades (III and IV).

Table 2: *Most Common Types of Cancer in Adults*

Cancer	Definition
Bowel Cancer	Cancer located in any area of the large intestine, specifically colon, rectum or appendix.
Breast Cancer	Cancer in cells of the breast. It can occur in females and males.
Lung Cancer	Cancer in the cells of the lungs. There are two types: small cell and non-small cell.
Prostate Cancer	Cancer cells in the prostate, a small gland located below the bladder and surrounding the tube that carries urine from the bladder through the penis.
Leukaemia	Cancer of the white small cells which are made in the bone marrow.
Lymphoma	Cancer in the lymphatic system that is part of the immune system which protects the body from illnesses.
Brain tumours or Central Nervous System	Cancer in the brain or spinal cord.
Germ cell tumours	Cancer located in the reproductive organs.
Melanoma	Type of skin cancer.
Thyroid cancer	Cancer in the thyroid gland that controls the use of energy in the body, makes proteins and is in charge of the body's sensitivity to hormones.

Specific treatments for cancer are carefully selected and usually involve one or a combination of different treatments such as surgery, radiotherapy or chemotherapy. The main objective of treatment is to cure the illness, prolong life and improve the patient's quality of life. Patients and their families can also benefit from psychological support.

Table 3: *Summary of Cancer Treatments*

Treatment	Definition
Surgery	Surgery can help diagnose, treat or prevent cancer. Surgery can remove the affected area before it has spread to other parts of the body, increasing the chances of cure.
Chemotherapy	Special drugs/ medicines to treat cancer but it can affect healthy cells causing side effects like hair loss.
Radiation Therapy	High energy particles or waves are targeted to destroy cancer cells.
Targeted Therapy	Involves the use of drugs or substances to identify and destroy cancer cells.
Immunotherapy	The body's own immune system is used to fight the cancer. Also called Biologic Therapy or biotherapy.
Hyperthermia	Further research is required but delivery of heat, hyperthermia is being used to fight different cancer types.
Stem Cell Transplant	Bone marrow transplants include peripheral blood, bone marrow and cord blood transplants that are used to treat cancers.
Photodynamic Therapy	Drugs called photosensitizing agents and light are used to kill cancer cells. These drugs are activated by specific types of light.
Laser	Laser is a powerful beam of light which can be very precise and used instead of scalpels for very precise and delicate surgical interventions for some cancers. Some treatments may be short term only so treatment may need to be repeated.

Different people respond differently to treatment, depending on the types and characteristics of treatment received but also on each person's body function. Some of the side effects common to several types of treatment are: weakness, fatigue, anaemia, diarrhoea, hair loss, memory

loss, weight changes, nail changes, skin changes, bone loss, heart and vision difficulties, pain, discomfort, blisters, vomit, nausea, cough, bone loss and headache.

Cancer in Ireland and the United Kingdom

According to the Cancer in Ireland Annual Report (2014), there were approximately 19,200 invasive cancers (excluding non-melanoma skin) diagnosed between 2009 and 2011. This represents 425 cases per 100,000 per year. Prostate (3,267 cases per year) and female breast cancer (2,781 cases per year) were the most common cancers in men and women, followed by colorectal (2,436 cases per year) and lung cancer (2,165 cases per year).

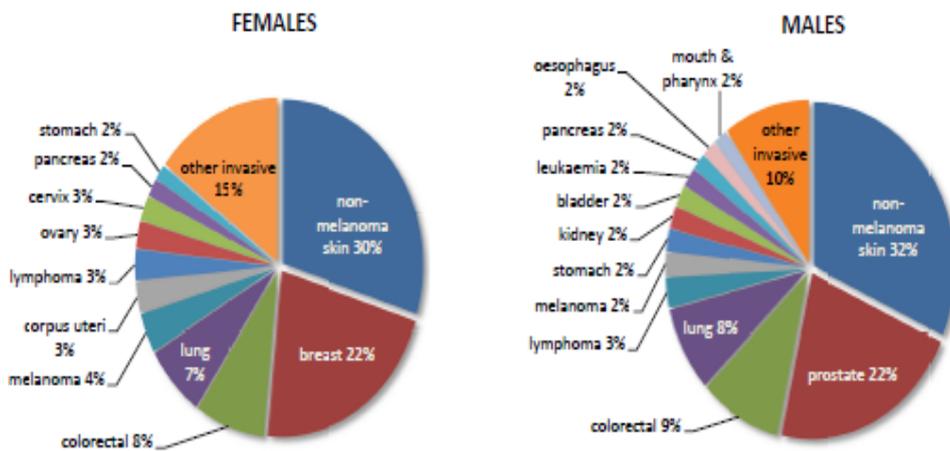


Figure 3. Relative frequency of invasive cancers diagnosed 2009-2011. Cancer in Ireland Annual Report (2014)

Cancer is the second leading cause of death in Ireland, after diseases of the circulatory system. A total of 8,871 deaths occurred in the year 2011. Lung cancer was the leading cause of cancer death, 18% in females and 23% in males (1,848 total deaths in 2011). The Cancer in Ireland Annual Report 2014 also identified that cancer incidence in Ireland and the UK in 2012 were very similar. Male rates were substantially lower and female rates higher than in the rest of the European Union. Regarding specific female cancers, female breast cancer in Ireland was 5% lower than in the UK but 13% higher than the European Union average. Cervical cancer rates in England, Scotland and Wales have decreased but rates have instead

increased in Ireland and it was estimated that rates were 33% higher than the European Union average in 2012.

Cancer in Latin America

Justo, Wilking, Jonsson, Luciani and Cazap (2013) carried out a review of cancer care and outcomes in the Latin American region, including Argentina, Brazil, Chile, Colombia, Costa Rica, Mexico, Ecuador, Peru, Panama, Venezuela and Uruguay.

According to Justo et al. (2013) a total of 114,900 women are diagnosed with cancer every year in Latin America. Of these, 37 000 die from the illness. Breast cancer is the most common type of cancer and is responsible for more deaths in women than any other type of cancer in the region. Gómez, Lewis, Sánchez and López (2009) estimated that 5.4% of all disability adjusted life years² (DALY) that are lost in developing countries correspond to cancerous tumours, 9% of which correspond to breast cancer only, compared to prostate cancer (4.8%). These differences occur because breast cancer usually has a bigger impact on disability and is diagnosed at an earlier age (Gómez et al., 2009).

Although Justo et al. (2013) highlight the lack of cancer registries they suggested that cancer incidence and mortality are increasing. It is expected that the number of deaths will double by 2030 reaching 74,000. In Latin America, ageing seems to be an associated factor and also 30 to 40% are diagnosed with metastatic breast cancer at stages III and IV.

Mortality rate due to cancer in Costa Rica has increased by 24% between 2000 and 2011. In 2011 it was the second cause of death for definite causes with a total of 4244 deaths and 10 thousand new diagnoses per year, specifically breast cancer was the most common type of cancer diagnosed in women (12,4%) in 2012, followed by stomach cancer (9,08%), colon cancer (5,52%), cervical (5,29%), leukaemia (4,45%) and liver cancer (3,89%). Cancer is generally diagnosed at advanced stages which may lead to a negative prognosis and this increases mortality (Cascante, 2013).

² DALY is a measurement of disease burden which determines the number of years lost due to illness, disability or early death

Psychological Impact of Parental Cancer in the Family

Parental Cancer as a Stressor

Issel et al. (1990) suggested that maternal cancer may be perceived as a threat by a young person and disrupt their equilibrium, which could be experienced as a stressor. Leedham and Meyerowitz (1999) described parental cancer as a “unique stressor” with particular characteristics as children may face short term (hospitalized parents, increased responsibilities) and long term losses (parental death, elevated risk of cancer) simultaneously.

Cancer has been defined in previous research as a stressor which can affect the whole family, even if only one member is ill (Finch & Gibson, 2009; Hilton, 1993, Heiney et al., 1997; Forrest et al., 2009; Edwards et al., 2008; Su & Ryan-Wenger, 2007; Faulkner & Davey, 2002; Hymovich, 1995). Edwards et al. (2008) reported that the experience of having a parent with cancer could lead to stress symptoms in children. Poorer family functioning was associated with higher stress levels. Edwards et al. (2008) concluded that a minority of adolescents have psychological and stress related problems.

Impact of Family Structure on Adolescent Adjustment

Family members are not passive observers; instead they are active participants who have a vital role in the treatment and recovery of the ill family member (Northouse, 1984). From a Family Systems Theory perspective, families are in a dynamic state, responding to changes in and outside the family. Cancer can cause changes as family members learn new information, new coping strategies and experience changes which occur during the course of the disease: initial phase, adaptation phase and terminal phase (Northouse, 1984). Gazendam-Donofrio et al. (2007) found that families facing parental cancer tend to function positively, were more expressive, organized and reported less conflict than the norm.

According to Hilton and Elfert (1996) families with adolescents experienced a ‘turmoil’, more so than other families, but Vess, Moreland and Schwebel (1985) reported the initial findings from a longitudinal study

of the effects of cancer on family role functioning and found that families with adolescents, rather than with younger children, seem to experience less conflict and had a more effective reallocation of roles.

Children from well adjusted and flexible families were more satisfied with how they coped with cancer as they were able to handle problems, provided mutual support and managed to shift their roles to fit the demands; poorly adjusted families, instead, grew further apart (Hilton & Elfert, 1996). Gazendam-Donofrio et al. (2007) identified that adolescent functioning was associated with intra-family relationships and only weakly related to family structure. Families with more open cancer communication and expressiveness reported lower levels of conflict and less distress.

Family Communication and Parental Cancer

Costas-Muñiz (2011) found that higher levels of family cohesion and communication resulted in less family conflict and less symptoms of depression anxiety and hopelessness in Hispanic adolescents coping with parental cancer (compared to norms). Maynard et al. (2013) found that families that encouraged open communication of feelings about the cancer diagnosis had better outcomes. According to Hilton (1994), sharing meaning was a central strategy for families as this allowed them to be informed about events and issues and to understand how other family members felt and coped, this allowed family members to be synchronized with each other, demonstrate concern and support, carry out decisions and improve family satisfaction and adjustment. Hilton (1994) found sharing takes place both verbally and non-verbally. These communication patterns are influenced by previous family communication styles, gender and beliefs about sharing.

Clemmens (2009) suggested that communication was important for adolescent's security and knowledge about cancer. Open communication provided a feeling of safety and it allowed them to improve their coping with the stress and unfamiliarity of maternal breast cancer. Communication was also described as important by Gazendam-Donofrio et al. (2007) as families with more open cancer communication and expressiveness reported lower levels of conflict and families which express emotions openly also report less distress. Huizinga et al. (2005) investigated parent-adolescent

communication in families with parental cancer and showed that adolescents could experience less open communication with their mothers as a way of protecting themselves and their mothers. This is known as “the phenomenon of double protection”. They also found that daughters who communicated more openly with their healthy parent had less post traumatic stress symptoms, however, daughters still perceived communication with their healthy parent as less open than with their ill mother. Lewandowski (1996) also identified that children and adolescents have a strong need to be informed when their parents have cancer. Parents sometimes decide not to discuss the situation to ‘protect’ them but this does more harm than good (Lewandowski, 1996).

Jantzer et al. (2013) evaluated risk and externalizing behaviours in adolescents dealing with parental cancer, compared to adolescents that did not have the experience (control group) in a longitudinal study. The study found that adolescents from high risk families with poor psychosocial functioning, poor parenting and communication were particularly vulnerable to distress, externalizing and risk behaviours. Rosenfeld et al. (1983) found girls who were not given enough information felt ignored and believed they were not given enough explanations about the illness, some were angry after several years because they believed they were not considered mature enough at the time.

Family Coping with Parental Illness

Issel et al. (1990) examined the ways in which children coped with maternal cancer and the ways in which their families helped them cope. The study was based on Family Systems Theory. Issel et al. (1990) identified ways in which the family helped children and adolescents cope. These were: acting normal, spending time together, talking about topics that were not illness related, talking about cancer, not talking or thinking about cancer, helping out around the house, being considerate. Time spent together as a family is also important, according to Issel et al. (1990) as it allowed all members to energize each other and establish a new equilibrium. Parental accessibility was evident as a high percentage of adolescents and children reported that a parent helped them cope; however, Issel et al. (1990) also

coined the term '*nothing*' to refer to children reporting that their families didn't help them cope at all. The research suggested several explanations for this, firstly, maternal cancer may have not posed any difficulties for the family; particularly if the ill person had already recovered from treatment side effects at the time of the interview. A year after diagnosis children could have perceived that their mother's illness was already over and the families could have adjusted by the time of the interviews. Children may have also been unable to interpret family actions or their own strategies as coping strategies. Lichtman et al. (1984) identified that poor maternal adjustment was correlated with disruption in family relationships as mothers may have viewed everything more negatively.

Buchbinder, Longhofer and McCue (2009) carried out qualitative semi structured interviews with families dealing with parental cancer and found that cancer in the parent caused disruptions to family routines, however, sometimes these changes created new opportunities to connect between family members, strengthen the family unit and create a positive attitude towards family life. Some families found useful ways to stabilize family routines.

Buchbinder et al. (2009) suggested that support from families and friends were an essential part of maintaining family routines. Some families coordinated routines to share information and had specific times when family members could ask questions. Families also created coping rituals to express their emotions, for example, evening prayers and family celebrations.

Regarding family support, the healthy parent seems to have an important role. Forrest et al. (2009) studied the healthy parent role. Fathers in this study tried to keep the family system intact by taking over roles and responsibilities, as well as providing emotional support for partners and children. Fathers tried to regulate the flow of information by answering questions about the illness and prognosis, as well as about issues related to death. Fathers wished to be open and honest but felt unprepared to answer emotionally charged questions, yet they refused to seek psychological help. Huizinga et al. (2011) also identified that healthy parents were sometimes important figures in children and adolescent's support networks, however,

some were overwhelmed and could not provide the emotional support which the child needed.

Adolescent Relationship with the Sick Parent

Lewis and Hammond (1996) suggested that the quality of the parent-child relationship has an impact on adolescent experiences of parental cancer. Adolescents may need assistance to understand changes in the relationship with their parents which have been caused by illness and that these have nothing to do with adolescent's personal worth.

Rosenfeld et al. (1983) described that there may be differences in families as, for example, mother daughter relationships improved for some of the daughters since maternal mastectomy whereas others did not report any changes and one believed the relationship had worsened.

Lichtman et al. (1984) identified that poor maternal adjustment was correlated with disruption in family relationships as mothers may have viewed everything more negatively. Litchman et al. (1984) documented the changes which occur between women diagnosed with breast cancer and their children. The study identified that the relationships between mothers, adolescents and preadolescents were the most vulnerable, particularly if the mother had undergone mastectomy. Clarke (1995) identified that daughters of mothers diagnosed with breast cancer felt isolated from their mothers who were described as introverted, busy and worried.

Davey et al. (2011) described that adolescents noticed changes in normal parental behaviour. These changes were usually perceived as negative and were linked to side effects of treatment such as irritability, impatience, moodiness and paranoia. Some of these changes caused conflict in the parent-child relationship. Adolescents described their sick parent as unavailable physically and emotionally as a result of treatment. Issel et al. (1990) identified that children tried to anticipate what the mother would want, as if they were '*in their mother's shoes*'. This happened less frequently with adolescents and Issel et al. (1990) views this as consistent with a developmental explanation where adolescents are establishing their own identity.

Davey et al. (2005) reporting on family roles, showed that adolescents perceived their mothers as more emotional and vulnerable. Their response was to be more affectionate and get more involved in household chores (cooking, cleaning, and shopping) as well as taking care of their mothers. Young people carried out a variety of tasks for their ill parent like feeding, dressing, giving medication, changing IVs and providing companionship by listening, talking or playing games with the sick adult (Gates & Lackey, 1998). Buchbinder et al. (2009) also found that involving children in care duties was a way to mitigate fears in children for example, fears of medical technology.

Gall and Kafi (2014) carried out a study with mother- daughter dyads experiencing maternal breast cancer. The study suggested that maternal cancer has a significant impact on the psychological and emotional well- being of mothers and daughters, as the cancer diagnosis and treatment triggered a deep fear for the potential loss of their mothers. This also disrupts the relational adjustment process between mother and daughter.

Impact of Parental Cancer on Family Needs

Lewandowski (1996) suggested that the needs, fears, responses and coping strategies of children when a parent has cancer, are often unrecognized. Call (1990) suggested that children of cancer patients are usually the 'forgotten victims'. It is difficult for parents to consider their children's needs when going through the shock of diagnosis. During treatment, time spent with children may also be limited. Lewis and Hammond (1996) emphasized the importance of responding to adolescent needs as while they may be perceived as independent by their parents, this may not always be the case. Rainville et al. (2012) identified that young people have to repress their own needs to be able to stay close to their parent and also to helping in their house, doing household chores for example. Adolescents with unmet needs may develop psychological and/or behavioural symptoms which have an impact on their usual functioning. Northouse (1984) also indicated that studies have identified that family members usually deny their own needs for the needs of the ill family member.

Fridriksdottir et al. (2011) carried out a study of the needs and unmet needs of family members of cancer patients, their distress levels and quality of life. The study found that the most important needs of family members were related to patient care and having honest and comprehensible information. The least important need was their own health; the focus was on the patient and not themselves. Some families had difficulties finding a balance between time spent with the ill member and the needs of other members. Members may feel they hinder the patient's recovery or experience guilt when they spend time or enjoy themselves in other activities. Achieving this balance may be more difficult if the illness continues over a long period of time (Northouse, 1984).

Impact of Illness Stages on the Family

Diagnosis.

Northouse (1984) carried out a review of the impact of cancer on the family as well as the specific problems family members experienced during the patient's illness. This review described the initial phase of cancer (diagnosis) as the most stressful one for patients and their families, as family members may feel excluded from the focus of care, communicating with hospital staff and have difficulties managing their emotional distress. Interpersonal relationships may become strained as family members assimilate new information, increase interactions with family members and people outside (e.g. hospital staff). According to Northouse (1984) a cancer diagnosis can generate anxiety within the family which may spread to other members and cause strain and tension. Family members may also feel guilty for not having noticed symptoms earlier.

Hilton (1993) analysed family adaptation to breast cancer since diagnosis and up to 12 months after. They interviewed families at five points, children included in the study ranged from 3 years old up to adults; therefore not all findings are exclusive to adolescents. Hilton (1993) found that families experienced uncertainty mostly during initial diagnosis. They were concerned about reliability of procedures, the effectiveness of treatment and about potential cure or death. The meaning of cancer for families had an impact on the potential pessimism and optimism they

experienced, mostly if that was the first time they experienced serious illness and the first time the mother was ill, some families reported they lacked knowledge and specific information on cancer, others preferred to have minimal information instead. Some families had difficulties sharing their concerns and some family members expected other family members to meet their needs, however, when this didn't happen, it caused problems. Some families did not know how to provide effective support or did not have the time. Overall, Hilton (1993) explained that adjusting to changes caused by cancer demands was difficult for some families as some were dealing with other simultaneous issues and not just parental cancer.

Also at the time of diagnosis, Gabriak, Bender and Puskar (2007) found that adolescents tend to perceive the disease as a threat to themselves and their families but this is an immediate reaction that changes over time. According to Gazendam- Donofrio et al. (2011) during the first year after diagnosis, uncertainty and helplessness decreased significantly. Lewis et al. (1985) identified that family members and the patients may feel powerlessness during the diagnostic phase, symptom exacerbation, treatment and dying process. These feelings may be exacerbated if family members perceived a lack of effective communication with the physician or were not involved in the treatment plan. Leedham and Meyerowitz (1999) identified that adolescents had substantial difficulties during the acute phase of diagnosis, including strong negative emotional reactions such as anger, confusion, surprise and worry, however participants also mentioned positive immediate responses such as improvement in the relationship with the sick parent and/or with the healthy parent. The relationship with friends improved and positive changes in their families were experienced by two fifths of adult women who experienced parental cancer as adolescents (average age was 14 years).

Treatment.

During the treatment phase, Kornreich, Mannheim and Axelrod (2008) conducted a literature review on how children live with parental cancer Kornreich et al. (2008) showed that children experienced the most stress in response to the physical signs and side effects of parental illness (vomiting or hair loss) and the disruption of their normal routines due to

treatment and disease complications. Recovery from surgery and treatments may limit or prevent the ill family member from resuming the previous role they had in the family as they may be fatigued and experience a decrease in their usual activity level. Gazendam- Donofrio et al. (2011) carried out a study to examine the emotional reaction of adolescents to parental cancer. According to this study treatment type was an important variable to evaluate because, for example, surgery could mean that treatment would be completed more quickly and cause less distress in the family. Single modal and non-surgical (chemotherapy, radiotherapy) as well as multimodal treatment (surgery, chemotherapy, radiotherapy, others) may be long term treatments and cause more distress. Adolescents of parents who underwent surgical treatment showed more positive emotions than when parents had long term treatments, as they might have witnessed fewer outward signs of illness.

Type of treatment is also related to communication. Daughters of parents with non-intensive treatments perceived communication as more open. Some sons also reported fewer communication problems. Huizinga et al. (2005) consider this may be due to fewer side effects, less visible illness, fewer absences from the house and better prognosis.

After treatment.

Northouse (1984) suggested that the recurrence of cancer may create uncertainty in the patients and the families. Uncertainty is also linked to the causes that lead to parental cancer and what could be done to prevent it.

Hilton (1996) identified several factors which influence getting back to normal. If families believed cancer could be cured then they perceived it as short term and managed to return to their previous patterns and behaviours quickly. Families who viewed cancer as a long-term illness struggled to return to normality.

Parental cancer can have long term consequences in young people over time. Wong et al. (2009) identified negative long term outcomes in participants who faced parental cancer when they were younger which included feelings of loss and void; they reported being particularly concerned for their own health and the possibility of getting a cancer diagnosis themselves. Hilton and Gustavson (2002) reported that some

children in their study had long term consequences associated with maternal breast cancer, even long after the treatment was finished. Some had initial resentment but others acquired perspectives about themselves and had to grow up faster, particularly those who were in charge of more household chores and responsibilities.

Adolescent Adjustment to Parental Cancer

Thastum et al. (2009) found that children and adolescents of parents with cancer are at a higher risk of psychosocial problems than children of healthy parents; mostly latency aged boys³ and adolescent girls. Thastum et al. (2009) found that children and adolescents were at higher risk when the father was ill than when the mother was ill, however the reasons for this finding are not identified. Krattenmacher et al. (2012) identified that most adolescents functioned well but one third reported psychosocial problems. Visser et al. (2004) suggested that adolescents seemed to be particularly vulnerable because of the conflicting demands they were facing such as a developmental need for separation from the family and their need to establish relationships outside their families. Huzinga et al. (2005) carried out a study to evaluate stress responses of children in the Netherlands (4 to 18 years) who have a parent diagnosed with cancer. This study identified that a significant percentage of adolescents suffer from intrusive thoughts, avoidance symptoms, internalising and cognitive problems. Particularly vulnerable are those who also react with anxiety and daughters of parents facing a recurrent diagnosis.

Compass et al. (1994) identified that adolescent girls experiencing maternal breast cancer showed strength, resilience and hope when facing the challenges of the illness and they also provided for the needs of their mothers; however, they still needed limits, nurturing and security provided by their family. Rosenfeld et al. (1983) carried out a pilot retrospective study on adolescent daughters of mothers who had undergone mastectomies due to breast cancer. These girls saw their mothers' cancer as a threat with

³ Latency aged children are between 7 and 11 years of age (Christ et al., 1993).

an uncertain outcome. Some minimized the situation but all of them expressed worry to some extent and younger girls seemed overwhelmed and some reported having psychosomatic and mood disturbances including a decline in school performance, sleep disturbances, loss of appetite, depression, sadness, headaches, dizziness and abdominal pains. According to Rosenfeld et al. (1983) holding their suffering may have predisposed girls to psychosomatic illness or depression.

On the other hand, Vanatta et al. (2010) and Huizinga et al. (2003) concluded that adolescents of women with breast cancer experienced little or no behavioural effects over an extended period of time. Lindqvist, Schmitt, Santalahti, Romer and Piha (2007) carried out a study to explore the impact of parental cancer on children's and adolescent's mental health in Nordic countries. Lindqvist et al. (2007) found no differences between adolescents in the clinical and the control group (11 to 17 years, no previous experience with parental cancer) regarding family functioning, internalizing and externalizing problems as well as their total scores in psychological symptoms.

Adolescent Emotional Response to Parental Cancer

Welch, Wadsworth and Compass (1996) examined children, adolescents and parental reports of behavioural and emotional problems in children and adolescents who had a parent recently diagnosed with cancer. The study reported that symptoms of anxiety, depression and emotional and behavioural problems were within the normal range for adolescents and preadolescents. Adolescents tend to self report higher levels of depression and anxiety than those reported for them by their parents, suggesting that parents may be unaware of emotional and behavioural problems in their teenagers during a period of high stress or that adolescents do not actually disclose their emotional distress to their parents.

Other studies have also examined the reactions of young people experiencing parental cancer. They expressed fear of parental symptoms (vomiting, bleeding, and disfigurement), fears of side effects and death. Some children, mostly younger ones, felt guilt, anger, withdrawal and lack of affection (Finch & Gibson, 2009; Forrest et al. 2006; Hymovich, 1995;

Kennedy & Lloyd- Williams, 2009). Adolescents may fear that their parents may become an embarrassment to them and they may also experience ambivalence between time spent with their ill parent and their developmental need for separation (Hymovich, 1995). Compass et al. (1994) found that adolescents and young adults had high levels of anxiety and depression symptoms. Forrest et al. (2006) identified that younger and older children (6 to 18 years) reacted in similar ways including emotional upset, shock, tears, fear, anxiety, and anger with God or anger towards their mother, teachers or peers. According to Finch and Gibson (2009) parental cancer is a vulnerable and isolating experience for adolescents as it is contrary to the demands of their developmental stage which include a need for security and development of self-identity. Davey et al. (2003) identified that adolescents felt shock, devastation and grief at the time of diagnosis. They were worried about inheriting the disease, recurrence and not knowing if the parent would fully recover. Stiffler et al. (2008) suggested that adolescent girls whose mothers were diagnosed with breast cancer struggled with many issues including conflicting emotions between wanting to help their mothers and wanting to remain normal, they felt angry and guilty.

Previous research has suggested that adolescents may experience difficulties in understanding and dealing with their emotional reactions. Kristjanson et al. (2004) described that adolescents wanted to know if certain feelings (anger, guilt) were normal for them. Adams - Greenly et al. (1986) suggested adolescence is a time of stormy emotions and moods which could overwhelm adolescents at a time of cancer in their families. Adolescents may have felt unable to control those feelings and feared being inappropriate; they may have felt unable to cope internally so they would direct that anger externally and get involved in experimenting with drugs, sexuality, stealing and aggressive behaviours. Adolescents may also need to understand that the anger they felt was directed at the disease and not at the parent. Adams- Greenly et al. (1986) suggested that adolescents may over idealize the ill parent and direct their anger to the healthy one. Visser et al. (2007) suggested that children and adolescents may not experience problems during the first year after diagnosis; but they may show their "true" feelings once the family returns to normal functioning; if this was the case,

providing an intervention to improve adolescent adjustment in the first year following diagnosis would be useful to help avoid emotional and behavioural problems in the future.

Illness Related Changes Experienced by Adolescents

Findings show that maternal cancer was a life changing experience, normal patterns of life were altered and adolescents had more household responsibilities (Clemmens, 2009). Wellisch (1979) carried out research on the meaning and influence of parental cancer in adolescence and identified possible difficulties experienced by adolescents such as role shifts.

According to Pedersen and Revenson (2005) role conflict and role overload may result in adolescents having their social relationships interrupted, increasing their daily hassles and stress responses. Kornreich et al. (2008) suggested that adolescents may have to face additional responsibilities and this may lead to emotional and behavioural problems due to changes in family routines and they may have less time to engage in social activities.

Maynard et al. (2013) reported that being involved in household chores was beneficial for young people because it contributed to building up family relationships and increasing their sources of support. Maynard et al. (2013) also suggest that these activities may be a way to maintain normalcy; they can be a distraction or an opportunity to relate to the parent outside the context of illness.

Grant and Compas (1995) identified that girls who had additional family responsibilities experienced more anxious-depressed symptoms and these responsibilities may be detrimental because girls may not have developed adaptive coping abilities to care for others and it conflicts with other developmentally appropriate goals such as forming relationships with friends and developing increased autonomy outside the family. Rosenfeld (1983) found that some girls reported happily taking over household chores, however others showed resentment.

Suand Ryan-Wenger (2007) found that adolescents (14-19 years) had contradictory feelings towards increased responsibilities and decreased social activities, but at the same time they wished to take care of their mothers. According to Wellisch (1979) parents have to be sensitized about

role shifts, as these may cause desperation and acting out behaviour in adolescents as a reaction to the situation. Rosenfeld et al. (1983) suggested that taking over household chores may have been used as a coping strategy which could have a positive impact on their autonomy and sense of personal worth. Young participants mentioned care giving tasks as 'hard but gratifying'. Adams - Greenly et al. (1986) suggested it is important to ensure that the burden is not too great on adolescents.

Another change experienced by adolescents was the relationship with hospital settings and personnel. Finch and Gibson (2009) reported that adolescents did not perceive a role for themselves in hospitals. Some preferred not to talk about their experience with a 'stranger', i.e. medical health staff. Huizinga et al. (2011) also identified that oncology personnel tend to focus on the parent's treatment but it was also the case that children and adolescents themselves did not want to share their thoughts and feelings with a person that was 'unfamiliar' to them. According to Lewis, Casey, Brandt, Shands and Zahlis (2006) thousands of children are potentially affected by the diagnosis of breast cancer in their mothers. These children have been 'treated with benign neglect' both by health care and researchers. Hilton and Elfert (1996) emphasized children and adolescents' needs should be suggested by health personnel. Wellisch (1979) explained that adolescents should not be forced to visit their parents in hospital if they do not wish to do so, instead they could substitute it with phone calls. Adolescents that are forced may feel the pressure to act out, flee, get involved in self destructive behaviours, feel guilty, angry, hide their feelings or have overwhelming dependency needs.

Adolescents also described positive changes in their lives associated with parental cancer. Davey et al. (2005) reported that adolescents suggested that cancer had changed their lives as now they appreciated their mothers more, were more conscientious about helping other people and some felt more mature from the experience. Wong et al. (2009) found positive growth in adolescents including improvement in their character and maturity. Some had a greater appreciation for life and were grateful for people in their life. Relationships with the family had strengthened as well as the interest in cancer had increased and participants were willing to give

back to the community by pursuing a career in medicine for example. Kissil et al. (2010) reported post traumatic growth (PTG) in adolescents who were coping with parental cancer including, a sense of personal strength, maturity, enhanced interpersonal relationships, strong appreciation for life and changed values. These findings indicate that adolescents have the cognitive ability to process gains and losses in their experiences; however the researchers pointed out that the majority of participants were female who generally report higher levels of post-traumatic growth.

Adolescent Coping Mechanisms

Adolescents use a variety of coping strategies including, athletics, music, reading drawing, being with friends, keeping a diary, praying, thinking about the illness, not thinking about the illness, doing chores, thinking positively, meditation, faith, hope, humour, talking, distraction, talking, keeping busy, reasoning, keeping normality, yoga, reach for social support, spirituality and games (Issel et al., 1990; Gates & Lackey, 1998; Stiffler et al., 2008; Clemmens, 2009; Kennedy & Lloyd- Williams, 2009; Davey et al., 2011).

Adams- Greenly et al. (1986) mentioned adolescents may have a need for privacy and used coping strategies to deal with the feelings that they found hard to share. Clemmens (2009) described that despite available external supports (peers, church) some adolescents needed to move inward, which meant relying on themselves to solve problems, make decisions and escape from the maternal illness situation.

Previous research has suggested that keeping a sense of normality is an important coping mechanism for adolescents (Adams - Greenly et al., 1986; Nelson et al., 1994). Davey et al. (2003) found that for younger adolescents (11-13 years) keeping their normal routines and activities was important. Adolescents, according to Kristjanson et al. (2004) appreciated that they could take part in 'normal' activities, which helped them feel supported, continue with their lives and be hopeful.

Krattenmacher et al. (2012) suggested that adolescents reported worse functioning if they used avoidance oriented patterns, wishful thinking and distraction. Avoidance oriented coping included more problem

behaviour, worse health related quality of life as this lead to reduced availability of more effective coping strategies and clinically significant symptoms. Nelson, Sloper, Charlton and While (1994) identified that children's coping was influenced by their appraisal of the situation and its demands as well as the material, physical, social and psychological resources available to them.

Social support was important in adolescent coping, Issel et al. (1990) identified that friends and parents were the ones who best helped children (6 to 20 years) cope. Hilton and Elfert (1996) found adolescents varied in whether they sought support or not. Some chose to speak with siblings, friends and co-workers about maternal cancer, but others didn't consider this useful as they thought friends would not understand what they were going through and family members could make a 'fuss'. Rosenfeld et al. (1983) identified that some girls decided to tell friends and other people about maternal illness, however, others stopped telling as they did not want to be pitied or embarrass people. Vanatta et al. (2008) mentioned friends could be a buffer against stressful events and act as a protective factor against other negative outcomes such as depression, however, they also recognized that further research is needed in which the quality and quantity of these friendships are taken into account. According to Bal et al. (2003) adolescents turn to their friends and family for day to day companionship but during times of high stress, adolescents prefer to turn to their families. Issel et al. (1990) explained that peers are important for adolescents so older children would usually ask their friends for help. Nelson et al. (1994) described the role of peers as an important source of support for adolescents, some participants mentioned the time spent with their friends helped them forget about the illness for a while and enjoy themselves. Forrest et al. (2009) described that adolescents turned to friends and adults outside the family to obtain emotional support. Finch and Gibson (2009) found adolescents would turn to people they trust for help. Friends for this population were of particular importance. They provided a sense of emotional support, advice, a sense of being understood and they were able to relate 'in their own terms' (Finch & Gibson, 2009).

Friends, however, were not always supportive for adolescents. Hilton and Gustavson (2002) and Davey et al. (2005) suggested that young people thought their friends would not understand their experience of parental cancer. Davey et al. (2003) found that some adolescents expressed not wanting to tell their friends as they were afraid of the attention and being teased by others. Feiske, Taska and Lewis (1998, cited by Bal et al., 2003) said that adolescents who rely on their friends as their major source of support are at a higher risk of poor adjustment, as this suggest that the person doesn't have family resources for protection. Giesbers et al. (2010) found that children (average age 15.3 years) lacked support from their environment, particularly from their peers. Young people described that at the beginning of parental cancer, peers were interested but after a while this support stopped, they felt a lack of understanding and withdrew or hid their feelings. Some participants experienced problems in school with schoolwork and exams as their peers were calling them names including the word cancer.

Other supports for adolescents were school counsellors, coaches and teachers Chalmers et al. (2000) described adolescent perceptions of the role of school in helping them cope with the experience of maternal breast cancer. For some adolescents, school was the place to escape from the situation of maternal cancer; therefore they preferred that no school personnel discussed the situation (Chalmers et al., 2000). Huizinga et al. (2011) identified that teachers were usually concerned about the parent's health but overlooked the children's needs. Kristjanson, Chalmers and Woodgate (2004) described that family, friends and the school provided an important sense of 'normality' that was appreciated by adolescents as it helped them cope. Finch and Gibson (2009) described that some adolescents did not want their schools to be concerned about parental cancer; instead they thought it was the place they had to be 'normal'. On the other hand, some adolescents believed the school had not been supportive enough and teachers did not acknowledge their situations enough.

Kristjanson et al. (2004) found that adolescents liked reciprocal support (providing and receiving), and not only being recipients of support. Kristjanson et al. (2004) suggested that adolescents appreciated positive

verbal and nonverbal supportive gestures, for example hugs, however, they could also perceive support when it was not sincere. Therefore, support could be helpful or unhelpful depending on what was given and by whom. They did not like when people overreacted, treated them differently or said hurtful jokes.

The Impact of Developmental Demands on Adolescent Adjustment

Lewis et al. (1985) described the experience of maternal cancer as the 'ultimate test' for an adolescent as they are attempting to withdraw from their mothers, and instead they are needed by their mothers. Ohannessian (2007) described that the fundamental changes need to take place during adolescence. This may lead to an increase in family conflict as adolescents seek more autonomy. However these short term conflicts may lead to higher levels of stress and adjustment problems. Cancer may cause the developmental processes of families to be left on hold.

Adams - Greenly et al. (1986) suggested it was normal and appropriate for adolescents to struggle with emotions about dependence and independence from their parents. Serious illness in a parent may cause the separation-individuation to be more acute. In this process of separation-individuation, some adolescents may devalue their parents and family values, however this normal process may be affected by potential or real loss of a parent, as adolescents may have been frightened, guilty or angry at the restrictions to their freedom. Davey et al. (2005) and Spira and Kenemore (2000) suggested that adolescents had a need for separation and a continued connection with their mothers.

Gender Differences in the Experience of Parental Illness

Gender differences have been found in adolescent adjustment to parental cancer, particularly for girls (Ohannessian, 2007; Litchman et al. 1984). Various studies have found that adolescent daughters reported more feelings of discomfort about the illness than other developmental groups (Edwards et al., 2008; Stiffler, Baranda, Hosei, Haase, 2008; Osborn, 2007; Kissil et al., 2010; Gabriak, Bender & Puskar, 2007; Turner, 2004; Visser et al., 2005; Welisch et al., 1992; Kristjanson et al., 2004).

Davey et al. (2005) found that boys tended to be more reserved about their feelings and mostly coped by engaging in distractions or being involved in sports and other activities. Su and Ryan-Wenger (2007) identified that girls reported more stressful life events and experienced depression. Boys tend to have disruptive behaviours due to stress. Lichthman et al. (1984) identified that mothers seemed to rely more on the support of their adolescent daughters, this created further demands that the daughters were unable to fulfil. Brown et al. (2007) found that daughters of mothers with breast cancer showed more symptoms of depression than sons. Sons had extreme fear about maternal prognosis, denied the cancer, remained distant from their mothers or rejected her. Visser et al. (2004) identified that conversations with sons, mostly if they were part of single parent households were more limited. Boys were even less expressive about their feelings than girls and tended to turn inward.

The study by Litchman et al. (1984) also found that daughters showed extreme fear of maternal prognosis, they moved out of the maternal house, became distant or avoided cancer. Distress was higher in adolescent girls with mothers diagnosed with cancer, than in boys, suggesting they could be a vulnerable group (Huizinga et al., 2011; Krattenmacher et al., 2012; Compass et al., 1994). According to Huzinga et al. (2005), Hilton and Elfert (1996) and Visser et al. (2004) girls were aware of a greater risk than boys of having breast cancer and were concerned about this. Grant and Compas (1995) described that adolescent girls whose mothers were ill were more distressed than girls whose fathers were ill or boys whose mums or dads are ill. Adolescent girls experiencing parental cancer reported higher levels of depression and anxiety than boys (Wellisch et al., 2012; Welch et al., 1996; Turner & McGrath, 1998).

Welch et al. (1996) suggested that girls with ill mothers are a particularly distressed group, compared with boys, and found increased family responsibilities to be the biggest factor linked to their distress. Ohannessian (2007) identified that girls tend to report more adjustment problems than boys. This research suggested that parents may expect more autonomy from girls than from boys, so they may be more tolerant of discrepancies from boys and not from girls.

Adolescent Age and Cognitive Abilities

Research suggests that adolescents have reached a cognitive stage where they can accommodate complex and abstract information (Hymovich, 1995). This study suggested that adolescent intellectual mastery allows adolescents to understand the inner processes involved in cancer. Adolescents tend to associate cancer with permanent disability, intrusive procedures, treatment procedures, somatic changes in physical function and appearance. Kornreich et al. (2008) described that adolescents (12-18 years) have a different experience to younger children as they have greater cognitive ability, and can engage in abstract and symbolic thought. This makes them more aware of the potential loss of their parent as well as the pain they may be going through. Lewandowski (1996) suggested adolescents are more able to comprehend the situation on an abstract level, so they are able to understand the implications of cancer fully.

Kristjanson, Chalmers and Woodgate (2004) found that adolescents in this study, regardless of their age, were mainly concerned with knowing whether their mothers were going to survive. They also wanted information on medical facts such as seriousness of the illness, side effects and alternative therapies. Information on maternal feelings and changes were also important. Maynard et al. (2013) suggested that adolescents need information about which changes may occur in their ill parent and in their households. Kennedy and Lloyd- Williams (2009) found information was important for young people (8 to 18 years) when a parent had cancer, however, there was variability and individuality in the information needs identified. Hilton and Gustavson (2002) described that some children (4 to 28 years) were active seekers of information but others were not interested in finding out anything beyond what they were told.

Currently cancer is one of the biggest causes of death worldwide. The current research seems to reveal that this is one of the illnesses where worldwide inequalities are evident, as still more cases of cancer are diagnosed in less developed regions of the world every year. Cancer is the second leading cause of death in Ireland. Cancer and the secondary effects of treatment lead to an increased disease burden for patients, their families

and health systems worldwide. This suggests the ongoing necessity of spending resources in cancer research at a prevention and intervention level.

The current literature indicates that illness in one family member impacts on other family members, suggesting that research should have a systems approach to truly understand the impact that illness can have on a patient, their surroundings and their families. All studies suggest that this systemic approach is necessary and, therefore, adolescent adjustment needs to be explored from a more ecological perspective. There is, however, a contradiction in research findings regarding the impact of family on adolescent adjustment. Some studies suggest that families help adolescents to cope successfully while others indicate that families do not support adolescents who are left to struggle alone with unmet needs. One important point from the literature is that it should not be assumed that families experiencing illness will necessarily be in a state of chaos. Studies have suggested that some families are able to adjust successfully and the variables associated with successful or unsuccessful family adjustment include communication style, conflict, cohesion and coping. All of these aspects are, therefore, important to explore to understand family responses to illness .

Current research agrees that parental illness has an impact on other family members including adolescents, but there is ongoing debate in terms of what the actual impact is. Some studies suggest adolescents have negative outcomes but others have described the opposite. The reasons for these differences are not completely clear which suggest the need for more studies to explore the variables, that influence adjustment and to identify possible reasons for these differences in adolescent adjustment.

From a methodological viewpoint, the definition of adjustment has varied across studies and thus measurement tools have also varied, making comparison across studies difficult. The majority of studies are cross sectional and, therefore, there is a lack of understanding of the process of adolescent adjustment over time. The time since diagnosis across the literature is varied, for example, from one month up to five years after diagnosis (Litchman et al., 1984; Hymovich, 1993; Howes et al., 1994). This can make comparisons between findings challenging.

Another possible explanation for differences in research findings is that there is variety in the age range of participants, mixing participants from early childhood to late teens (Sieh et al, 2010; Issel et al., 1990; Hilton, 1993) and so ignoring developmental characteristics specific to each developmental stage. Research focused on family systems also seem to describe family experiences as a whole, ignoring that needs and experiences of different family members, therefore, the knowledge of individuals within the system is very limited. Adolescent experiences are particularly invisible when such a large range of ages are included in the same study and data is not analyzed from a developmental perspective.

Furthermore, within this developmental perspective, current research seems to suggest that girls may struggle more than boys at a time of parental cancer. Research, however, does not provide explanations for these differences suggesting that further research needs to go beyond a descriptive level to identify reasons or underlying causes. It would be important also to identify how to provide adequately for their needs taking into account gender based differences in experiences.

Summary

Parental cancer during adolescence can be a stressful and challenging experience as illness demands and family demands increase the demands that adolescents have to cope with simultaneously. Adolescents also experience changes in their families and relationships with their ill and healthy parents. Changes are also related to additional responsibilities and being in contact with new contexts such as hospital settings.

Cancer is conceptualized as a stressor that affects families differently according to family structures and characteristics. Cancer in a parent can affect the whole family and cause significant changes and challenge for adolescents. Family structure and characteristics have an impact on adolescent adjustment. Families with open communication and closer cooperative relationships facilitate adolescent adjustment.

Diagnosis seems to be the most stressful times for adolescents and their families. During treatment, adolescents struggle with parental physical and behavioural changes due to treatment and disease complications. After

treatment adolescents struggle with the possibility of having cancer themselves and the fear of recurrence.

There are mixed findings on the impact of parental cancer in adolescence. Some studies suggest adolescents struggle but others suggest they seem to adjust well. Girls appear to be more vulnerable than boys, although there are conflicting findings on this. Adolescents perceive that there is a lack of attention given to them in hospital settings which may increase their vulnerability and access to help. Adolescence is a time of separation and identity formation but parental cancer instead brings adolescents back into their family system which can be challenging and conflicting for them.

There is a common perception in adolescents that maternal cancer is a life changing experience as normal patterns of life are altered. Adolescents can identify positive gains from a very difficult experience such as a growing up and maturing.

Research Overview

Research objectives

1(a). Explore the subjective experience of adolescents' psychological adjustment to maternal cancer with particular focus on perceived social support.

1(b). Explore mothers' perceptions of their adolescent's adjustment to maternal cancer.

2(a). Design and pilot an online intervention to enhance adolescent adjustment to maternal cancer within two years since diagnosis.

2(b). Examine the role and relative impact of perceived stress, coping, perceived social support, maternal attachment and self-efficacy on adjustment (mood and wellbeing).

2(c). Explore the mediating and moderating effects of social support in the relationship between perceived stress, coping and adjustment.

Research Design

The AMC is an exploratory study which is focused on exploring and understanding the processes of adjustment of adolescents experiencing maternal cancer.

The research has a mixed methods approach specifically consisting of a concurrent design. This means that both qualitative and quantitative phases of the research study happened simultaneously. Therefore, the AMC Study has a convergent parallel design (Creswell & Plano Clark, 2011).

Recruitment Chronology

1. Design and piloting of the AMC Programme. The AMC Programme design was based on previously existing interventions for families and young people experiencing cancer in their lives. Social support interventions also informed the design and content of the programme. To verify the appropriateness of the programme, this first version was piloted by Irish adolescents (N=16) with no previous cancer experience. They were recruited to evaluate the

intervention for developmental appropriateness (These adolescents did not have any other involvement in the research process).

2. Forty adolescents (31 Irish and 9 international) experiencing maternal cancer were recruited.
3. A total of 15 adolescents completed qualitative semi structured interviews (15/40). The criteria of data saturation (no new information or themes emerge from the data) was used to determine the sample size required for the qualitative phase of the study. Once this was achieved, no additional interviews were required. The remainder of the adolescents recruited continued to the quantitative phase directly.
4. A group of ten Irish mothers with a cancer diagnosis completed semi structured interviews.
5. All adolescents recruited at phase 2 completed the baseline questionnaires (40/40).
6. Fourteen adolescents completed all phases of the AMC programme and so completed questionnaires at baseline, post-test and at two month follow-up (14/40).

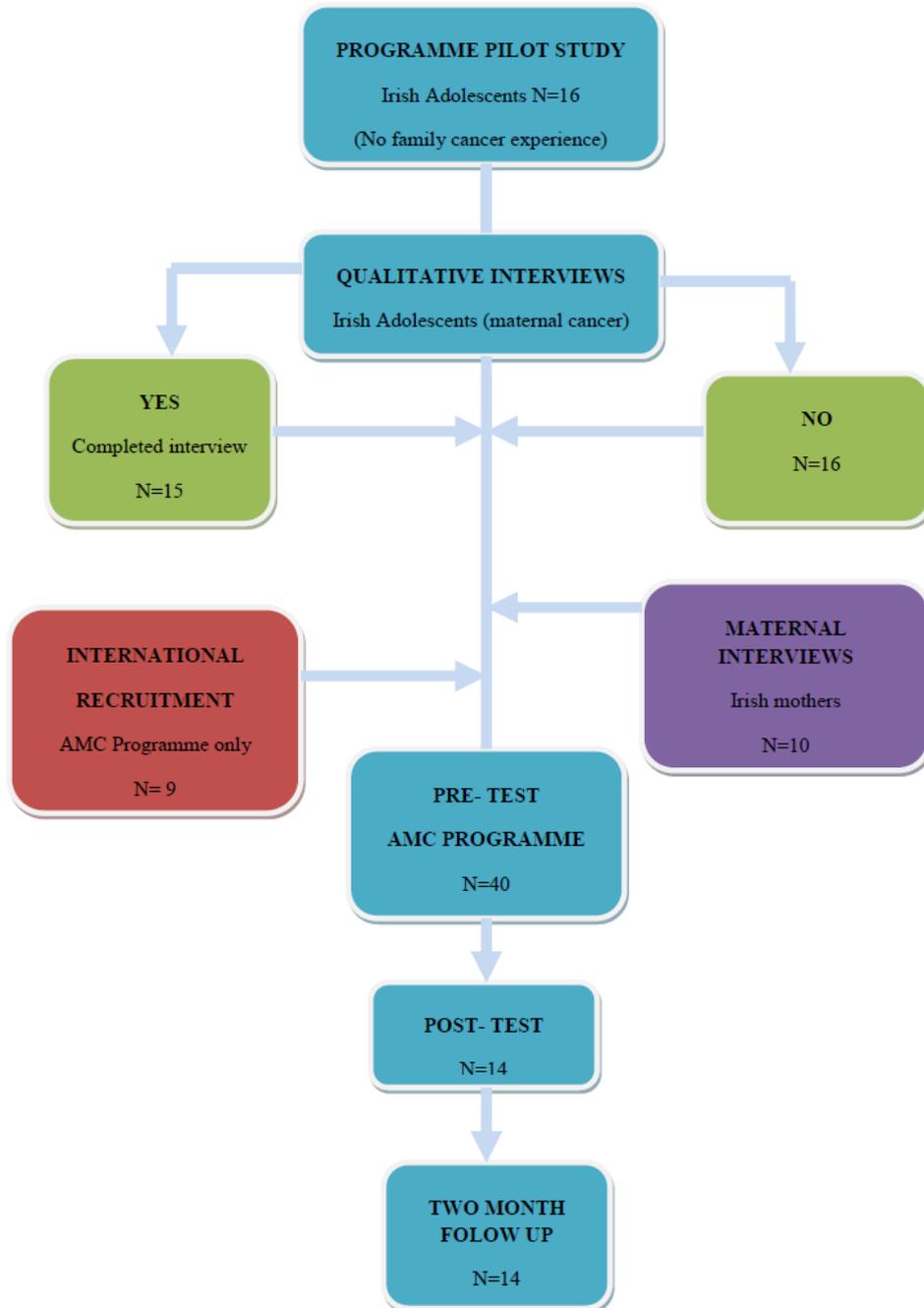


Figure 4. AMC Study Chronology

CHAPTER 3

META-ETHNOGRAPHY: A QUALITATIVE UNDERSTANDING OF THE EXPERIENCES OF PARENTAL CANCER IN ADOLESCENCE

Introduction

Previous research has conceptualized adolescence as a time of change and developmental challenges involving biological, cognitive and psychological changes (Lalor, et al., 2007) that can be stressful for any young person (Cicognani 2011). These challenges include identity formation, separation from authority to achieve independence Arnone (2014). According to Cicognani (2011) most adolescents have the resources to cope and adapt productively, however, research has also suggested that adolescents facing parental cancer may be at a more vulnerable state due to additional demands that may also be conflictive: separation from the family and their need to establish relationships outside their families and on the other hand, all the psychological, practical and social demands of the illness (Visser et al., 2004). Lewis et al. (1985) described the experience of maternal cancer as the ‘ultimate test’ for an adolescent as they are attempting to withdraw from their mothers, and instead they are needed.

This meta-ethnography explores the experiences of adolescents facing parental cancer in order to understand the meaning of this experience at this developmental stage, the characteristics, conflicts and possible simultaneous demands faced by a young person but also to help understand how they manage to cope and adjust. It is the first metaethnography conducted to date on the topic of adolescent adjustment to parental cancer. It is a secondary analysis of empirical data contained in existing published empirical qualitative research that will provide a renewed and comparative approach to current findings in the field which will help to accommodate possible inconsistencies and underlying similarities in research findings. This meta-ethnography is based only on self reports from adolescents as Alderson (2008) suggested that the best source of information on a child’s life is the child himself even if “*we are still not good enough at hearing them, in the sense of taking full account of what they tell us*” (Roberts, 2008, p. 260). Alderson and Morrow (2011) suggest that when the views of

young people are not known due to lack of research it can be harder to ensure that the best services and opportunities are being provided for them, or even to know how to improve existing services that may be harmful. Woodhead and Faulkner (2000) suggested that valuing children's experiences and perspectives is the essential basis to develop genuinely child-centred policies.

Therefore, this synthesis will focus on describing the current research on adolescent adjustment to parental cancer. It will particularly emphasise the similarities and discrepancies and the possible underlying issues, both experiential and methodological that may be associated with these conflicting findings and so possibly translate adolescent accounts into effective interventions that can target their expressed needs.

Method

Qualitative synthesis is a method that emerged exclusively for synthesizing qualitative research to build cumulative knowledge and to make an informed judgement about the current state of knowledge and judge the quality, scope and comprehensiveness of published reviews. Qualitative synthesis is a secondary analysis that can involve a re-interpretation of published findings that may provide more clear and succinct findings for practitioners and policy makers than is the case from individual studies or narrative reviews (Britten, Campbell, Pope, Donovan, Morgan & Pill, 2002).

Meta-ethnography is a type of method for synthesising qualitative research across different studies (Campbell et al., 2003). Meta-ethnographies are focused on finding explanations for social and cultural events based on the perspectives of participants (Noblit & Hare, 1988). The benefit of meta-ethnography as a method is that it aims to “preserve the interpretive properties of primary data” (Atkins et al., 2008, p. 2) which means that patterns and insights are integrated across studies while maintaining the integrity of individual studies.

To preserve the holism and uniqueness of each study, a meta-ethnography requires the reciprocal translation of one study into another to determine how concepts are related to each other while preserving the structure of relationships between concepts within a specific research study,

reducing the possibility of de-contextualization, keeping the meaning of primary data but also providing a higher level of analysis to generate new conceptual models (Embuldeniya et al. 2013).

According to Kennedy and MacNeela (2014) the use of meta-synthesis of qualitative studies has proven useful in different psychological fields such as health psychology and can also make an independent contribution to a specialized area of empirical research, as qualitative synthesis may provide a mechanism to understand more about how a collective body of qualitative research studies contribute to the understanding of a specific topic within a field. It can also provide a broad approach to evidence based research, practice and policy by identifying how knowledge can be created and used in a specific field and provide an understanding of how, when and why and intervention may or may not be effective (Erwin et al., 2011).

Noblit and Hare (1988) outlined seven phases that are involved in a meta-ethnography. These are defined separately but may eventually overlap or be parallel.

Phase 1: Getting started

This phase involved identifying a focused research question that determined the “boundaries of the scope and depth of the synthesis” (Atkins et al., 2008, p.8). The research question for this meta-ethnography was: What are the experiences of adolescents adjusting to parental cancer and the specific role of mood, satisfaction with life, social support, coping, stress, self - efficacy and the relationship with the ill parent?

Phase 2: Deciding what is relevant to the initial interest.

This phase consisted of identifying a justification for studies which were relevant taking into account the principles of a meta-ethnography; synthesis of the findings and interpretations of the different studies included. This phase also included a definition of the focus of synthesis, location of relevant studies, inclusion and exclusion criteria and quality assessment.

Regarding the inclusion criteria, studies included had to be published in the English language in peer reviewed journals. They had to be qualitative and include the perspective of adolescents. Accounts had to be self reports, excluding perceptions of other family members or other

members of their social network (parents, siblings, and teachers). The time since diagnosis was varied, but parents needed to have had a diagnosis of non-terminal cancers and be alive at the time of the adolescent interview. Retrospective studies (adults recalling their experiences of parental cancer as teens), were excluded.

Scopus and PubMed data bases were searched for relevant studies (Figure 4) up to July 2014, therefore empirical research after this date is not included. Search terms included a combination of words: Children, adolescent, coping, adaptation, adjustment, parental cancer, maternal cancer⁴.

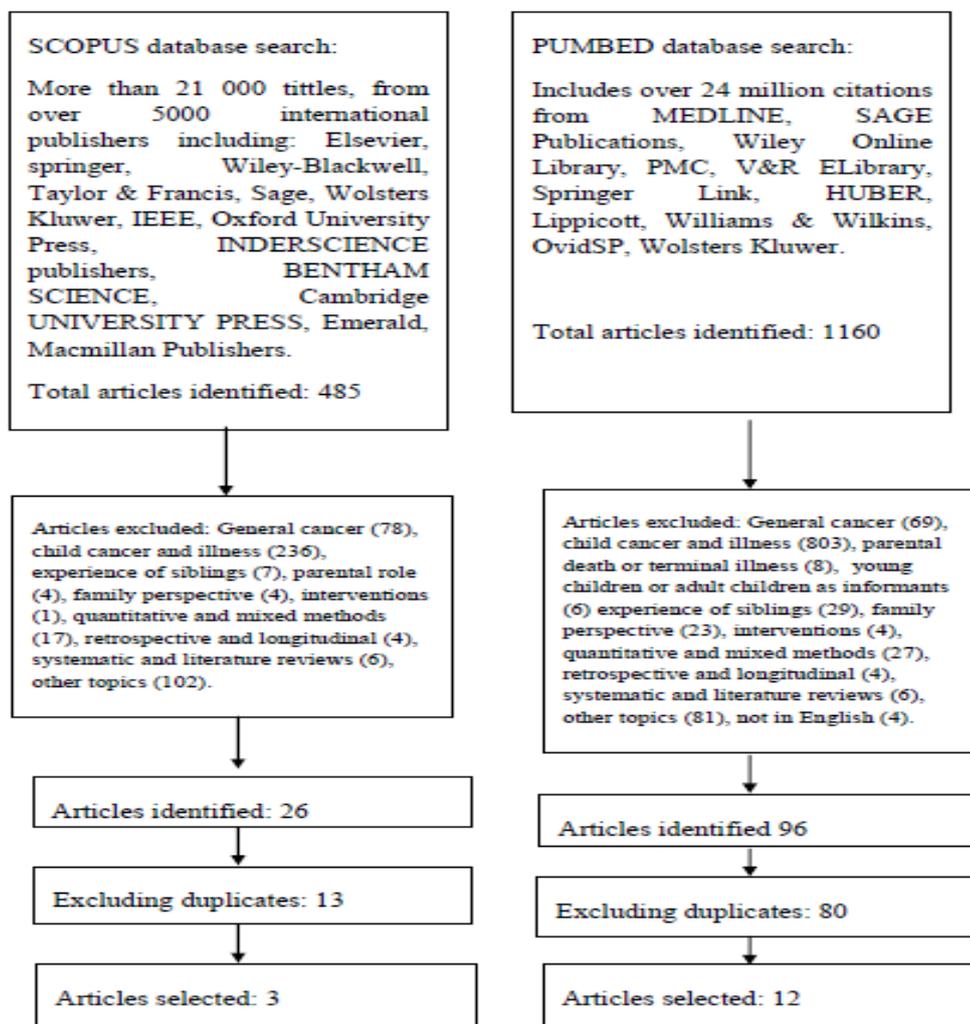


Figure 5. Chronology of Scopus and PubMed search.

⁴ The specific search terms can be obtained by contacting the main researcher.

The research on Scopus identified a total of 485 articles. These were manually reviewed and articles were excluded with the following criteria:

- (i) The category 'general cancer' included articles related to different topics about cancer for example medical treatments, fertility issues, marital relationships and usually had adult participants. A total of 78 articles were excluded.
- (ii) 'Child cancer and illness' included studies where children were diagnosed with cancer or with another chronic illness and studies about the difficulties of parents when children were ill. A total of 236 articles were excluded.
- (iii) The 'experience of siblings' included studies where brothers or sisters had a cancer diagnosis. Seven articles were excluded.
- (iv) 'Parental role' directly dealt with the experiences of the healthy male partner when the mother was diagnosed with cancer. Four articles were excluded as the focus of the meta-ethnography was the perspective of young people and their lived experience.
- (v) 'Family perspective' meant that the children were not self informants, their parent or other members of their social networks were also part of the studies. Four articles were excluded. One article was an intervention; which was not exclusively for adolescents.
- (vi) Quantitative and mixed methods were excluded as the focus of the meta-ethnography was qualitative data and interviews were the chosen method of data collection, therefore 17 articles were excluded.
- (vii) 'Retrospective' studies were excluded as participants were adults looking back at the time when they were adolescents and not adolescent participants talking about their own lived experiences.
- (viii) Quantitative longitudinal studies were excluded because they did not fit the criteria for qualitative methodology selected for this study and so four studies were excluded.
- (ix) Systematic and literature reviews were also excluded as these do not include raw data but are synthesized methods and, therefore, not suitable for analysis from an ethnographic method that preserves the essence and integrity of the data. Six articles were excluded; a total of 102 articles dealt with other topics usually unrelated to cancer but identified by the databases due to the combination of cancer with other search terms. A total of 26 articles were kept as candidates. These became 13 after eliminating articles identified by both data bases (duplicates); three

articles were kept for further analysis as they matched the inclusion criteria and were of good quality.

The search on PubMed identified 1160 articles. Articles were excluded with the same criteria as for the Scopus search: General cancer (69); child cancer and illness (803); parental death or terminal illness (8); young children or adult children as informants (6); experience of siblings (29); family perspective (23); interventions (4); quantitative, mixed methods or qualitative methods other than interviews (27); retrospective and quantitative longitudinal (4); systematic and literature reviews (6); other topics (81); not in English (4). A total of 96 articles were identified which became 80 after eliminating duplicates. A total of 12 were kept for further phases of the analysis as these matched the inclusion criteria and were of good quality after the quality check.

Overall, a total of 15 articles sourced in the two databases were selected for definite inclusion, two of which were duplicates so the total number of articles included in this meta-ethnography is 13 (Table 4).

Table 4: *List of Articles Included in the Meta-ethnography*

Author name and year	Title
Maynard, Patterson, McDonald and Stevens (2013).	What is helpful to adolescents who have a parent diagnosed with cancer?
Clemmens (2009).	The significance of motherhood for adolescents whose mothers have breast cancer.
Finch and Gibson (2009).	How do young people find out about their parent's cancer diagnosis: A phenomenological study.
Stiffler, Baranda, Hosei and Haase (2008).	When mum has breast cancer: adolescent's daughters' experiences of being parented.
Issel, Ersek and Lewis (1990).	How children cope with mother's breast cancer.
Rosenfeld et al. (1983).	Adaptation of children of parents

	suffering from cancer: a preliminary study of a new field for primary prevention research.
Hilton and Gustavson (2002).	Shielding and being shielded: Children's perspectives on coping with their mother's cancer and chemotherapy.
Forrest, Plumb, Ziebland and Stein (2009) ⁵ .	Breast cancer in young families: A qualitative interview study of fathers and their role and communication with their children following the diagnosis of maternal breast cancer.
Davey, Tubbs, Kissil and Nino (2011).	'We are survivors too': African-American youth's experiences of coping with parental breast cancer.
Thastum, Johansen, Gubba, Olesen and Romer (2008).	Coping, social relations and communication: A qualitative exploratory study of children of parents with cancer.
Kissil., Nino, Jacobs, Davey and Tubbs (2010).	'It has been a good growing experience for me': Growth experiences among African American youth coping with parental cancer.
Hilton and Elfert (1996).	Children's experiences with mothers' early breast cancer.
Fitch and Abramson (2007).	Information needs of adolescents when a mother is diagnosed with breast cancer.

Phase 3: Reading the studies

This phase involved synthesising by repeatedly reading the articles and identifying interpretative metaphors (themes) and details in the accounts that inform the concerns of this review. This synthesis focused on the results

⁵ Adolescent example quotes were included, therefore, this study was kept in the analysis.

section of each article including both the themes (concepts) proposed by the authors and the evidence provided by adolescent quotes.

Phase 4: Determining how the studies are related

Studies were synthesized by examining the relationships between them using a list of key metaphors, ideas, phrases and relations to juxtapose them. Initial assumptions about the relationships were made at this phase, concepts in each study were compared one by one to determine the extent to which these were endorsed and contradicted.

Author generated themes were input to a grid of themes, article by article. In this meta-ethnography, the initial grid of themes was then analyzed to identify groupings of similar themes or topics emerging. Two authors (main researcher and a qualitative research expert) discussed the accuracy of these emergent themes until consensus was reached. The authors used a method described by Wyverkens et al. (2014) called ‘hermeneutics of faith’. Joseelson (2004) described the hermeneutics of faith as a way to restore the meaning to a text, focusing on examining the message inherent in a specific interview text, while providing a ‘voice’ to the participant’s sense of subjective experience and meaning making. The aim of this analysis is to re-present, explore and understand the subjective world of the participant, or their social and historical worlds, trying to ‘understand the other as they understand themselves’ (p.6), without denying that the process of interpretation of the researcher may have an impact on what and how it is told.

Phase 5: Translating the studies into one another

At this stage, the research studies, themes and participant quotes were treated as analogies as this maintained the particularities, holism and allowed comparison between articles. These translations keep the central metaphors (themes) and concepts in the original articles. The terminology used in the articles was kept in order to remain faithful to the meanings and concepts (Britten et al., 2002; Wyverkens et al., 2014). Since the synthesis in the previous step compared and contrasted themes to endorse and contradict themes, the refutational arguments could emerge, these were kept and categorised separately into different emergent themes.

Phase 6: Synthesizing translations (themes)⁶

This phase involved deciding if the translations can be compared with one another. Themes were organized in a grid and analyzed to establish possible relationships between the studies, including those that were specific only for one study, and refutational and reciprocal themes to develop a line of argument (Britten et al., 2002). The building blocks of the synthesis were the second level of analysis, from which several third order interpretations emerged. The line of argument was then developed.

Phase 7: Expressing the synthesis (discussion)

Meta- ethnographies need to have intelligible concepts that are appropriate for the intended audience, therefore this phase involved identifying and assessing the intended audience to see the phenomena in question from their perspective and interpretations and to ensure that they also find it useful and insightful (Noblit & Hare, 1988).

Quality evaluation⁷

All articles were evaluated for quality using the terms included by Fingfield (2003) including: Stated purpose, research question, inclusion criteria, study demographics, data handling and collection, data analysis and interpretation, and evidence for data (Table 5).

All articles that were included stated a research purpose, except for Rosenfeld et al. (1983) but it included a statement which described the purpose for carrying out the study. Some articles proposed explorative and descriptive research purposes by studying children and adolescent's experiences of parental cancer (Maynard et al; 2013; Clemmens, 2009; Finch & Gibson, 2009; Stiffler et al., 2008; Hilton & Gustavson, 2002) adaptation (Rosenfeld et al., 1983) and child responses to cancer (Hilton & Elfert, 1996). Five of the studies had listed more focused or specific purposes: Coping (Issel et al., 1990; Davey et al, 2011) father-child

⁶ The translation synthesis and themes can be obtained by contacting the main researcher.

⁷ The quality check results can can be obtained by contacting the main researcher.

communication (Forrest et al., 2009); benefit finding (Kissil et al., 2010) and information needs in adolescents (Fitch & Abramson, 2007). Thastum et al. (2008) included a mixture of several aspects: ways of informing children, perception of parental emotional state, child coping, child coping related to parental coping concerns and child social support. Despite differences in the purposes of research studies, they still provided an understanding of adolescent experiences with parental cancer and were, therefore, included to obtain a comprehensive and detailed account of adolescents' experiences and the aspects of their lives and worlds that were influenced or affected by parental cancer.

Some studies included a variety of types of cancer diagnoses (Maynard et al; 2013, Finch & Gibson, 2009; Rosenfeld et al., 1983; Thastum et al., 2008) but the majority were solely focused on breast cancer (Clemmens, 2009; Stiffler et al., 2008; Issel et al., 1990; Hilton & Gustavson, 2002; Forrest et al., 2009; Davey et al, 2011; Kissil et al., 2010; Hilton & Elfert, 1996).

All studies specified participant demographics. Most studies included both male and female participants. Two were solely interested in the experience of daughters (Stiffler et al., 2008; Rosenfeld et al., 1983) and none were exclusively focused on male experiences. Not all studies included adolescent participants only; some included the perspective of other family members, mostly parents (Maynard et al., 2013; Forrest et al., 2009; Thastum et al., 2008), however studies were included if adolescent experiences were clearly identifiable and supported by examples of adolescent quotes. Some studies had a wide range of participant ages, including adolescents and younger children (Issel et al., 1990; Forrest et al., 2009; Hilton & Gustavson, 2002). Time since cancer diagnosis ranged from less than a year after diagnosis (Forrest et al., 2009) up to ten years (Thastum et al., 2008; Fitch & Abramson, 2007).

All studies specified the method used for data collection. The majority of studies used semi-structured, face-to-face interviews. Regarding data analysis and interpretation, twelve studies specified the type of analysis used: Phenomenological thematic analysis (Maynard et al, 2013) phenomenological interpretive paradigm (Clemmens, 2009); interpretive

phenomenological analysis (Finch & Gibson, 2009), empirical phenomenological research (Colaizzi 1978; Stiffler et al., 2008), descriptive phenomenological analysis (Thastum et al., 2008), qualitative grounded theory (Hilton & Elfert, 1996).

The majority of studies mentioned qualitative methods including: Content analysis (Issel et al., 1990); qualitative participatory action research (Hilton & Gustavson, 2002); thematic analysis (Forrest et al., 2009); content analysis (Davey et al., 2011; Kissil et al., 2010). Fitch and Abramson (2007) carried out both content and theme analysis. Rosenfeld et al. (1983) did not mention a specific method of data analysis but described inter-coder reliability and this is why the study was not excluded from the meta-ethnography.

Table 5 *Summary of Article Quality Check*

	Location	Age	Sample	Cancer type	Time since diagnosis	Method
Maynard et al. (2013)	Australia	14-22	Female (9) Male (6)	Stomach, breast, renal, lymphoma, mouth, leukaemia, ovarian	2.3 years	Interviews, Phenomenological thematic analysis
Clemmens (2009)	United States	13-19	Male (5) Female (6)	Breast	1 year	Interviews, Phenomenological Interpretive Paradigm
Finch & Gibson (2009)	United Kingdom	14-18	Male (4) Female (3)	Breast, non-Hodgkin's lymphoma, myeloid leukaemia	4-12 months	Interviews, Interpretive Phenomenological Analysis
Sitffler et al. (2008)	United States	10-15	Female (8)	Breast	1 to 12 years	Interviews, Theme analysis
Issel et al. (1990)	United States	6-20	Male (NA) Female (NA)	Breast	2.5 years	Interviews, Content analysis
Rosenfeld et al. (1983)	Jerusalem	12-20	Female (8)	Breast	2-3 years	Interviews, Inter coder reliability
Hilton & Gustavson (2002)	Canada	7- 21	Male (4) female (7)	Breast	2 years	Participatory action research, Comparative

Forrest et al. (2009)	United Kingdom	6-18	Male (15) Females (16)	Breast	2-5 months	analysis Interview, Coding NVivo
Davey et al. 2011	United States	11-18	Male (3) Female (9)	Breast cancer	2-32 months	Focus groups, Content analysis
Thastum et al. (2008)	Denmark	11-17	Male (8) Female (13)	Breast, lung, lymph, cervical	2-153 months	Interview, Phenomenological method
Kissil et al. (2010)	United States	11-18	Male (3) Female (9)	Breast	2 years	Focus groups, Content analysis
Hilton & Elfert (1996)	Canada	2-21	Male (9) Female (13)	Breast	12 months	Grounded theory
Finch & Abramson (2007)	Canada	13-19	Male (3) Female (10)	Breast	10 years	Interviews, Content and theme analysis

Results

The process of comparison and refutation of themes were grouped by an informed interpretation of the researcher into three units of analysis that could reflect, as closely as possible, adolescents own accounts and views of their experiences, through the process of hermeneutics of faith. The first theme is looking at adolescent fears and uncertainties when faced with the reality of parental cancer, an experience for which they were not prepared intellectually and emotionally. Theme one: An individual journey from diagnosis to the future. The second theme emerged by going beyond the individual level to understand the context in which experiences occurred for adolescents, particularly focusing on the reciprocal interaction between adolescents and their families. Theme two: My family and me: Our shared experience. The third theme is focused on adolescent abilities and coping strategies to manage the experience of parental cancer, including both internal and external resources. Theme 3: Coping and dealing with the unexpected.

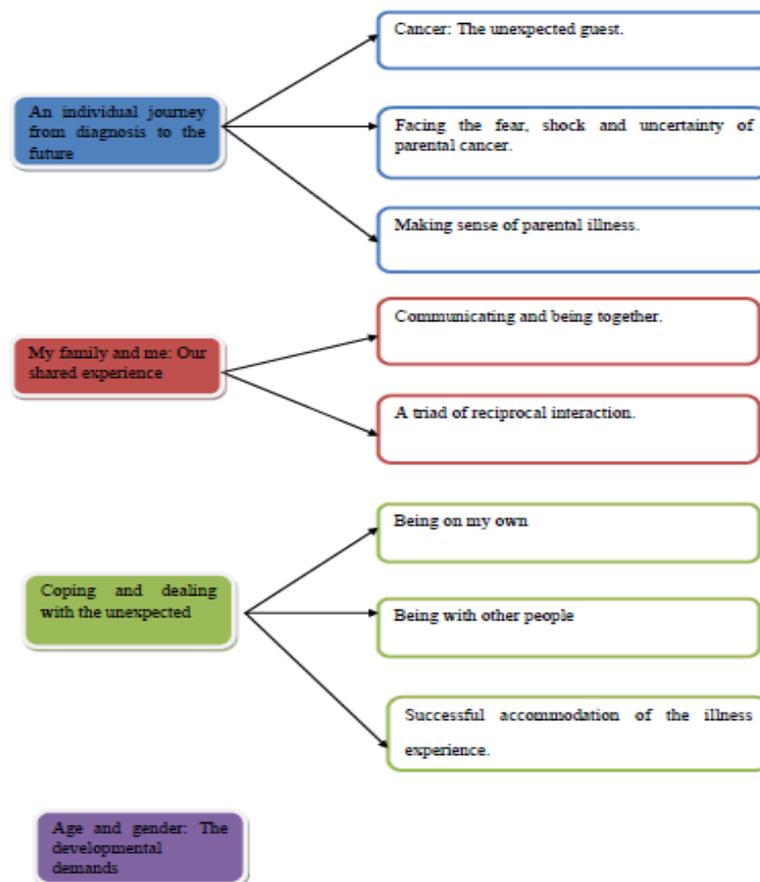


Figure 6: Themes identified in the meta-ethnography

An Individual Journey from Diagnosis to the Future

This theme is the synthesis of adolescent personal descriptions of parental cancer, which was portrayed as a journey from diagnosis, treatment and post treatment to the future, even if some studies were only targeted at a specific illness stage, each stage conserved its own identity and characteristics. Studies seem to agree and group these stages separately: Diagnosis, treatment and post treatment. The individual approach refers to the uniqueness identified in the lived experiences, even if all adolescents were facing parental cancer. The theme is specifically looking at the knowledge and perceptions of cancer but also at the emotional reactions to their parent's cancer, depicted as an unexpected experience that adolescents were intellectually and emotionally unprepared for.

Cancer: The unexpected guest.

This analysis described the experience of maternal cancer as a disruptive situation that brought fear and uncertainty into adolescents lives, particularly because the understanding of cancer they had at the time was limited and based on preconceived and very negative perceptions. Adolescents struggled with fear and uncertainty throughout the illness, not only at diagnosis, but also with the new challenges that emerged as the illness process unfolded.

Adolescents had a very negative perception of cancer and described it as a threat with uncertain outcomes (Rosenfeld et al., 1983) and also as a serious and threatening life event (Finch & Gibson, 2009). Cancer was also described as a serious issue (Forrest, 2009) and as “*nothing to play with*” (Kissil et al., 2010). Adolescents lacked facts about cancer and its treatment (Rosenfeld, et al, 1983). “*Mostly I just didn't know what it meant. Like I knew cancer was bad, but really didn't understand about it*” (Finch & Abramson, 2007, p.18). Adolescents associated cancer with death and this generated emotions such as fear (Finch & Gibson, 2009; Stiffler et al., 2008; Hiton & Gustavson, 2002), devastation and upset. “*I was like, devastated. Really upset, like, at first, I really thought she was going to die*” (Fitch & Abramson, 2007, p.18). Adolescent dealt with the fear of parental death with denial: “*I don't think cannot think that she will die*” (p.936).

Facing the fear, shock and uncertainty of parental cancer.

Adolescents experienced negative and unpleasant emotions at the time of diagnosis, particularly as a reaction to a drastic and unexpected event. Studies evaluated and described these emotions: Shock, surprise, disbelief, denial and guilt (Clemmens, 2009; Finch & Gibson, 2009; Forrest et al., 2009; Davey et al., 2011; Kissil et al., 2010; Stiffler et al., 2008); fear worry anger anxiety, stress and depression (Clemmens, 2009; Stiffler et al., 2008, Davey et al., 2011; Finch & Gibson, 2009; Forrest et al., 2009; Hilton & Elfert, 1996); distress, frustration, devastation, concentration/ memory difficulties (Clemmens, 2009, Forrest et al., 2009; Kissil et al., 2010); loss, vulnerability, helplessness, isolation, loneliness and sadness (Clemmens, 2009; Davey et al., 2011; Finch & Gibson, 2009; Stiffler, 2008).

Emotions were expressed in different ways and some adolescents had difficulties dealing with them. Hilton and Elfert (1996) reported that uncertainty, stress and anxiety were expressed as an increase in arguing, yelling, anger and upset between different members of the family. *“So we scream at each other...we often take our anger out on each other”* (p. 100). Some had difficulties in managing their emotions and reactions and described that their emotions would ‘get the better of them’. *“If I was having a bad day, I would displace my anger on everything. She would ask me a simple question and I just couldn’t handle it- I’d just start yelling”* (p.937). Finch and Gibson (2009) identified that adolescents wanted to be emotionally strong as a mechanism to cope with the changes and feelings they experienced due to parental cancer diagnosis but they also struggled to accept and understand the cancer diagnosis which led to feelings of shock, upset, anger and bitterness. *“Why did this happen to mum?”, ‘(...) it was unfair’. ‘I felt like I just wanted to run away from it all, just get out of the house, there was so much crap to deal with. I just wanted to forget it all”* (Fitch & Abramson, 2007, p. 18).

Although studies identified that adolescents struggled with their emotions this was not always applicable for all adolescents. The studies provide two separate possible explanations, firstly, maternal cancer may not have been a difficult experience for some adolescents and secondly, two studies provided developmental explanations as it was considered that adolescents may lack self emotional awareness. Hilton and Gustavson

(2002) described differences in young people's awareness of their own emotional states. Some were aware of their anxiety, fears and worries and others were oblivious (Stiffler et al., 2008). Hilton and Elfert (1996), identified that for some adolescents, the cancer experience was not perceived as a major life issue, but as an additional stress factor in their lives among others. Adolescents mentioned marriage break ups and other family issues.

Adolescent fears and worries seem to remain over time and extend after treatment. Studies described a need for 'normality'. Clemmens (2009) identified that the completion of treatment could provide this sense of normality '*I was hoping that once the radiation was finished things would get back to normal around here*' (p.574). Long term effects of the illness were sometimes difficult to revert, for example, Hilton and Elfert (1996) described that adolescents experienced more independence during illness and found it difficult to return to the way things were before. Adolescents also struggled with the fear of possible cancer recurrence (Davey et al., 2011; Stiffler et al., 2008) but also about the possibility of having cancer themselves '*I wonder like if I would have it but, who would be there for me...I don't want to be living too far and meet new people and nobody there to take care of me*'. (15-18 year old daughter) (Davey et al., 2011, p.82).

Issel et al. (1990) described a completely different experience, maternal breast cancer may have not been a difficult experience for adolescents and their families and an average of one year after diagnosis, adolescents may have already recovered from the experience. Adolescents closer to the event (Clemmens, 2009) tend to long for normality and struggle with the uncertainty of their future but several years after the diagnosis (Issel et al., 1990) adolescents do manage to come to terms with the experience of parental cancer.

Making sense of parental illness.

Studies suggested that adolescents had different needs and interest in information about cancer; however the lack of it could lead to additional uncertainty and fear. Hilton and Gustavson (2002) found that not all young people had the same perspective, some 'shielded' themselves from additional information but others were interested in researching additional

information. Young people's level of understanding and their response towards information depended on what others told them, what they read or what they heard. '*I understood the things I was told...that she would be alright and she'll be home soon (and wanted no further information)*' (p.201). The ill parent was identified as the main informant by Hilton and Elfert (1996). Studies specified that different households had different communication styles and needs regarding the cancer experience, some families were described as "*upfront and honest*" and "*really kept us kids involved*" when diagnosis was disclosed early on, but other adolescents learned about diagnosis later, however they did understand that their parents had reasons for not telling them earlier: "*I was in the middle of examinations*", "*I was too young at the time*" (Fitch & Abramson, 2007, p.18). Some families wanted to keep the issue private and young people respected their family's privacy approach to the cancer issue (Hilton & Gustavson, 2002).

Maynard et al (2013) reported that adolescents (14 to 18 years) appreciated when information was not withheld from them as this helped them prepare for the secondary effects of treatments, changes, understand parental behaviour, reduced their anxiety and made them feel included instead of isolated from their families. When adolescents were not given enough information they felt ignored (Rosenfeld, et al., 1983), hurt (Hilton & Elfert, 1996), and had a sense of separation and uncertainty (Fitch & Abramson, 2007). "*I felt in some ways I was kept in the dark a lot. Really not told everything that was going on. I guess they didn't want me to worry*" (Fitch & Abramson, 2007, p.18).

Other challenges for adolescents were related directly with the context of illness. Adolescents were usually not familiar with hospital settings and treatments. The studies suggest adolescent experiences as a duality, some described feeling safe and secure in the hospital setting as they could talk and obtain factual information, for others, the hospital generated anxiety and discomfort.

Findings regarding adolescent relationships and perceptions of the hospital setting and personnel are contradictory. Maynard et al. (2013) found that adolescents felt positively about meeting the doctor and treatment

setting as this would allow them to obtain information directly from the physician and humanize the doctor in charge of parental treatment. *“Seeing the doctors and stuff, was good because allowing me to see the doctor meant I could put a face to that person”* (p.686). Forrest et al. (2009) described that teenagers thought they would benefit from meeting their mother’s clinician to talk about treatment. Adolescents that had spent time with the ill parent also described their experience as positive (Thastum et al., 2008). Fitch and Abramson (2007) reported that adolescents wanted to talk to a doctor directly, and to know as soon as possible if something was wrong. Other studies, instead, described that adolescents felt anxious and fearful of the hospital setting (Finch & Gibson, 2009) and perceived the hospital as frightening and boring (Thastum et al., 2008). Davey et al. (2011) reported that adolescents felt a lack of appreciation and validation from medical staff. *“Yeah, even though they are survivors we are survivors too. What they go through we go through, they are our parents. Of course we are going through it with them”*, 11-14 year old daughter (p.82).

Maternal treatment, and possibly the fear and lack of familiarity with these procedures, made adolescents feel stressed and worried at the time of treatment. Adolescents experienced stress at the time of treatment; specifically Rosenfeld et al. (1983) reported that young people had higher levels of stress at the time of their mother’s mastectomy and chemotherapy. Forrest et al. (2009) described chemotherapy as the worst aspect of maternal illness because of secondary effects of illness like changes in maternal energy levels and emotions. *‘...We just know if mum’s slightly grumpy, it’s not our fault, it’s just the drugs making her slightly um er cranky and grumpy, and um we know that now like the next day after the chemo’s gone in, we must put her to bed and not make her do anything’* (Boy aged 14) (p.99). Finch and Gibson (2009) reported that the role of the treatment stage was to materialize or make the illness experience for adolescents ‘real’.

My Family and Me: Our Shared Experience

Adolescents and their families influenced each other in a reciprocal interaction throughout the process of parental illness. Adolescent experiences of adjustment were influenced by their families in positive but also in challenging ways. Good, positive and emotionally close interactions

and family relationships facilitated the process for adolescents, as they reduced the burden, provided support and safety for adolescents. Negative interactions, for example in dysfunctional families, added to the burden of adolescents instead.

Communicating and being together.

Most studies emphasized the importance of family cohesion and closeness as one of the aspects closely associated to positive outcomes in adolescence. Parents were described as role models for adolescents in terms of how to cope and how to adjust. Maynard et al. (2013) identified that adolescents perceived parental availability, invitations to talk, efforts to maintain normality, awareness of their behaviours, and spending time together as positive experiences in the family of '*strengthening the family*', (p.690). Maynard et al. (2013) and Issel et al. (1990) described the positive impact of parental availability because it helped young people manage and as a way to obtain information about the illness and treatment, which contributed to adolescent coping.

Finch and Gibson (2009) offered an interpretation of closeness in family relationships due to the cancer experience. This closeness, referred to as '*reciprocal interaction*', encompassed mutual understanding between members: "*I don't know I think we're closer, I think we're just nicer to each other and um...more understanding of each other...cos we all know exactly what each other's going through*" Sarah (p.220).

Consistent with this perspective on how illness brought families together, studies reported that families spent more time together (Clemmens, 2009; Hilton & Elfert, 1996; Kissil et al., 2010), which in turn had a positive impact on young people (Issel et al., 1990). Overall, almost half of these studies suggest that cohesion and sharing among the family led to a better experience for adolescents (Maynard et al., 2013; Finch & Gibson, 2009; Clemmens, 2009; Hilton & Elfert, 1996; Kissil et al., 2010; Issel et al., 1990).

Family support, on the contrary, was not perceived as crucial in one of the studies. Issel et al. (1990) described that participants perceived their families had done nothing to help them, not because they did not want to but

because breast cancer did not pose difficulties for them, it was “*no big deal*”(p.10).

Studies also described negative experiences and conflict in the parent-child relationship. Conflict was associated with changes in parental behaviour such as increased irritability, impatience, moodiness and paranoia. ‘*My mom was meaner... was more strict...and did not want me to go out*’ (15-18 year old son, Davey, 2011, p. 83). Adolescents could also feel annoyed if they perceived the ill parent could do more than they were doing ‘*I think she demands a lot more than she should like instead of having us get her a glass of water, why doesn't she walk downstairs....Like, just for the little bit of exercise...it's not going to kill her*’ (Hilton & Elfert, 1996, p.102).

Open and honest communication was difficult for adolescents specifically regarding parental cancer (Issel et al., 1990). “*We'll talk about most things but when it comes to dad's sort of thing it's a bit more of a delicate subject*” (Fich & Gibson, 2009, p.218). Issel et al. (1990) described communication about other non-illness related topics, such as “*everyday talking*” (p.8) as a way to help young people cope with maternal cancer. There was sometimes a lack of open and honest communication whereby young people did not share their true emotions with their parents (Rosenfeld et al., 1983; Hilton & Gustavson, 2002) as talking about their emotions made them feel guilty and selfish (Maynard et al., 2013) or it was a burden for the ill parent (Clemmens, 2009; Stiffler et al., 2008; Forrest et al., 2009) “*I couldn't call my Mom to talk to her (like I normally would) because I would talk to my brother, but I couldn't talk to her...I talked to one of the counsellors at school so that I wouldn't get overwhelmed*” (Clemmens, 2009, p.573). Thastum et al. (2008) used the term ‘parentification’ to describe how children suppressed their own needs and interests to protect their parents and preserve family stability. ‘*I don't talk with my mother about my feelings; we talk about her feelings. It's quite unimportant how I feel, if only she gets well*’ (Girl aged 13) (Thastum et al., 2008, p.133).

A triad of reciprocal interaction.

The cancer experience brought change to different degrees into adolescents' lives and their families, some were individual but others

mutually affected all members of the family. Changes in the ill parent associated with cancer, led to changes in the healthy parent and both led to changes in the adolescents. This can be described as a triad of reciprocal change: Cancer, adolescent, family. The way families handled these changes had an impact on how adolescents themselves dealt with them.

The degree of change that families experienced was varied, ranging from 'life continued as normal' to 'major shifts' (Hilton & Gustavson, 2002; Clemmens, 2009) and 'everything changed' (Kissil et al., 2010). Both minor and big changes were difficult and upsetting to handle and caused problems within families: "*I think we got on each other's nerves more...like bucking each other...We didn't feel good so we would get on each other's nerves*" (Hilton & Gustavson, 2002, p.202). All of the studies that are suggesting major difficulties with change are within two years or less since diagnosis, which may justify why this was not an issue explored in studies that were carried out later from time of diagnosis, adolescent and their families may have adapted to change over time or illness related changes may actually stop over a certain period of time after diagnosis. This issue, however, needs to be explored further as it may just be that studies were not exploring change at all and, therefore, did not include it.

The perception of change in adolescents was also determined by how families dealt with these changes. Some adolescents were protected from family stress and strains. For these adolescents '*(life) just continued*' (Hilton & Gustavson, 2002, p.203). For other adolescents changes brought about by cancer, were experienced as a "*world turned upside down*" (Stiffler et al., 2008, p.935) as they struggled to cope with additional stressors, parental illness demands and changes in their lives.

Some adolescents were very aware of family strains and stresses due to the illness. Adolescents noticed that usual things that happened around the house were not happening and described this as a time of disruption and uncertainty (Fitch & Abramson, 2007). Some adolescents were also concerned about the financial demands on their parents and took part time jobs or student loans to help their families (Hilton & Elfert, 1996).

Adolescents also witnessed changes in their ill parent, as they became weak and frail, needing care and support (Finch & Gibson, 2009 and

Thastum et al., 2008). “...*I was concerned about her energy level and like how tired she was going to be during the chemo...and whether she could do the same things she was doing before*”, 15-18 year old (Davey et al., 2011, p. 83). Hilton and Gustavson (2002) described that physical changes in their mother were difficult. “*It was hard when you look at someone with hair for such a long time and then all of a sudden it’s gone*” (p.202). “*We can’t do a lot of things with mum anymore...she’s got to rest up a lot for our concerts and science fairs and everything*” (p.203). Adolescents also reported feeling pity (Thastum et al., 2008) and mourned the loss of their mothers as they were before the cancer (Stiffler et al., 2008). Issel et al. (1990) identified that adolescents were capable of anticipating what their ill mothers needed as if they were ‘*in her shoes*’.

Parental illness made adolescents feel helpless “*There is nothing you can do to change the situation*” (Hilton & Gustavson, 2002, p.201), impotent (Forrest et al., 2009) and frustrated “*I can’t do anything besides trying to cheer up my mother. I wish I could invent something new or be a doctor*” (girl aged 13, Thastum et al, 2008, p. 132). In response to parental illness, adolescents tried to be more helpful with their ill parent and also take additional responsibilities at home to reduce parental worry (Davey et al., 2011). Adolescents were protective of their ill parent (Stiffler et al., 2008; Thastum et al., 2008) and reached out to their mothers. “*Cuase I mean if you reach out to your mom when she’s going through something like this, she’s going to reach back*” (Clemmens, 2009, p.574). Adolescents were also involved in caring roles for the ill parent like changing dressings, going to the cancer clinic, assisting with hair care, wigs and breast prosthesis. “*I knew it had to be done...it was sort of like a big mother nurse role took over in my head*” (Hilton & Elfert, 1996, p. 102).

Some adolescents perceived helping in household chores as a positive experience (Rosenfeld et al, 1983; Thastum, 2008) that allowed bonding and union. “*It made the family much better. We all chipped in around the house, did things for our parents because it’s hard for them while mum’s sick and my dad is trying to keep the family working. So it’s good we all worked together and bonded as a family*” (Maynard et al., 2013, p.691). Not all adolescents, however, had a positive experience

helping around the house and doing additional chores, as this meant they had less time to spend with friends and peers. (Hilton & Gustavson, 2002; Kissil et al., 2010; Fitch & Gibson, 2007; Rosenfeld et al., 1983; Thastum, 2008; Stiffler et al., 2008). Adolescents perceived these additional duties as intruding into their normal social lives (Stiffler et al., 2008) and this generated conflict.; ‘*I really did not go out that often anyways because I wanted to stay with my mom and then the one time I go out and that happens I think I should not go out anymore. So I felt really bad*’ (Hilton & Gustavson, 2002, p.204). This suggests a conflict between adolescents developmental needs and parental illness demands, adolescents wanted to be ‘normal’ and spend time with peers but instead were needed at home to help with chores and the general running of the household.

Parental cancer had a variety of effects on the parent-child relationship, from improving, worsening or not changing it at all. No changes in the relationship between parent and child could provide stability for adolescents. ‘*I think a lot of what was good was that our relationship didn’t change. It is just still the same. We were still the same two people and acted the same around each other and not having that big relationship shift I think made it feel more stable*’ (Maynard et al., 2013, p.683). Some adolescents had an intense emotional bond, like friends and peers more so than parent-child. ‘*I think we actually grew closer because (...) when somebody is sick the relationship is a little bit different, you are worried about them and you talk to them more, so I guess the relationship is growing sort of*’ (Kissil et al., 2010, p.283).

Adolescent experiences were challenging due to the illness in one of their parents but dealing with the healthy parent was another challenge and they were aware of the struggles and stresses of the healthy parent, as well as the ill one. The majority of studies, however, have explored the experiences of adolescents when male fathers were the healthy ones and not females.

Adolescents described difficulties when they watched a father cry and this was interpreted as a sign of weakness which made the situation more difficult for adolescents as the person that used to be strong was no longer available to provide that strength (Thastum et al., 2008). ‘*It’s like I’d never*

seen dad cry before. It was pretty shocking. He's always the one who's always got it together...yeah my dad's very strong. He's...a rock really. But to see him break down and stuff was pretty harsh. Yeah that probably would have been the hardest thing for me'' (Maynard et al., 2013, p.682).

Adolescents also expressed empathy towards the healthy parent (Thastum et al., 2008). ‘*It did affect him. He's got like a bad temper, so I think that didn't help at all and he just took everything out on everyone, not intentionally, but because he found it so difficult.*’ 13 year old girl. (Forrest et al., 2009, p. 100).

Coping and Dealing with the Unexpected.

Maternal cancer was a challenge for adolescents, a difficult situation, unlike any other they had experienced in their lives before and which required adolescents to identify and make use of personal strengths, resources and coping skills to help them strive and adjust. From this analysis it was found that all adolescents had and used different skills, even if they were dealing with the same issue (parental cancer).

‘Being on my own’.

Some adolescents required spending time on their own as a coping mechanism (Maynard et al., 2013; Clemmens, 2009). ‘*So most of the time I'd spend either in my room or in the basement just by myself so I had to escape somewhere*’ (Clemmens, 2009, p.573). Adolescents wanted to rely on themselves, make their own decisions and solve their own problems but overall they were autonomous and had a personal sense of agency that allowed them to select the way they wanted to cope (Clemmens, 2009).

Other adolescents also used very private mechanisms to cope. These included: faith (Stiffler et al., 2008), prayer (Issel et al., 1990; Hilton & Gustavson, 2002), spirituality (Davey et al., 2011), keeping a diary (Issel et al., 1990), and meditation (Hilton & Gustavson, 2002; Davey et al., 2011), yoga (Davey et al., 2011), relaxation (Davey et al., 2011), and creating balance (Davey et al., 2011), listening to music (Clemmens, 2009; Issel et al., 1990), writing (Issel et al., 1990), drawing (Issel et al., 1990), watching TV (Hilton & Gustavson, 2002) and playing video games (Davey et al., 2011) ‘*When I just want to relax I just turn on the classical station and just*

lay down....close my eyes and relax, meditate, and do yoga'' (15-18 year old daughter, Davey et al., 2011, p. 82).

Adolescents also concentrated on their studies as a way of staying busy (Fitch & Abramson, 2007; Davey et al., 2011) ‘*I would cope by doing work and studying and doing things like that...keeping busy or cleaning or doing something. I had to keep busy''* (15-18 years, Davey et al., 2011, p. 80). Personal thinking processes were often used. Some studies described that adolescents made a conscious effort to think positively (Stiffler et al., 2008), rely on their sense of humour (Stiffler et al., 2008), foster a sense of hope (Thastum et al., 2008; Davey et al., 2011; Hilton & Gustavson, 2002), be optimistic (Thastum et al., 2008) use wishful thinking specifically wishing for new treatment and medications that would save their ill parent. ‘*My mother’s illness can probably be cured within a couple of years''* (girl, aged 13, Thastum et al., 2008, p.133).

‘Being with other people’.

Adolescents also coped with parental cancer with the aid and support of their peers; this allowed them to disengage from the illness and be involved in ‘normal’ social contexts and activities like other adolescents their age.

Adolescents played sports (Clemmens, 2009; Issel et al., 1990; Davey et al., 2011; Fitch & Abramson, 2007): ‘*I was shocked, yeah, and really upset but I didn’t want everyone at school to know. Like, I could go and do athletics and forget it. Like it was all so unfair and, well I guess I was pretty bitter about it''* (Fitch & Abramson, 2007; p.18), others spent time with friends (Clemmens, 2009) or just spent time outside the house (Stiffler et al., 2008).

Friends were very important sources of support for adolescents as they were described as capable of understanding and responding precisely to adolescent support needs at the time (Forrest et al., 2009; Issel et al., 1990), ‘*friends always know what to say to make you feel better''* (female, Finch & Gibson, 2009, p.219). Not all adolescents, however, enjoyed communicating with friends, according to Davey et al. (2011) some adolescents preferred to confide with nuclear and extended family as opposed to their friends.

Adolescents had different sources of social support, apart from their friends, including community, extended family and peers who shared the experience of parental cancer. These supports provided different types of support but also provided them with an opportunity to use their own strengths, abilities and the experience of parental cancer itself to also provide support for others facing a similar situation: *“I just like meeting new people and helping people through what pretty much I’m going through at the same time, and knowing that other people out there are going through exactly, well almost exactly, what I’m going through. And there is support out there for anyone like me if I need it”* (Maynard et al., 2013, p.692). Only two studies included information on support received from schools. According to Finch and Gibson (2009), support provided by schools varied, some young people reported that it was nonexistent and others suggested it was quite good: *“I would have liked them to sort of, I don’t know um acknowledge that I might actually be upset (rather than) ignore it which is what I feel they are doing”* (female, p.219). Fitch and Abramson (2007) described that the school was one of the places where adolescents found someone to talk to: *“this information has emotions to it. It’s not just facts. So when you hear it you felt something, you know. Like you need to have someone who understands you”* (p.19).

Community support, however, was not appreciated or wanted by all adolescents, Hilton and Elfert (1996) found that some adolescents did not want to talk about their experience with family and relatives because *‘they tend to get in the way and fuss unduly’* (p.101). Hilton and Gustavson (2002) found that some young people did not like talking about the experience and felt bothered when other people asked them about their ill parent: *“I didn’t want to tell the whole world so I guess I was a different person at school”* (p.202). Rosenfeld et al. (1983) suggested that some girls did not tell other people because they *‘did not want to be pitied’* (p.247) and they *‘did not want to embarrass anyone’* (p.247).

Successful accommodation of the illness experience.

Adolescent coping allowed them to adjust to the experience of parental cancer and this had positive gains in their lives, providing them with a positive self identity and the possibility of identifying with their peers

who did not necessarily share the same experience of parental cancer with them.

Supporting adolescent sense of agency further, studies reported that they had a conscious purpose that they wanted to achieve with the coping strategies they chose to use. They seemed to have a targeted idea of the directedness to their actions. Some of the motivations included spending time away from the cancer (Maynard et al., 2013; Fitch & Abramson, 2007; Clemmens, 2009); distraction and avoidance from the illness. Distraction and avoidance, for example, allowed adolescents to stop thinking about the severity of the situation. *“I tried not to think about how bad the situation may be”* 15-18 year (Davey et al., 2008, p.80). Thastum et al. (2008) specifically mentioned that adolescents in their study were very aware of their use of distraction to divert negative thoughts and emotions associated to the illness.

Achieving normality allowed adolescents to acquire a sense of security and being able to accommodate to the threat posed by the fear and the changes arising from the illness. Normality was achieved by maintaining routines in school, in after school activities and in family life. *“It gives you a sense of security, knowing that everything still happens”* (Maynard et al., 2013, p.682). The experience with cancer eventually became part of adolescent ‘normality’ (Davey et al. 2011; Kissil et al., 2010) *“It’s just been such a long time since we found out now...I’m kind of used to it. It’s just another part of life really”* (female) (Finch & Gibson, 2009, p.217). Studies however do not specify if this new ‘normal’ that adolescents adjusted to is something they can live with and not experience eventual maladaptation or distress.

Regarding positive gains, adolescents were able to identify positive aspects or benefits associated with their overall cancer experience. Adolescents went through a process of self-reflection and seeking meaning (Hilton & Gustavson, 2002; Stiffler et al., 2008; Thastum et al., 2008). Some adolescents experienced existential issues and described how the cancer experience had changed their perception of life and some things did not seem as important as they were before i.e., that their *“outlook in life changes”* (Finch & Gibson, 2009, p.218).

Hilton and Gustavson (2002) suggested that the illness had given adolescents a new perspective on themselves and they had grown up fast (Fitch & Abramson, 2007). *“I grew up really fast because all of a sudden you are expected to do so much but you aren’t used to it but you adjust...”* (p.204). Cancer also allowed them to see new strengths not identified in the past (Davey et al., 2011), a sense of increased personal strength, increased maturity and sense of agency (Kissil et al., 2010). Adolescents also described that they became more empathic towards other people *‘I’ve seen people with baldheads before and (...) it did look kind of ;funny (...) I knew that it was like cancer, so I knew it was really bad. But like now if I see people like that I’m like ‘Oh, you’re going through the same thing my mom is’ and so, there is a lot of people out there who are going through it’* (Kissil et al., 2010, p.283). Adolescents had a greater appreciation for life (Stiffler et al., 2008) and different priorities. *“I look at life in a different way; there is no guarantee to be a walk through the park for anyway or anybody (...) I’m not gonna take life for granted”* (Kissil et al., 2010, p.283). Some adolescents, however, could never achieve a positive outlook and were angry. They described the experience as an *‘injustice of faith’*, Thastum et al. (2008).

Age and gender: The developmental demands

Adolescent age and gender shaped the experience of parental cancer. Developmental demands such as independence, security and self identity are interrupted or delayed due to maternal illness. At a time when they were trying to pull away, they were pulled back into the family (Hilton & Elfert, 1996). Clemmens (2009) described adolescence as a time when young people need to explore emotional and cognitive independence from their parents yet need a secure attachment base from which to explore, but maternal cancer caused parents to be unaware of the internal emotional states of their adolescents. Finch and Gibson (2009) emphasized that adolescents may feel vulnerable and isolated at the time of parental diagnosis when security and self-identity are developmentally important. Stiffler et al. (2008) suggested that adolescents may feel guilty continuing with their normal adolescent lives when their parent was ill. Adolescents responded to the conflict between developmental and illness demands in

different ways. Issel et al. (1990) identified one of these strategies was denial. Perceiving the illness as ‘no big deal’ (p.10) was a way in which adolescents tried to build an identity separate from their parents.

Age differences were also identified in the ways adolescents coped. Issel et al. (1990) found that only older adolescents described that everyday talking helped them cope, compared with younger children. Regarding helping out and doing chores, more young participants than older ones said they were involved in helping around the house. Older adolescents and not younger ones seem to be considerate with their mother and being concerned about what she ate and wanting to please her. This specific age topic was not supported by participant quotes which may suggest an interpretation from the authors.

Studies also described gender differences in coping. Hilton and Elfert (1996) described that adolescent girls tend to focus on school and outside activities to reduce the time spent at home to avoid stress and conflict. Boys and girls seem to cope in different ways, for example a daughter explained her appreciation of maternal cancer as follows: ‘*it was scary to think about what life would be like without mum...I can’t sleep anymore*’, her brother instead said: ‘‘*Should I be worried?...I just blocked it out....maybe I should (worry)*’ (p.100). The girl worried, the boy blocked the situation; however this finding lacks support from other research.

Another gender difference identified by Hilton and Elfert (1996) was daughters’ acknowledgment of their increased risk of having breast cancer themselves in the future. This same study described that daughters were usually more involved in more intimate care giving duties. Daughters were allowed to see the maternal scars of breast cancer but not the boys. It is not clear, however, if these differences are due to the fact that the diagnosis was breast cancer or if it is just a gender related issue as traditionally females are linked with more care giving roles than males.

Overall, studies are suggesting the need to adopt a developmental awareness to parental cancer experiences in adolescents, as age and gender seem to be related with outcomes; however more research evidence is necessary to support this hypothesis.

Line of Argument Synthesis:

Factors Associated with Adolescent Experiences of Parental Cancer.

This meta-ethnography identified individual and contextual factors that have an impact on adolescent adjustment experiences. These differences determined if adolescents would experience more positive or instead negative outcomes.

Adolescents that experienced more positive outcomes seem to be those that had more knowledge and understanding of cancer, some even described cancer as ‘not a big deal’. These adolescents did not report experiencing drastic changes in their lives due to parental illness and generally had access to information or wanted to do research about cancer themselves. They generally had a more positive attitude toward hospital settings and illness and responded to maternal changes by being more protective and caring and involved themselves in more household chores as a way to willingly ‘reach out’ and support their ill parent and families. Young people in more cohesive, nurturing and supportive families also reported better outcomes. Some adolescents described benefits from having support and comfort from external sources, particularly their friends and school. Better adjusted adolescents purposefully used specific coping skills that allowed them to adapt successfully and even identified positive gains from the experience such as appreciation for life, maturity and empathy. These adolescents could adjust better to the illness and it became part of their new ‘normality’.

Adolescents that experienced more difficulties to adjust lacked factual information about cancer and struggled to cope with the emotions triggered by the cancer diagnosis. They described experiencing fear, devastation and upset that could last over extended periods of time. Those adolescents that had difficulties adapting to change reported more disruption and uncertainty; some of these adolescents were also unfamiliar with hospital settings or considered it as boring and frightening. They also struggled more and could experience additional stress in these contexts. Adolescents that experienced additional responsibilities and perceived them as disruptive expressed more frustration and difficulties. The family context also contributed. Adolescents involved in conflictive family relationships

and parental conflict reported more irritability and upset. Some of these adolescents lacked support from external sources such as friends and school, leaving them with fewer resources to cope with. Some adolescents also struggled with the long term consequences of parental cancer and so found it difficult to return to normality after treatment. These adolescents struggled over time with difficult emotions such as fear, uncertainty and ambivalence.

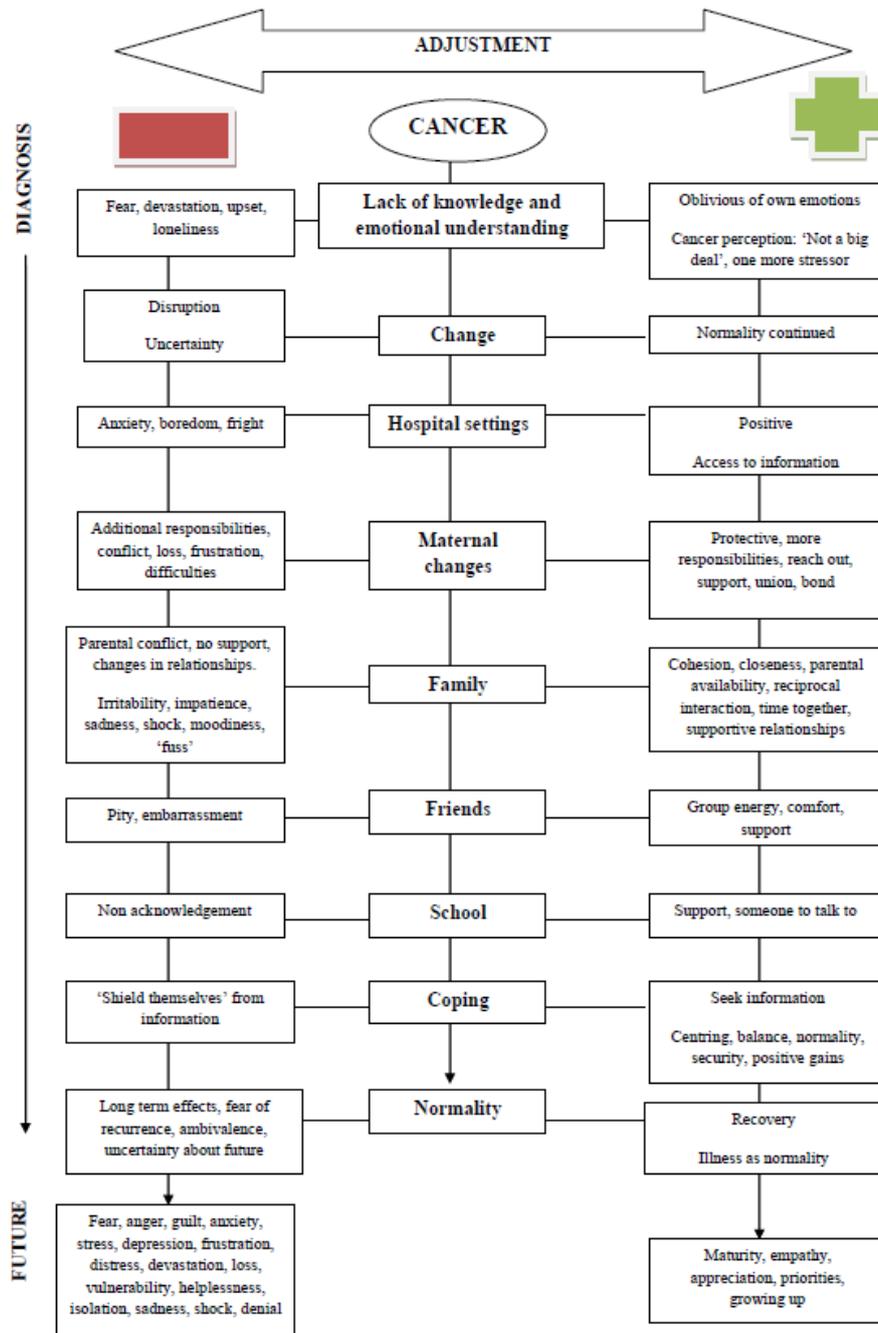


Figure 7 Line of argument synthesis

Discussion

This qualitative synthesis focused on a detailed description of the lived experiences of adolescents facing parental cancer with the objective of providing health practitioners, policy makers and researchers with additional tools to increase the understanding of needs and difficulties of adolescents facing this experience. The analysis identified individual approaches to the experience, the context in which the experience occurred and the skills adolescents have to deal with the challenges.

Parental cancer is an experience which demands a process of assimilation and accommodation to deal with the drastic changes imposed by parental cancer, not only for adolescents but also for the ill parent, the healthy parent and family routines and interactions. Most adolescents struggled to deal with the diagnosis of parental cancer, particularly because this was an unexpected experience and, therefore, they lacked the factual knowledge to fully comprehend it (Rosenfeld et al. 1983; Finch & Gibson, 2009; Forrest et al., 2009; Kissil et al., 2010). This uncertainty lead to experiencing emotions such as fear, devastation, upset and loneliness, except for those adolescents that instead ‘denied’ the illness as a way of protection. Research agrees that the majority of adolescents experience shock, disbelief, surprise, denial, guilt, fear, worry, anxiety, stress, depression, distress, frustration, devastation, loss, vulnerability, helplessness, isolation and sadness.

Findings of this study can be compared with previous research. Sales (1991) also described that in the initial phase, family members shared the common belief that a cancer diagnosis was a death sentence, as it disrupted the continuity of all family members and future plans. Diagnosis was described as the most stressful time for patients and their families (Davey et al., 2003; Hilton, 1993; Northouse, 1984). Leedham and Meyerowitz (1999) identified that adolescents experienced substantial difficulties during the acute phases of diagnosis and experienced strong negative emotional reactions such as anger, confusion, surprise and worry.

The accommodation required is emotionally difficult and unsettling for adolescents own self, which may be why some deflect or deny it. These adolescents perceived cancer as ‘not a big deal’ or part of several stressors

they already had in their lives. Another exception identified is the suggestion that some adolescents may not be aware or are oblivious of their own emotions and this creates even more difficulties for them to deal with the emotions associated with the news of parental cancer.

Parental cancer brings changes into adolescents' lives and their families. The analysis evidenced that changes, even small ones, can be disruptive for adolescents; however, there were exceptions to this, particularly in families that deliberately protected adolescents from illness related information, therefore, some adolescents described the experience as if their lives continued normally. Adolescent experiences of change, therefore, seem to be shaped by family coping styles.

Adolescents seem to struggle with uncertainty not only at the time of parental cancer diagnosis but throughout the illness and into the post treatment (Clemmens, 2009; Hilton & Elfert, 1996). At the time of post treatment adolescents longed for normality, only to find out that 'normality' did not exist as such anymore. Adolescents in this stage struggled with long term effects of the illness, fear of recurrence and ambivalence and uncertainty about their future and how the illness would affect it such as having cancer themselves. There were exceptions also because some adolescents explained that they had 'recovered' after one year and others explained that the illness became part of their normality (Issel et al., 1990). From a developmental perspective, parental illness seem to add to adolescent developmental burden and the already existent levels of developmental uncertainty involved in adolescence, Lalor et al. (2007) described adolescence as a time of energy, dynamism and potential, but also a time of uncertainty, awkwardness and searching for a place in society, dealing with the additional uncertainty may be difficult and challenging for adolescents.

Studies also agreed that the time of parental treatment was the moment when the illness became 'real' for adolescents particularly because they had to face drastic changes in their ill parents, both physical and behavioural and assume an 'illness identity'. The Identity Process Theory (Titmotijevic & Breakwell, 2000) assumes that the structure of identity is a dynamic social product that results from the interaction between

characteristics of the biological being (memory capacities, consciousness and organised construal) with the social context. People are active agents of the status of their identity and can revise it as required through the process of accommodation and assimilation, absorbing new components into the identity structure. According to this theory, specific experiences can become threats to identity if a person is exposed to a very different context to the one they were originally familiar with or if continuity, distinctiveness, self-esteem- and self-efficacy become unstable or disappear (Titmotijevic & Breakwell, 2000). For some adolescents the changes brought about by parental illness may be in fact threatening. For some adolescents in this meta ehtnography changes experienced due to parental illness were very difficult; they mourned the loss of their mum and felt impotent and frustrated (Stiffler et al., 2008).

Parental cancer can have a negative impact on parent-adolescent relationships at a time when secure attachment bases between parents and adolescents are beneficial for adolescents. Supportive and sensitive mothers allow adolescents to explore their own emotional responses but at a time of parental cancer, parents can become less aware of adolescent internal stress as they are dealing with their own stress and anxiety. Adolescents can respond by feeling misunderstood when they are left to cope on their own (Clemmens, 2009; Maynard et al., 2013). Stress and anxiety at the time of parental cancer can lead to conflicting family relationships, according to Hilton and Elfert (1996) uncertainty, stress and anxiety were expressed by adolescents as an increase in arguing, yelling, anger and upset between different members of the family.

Adolescents would generally be involved in more chores and responsibilities. Some perceived this as a way to reach out to the ill parent that led to bonding and union. There were exceptions, however, some adolescents felt these responsibilities did not allow them to spend time with their friends and this could cause conflict in the family. This can have psychological implications for adolescents as they are trying to deal with two different and incompatible sources of demands (Visser et al., 2004; Ohannessian, 2007). Adolescent are simultaneously responding to illness demands and developmental demands such as the need for identity

formation, separation from authority and achieving independence (Arnone, 2014; Lalor et al., 2007). This conflict could lead to adolescents feeling guilty (Stiffler et al., 2008).

Another element at the time of treatment is the adolescent relationships with hospital settings. Adolescents seem to describe meeting the medical staff as a positive experience because it allowed them to obtain information and ask questions. Exceptions were identified because some adolescents felt unappreciated, anxious, bored and frightened in hospital settings. This finding suggest a possible limitation in the current approach of medical professionals, focusing exclusively on the patient and neglecting more family centred approaches that respond to the patient within the context and impact that the illness has on other family members. Previous research (Huizinga et al., 2011; Wolf, 2015; Sieh et al., 2012) has already suggested the need to adopt a family centred approach which concentrates on the strengths and needs of all members, this suggest that there is also a lack of translation of research findings into policies that can improve the quality of services.

Adolescents' difficulties and experiences are also affected by context, in particular, family structure seems to lead to different outcomes; family cohesion, closeness, communication, mutual support parental availability, reciprocal interaction and spending time together have all been associated with more positive outcomes (Thastum et al., 2008; Maynard et al., 2013; Costas-Muñiz, 2011; Clemmens, 2009; Osborn, 2007; Finch & Gibson, 2009). Parental conflict, instead, can lead to irritability, impatience, moodiness and paranoia. Drastic changes in relationships with the healthy or the ill parent can cause sadness and shock. Exceptions were identified as some adolescents described that their families did not do anything for them because parental illness did not pose any difficulties for them. Illness, therefore, needs to be understood from a Family Systems perspective where the condition of one member has an impact on other members, because the system is interconnected (Heiney et al., 1997; Faulkner & Davey, 2002; Hilton, 1993; Su & Ryan-Wenger, 2007).

Studies found that open and honest communication was linked with more positive outcomes as anxiety was reduced when adolescents felt

information was not kept from them. Adolescents who handled the illness as a private issue struggled as they felt ignored, uncertain and had to suppress their own emotions. There were exceptions, as some adolescents did not want to communicate with their family to avoid the 'fuss'. Fitch and Abramson (2007) described that adolescents needed someone to talk to, have someone to be there for them, preferably somebody they knew and felt comfortable being around but Stiffler et al. (2008) suggested that adolescents struggled to find someone to talk to about their experiences of parental cancer.

Studies in this meta-ethnography also seem to agree that there is a large variety in adolescent coping styles and skills, some prefer to cope by themselves but others instead prefer to take part in group activities and avoid being alone. Despite the uncertainty and the threat to attachment structures and conflicting demands that disrupt their normal lives, those adolescents that cope successfully achieve normality, security, balance and centring. Friends and community are mentioned as important sources of support and comfort. Adolescents, however, mentioned exceptions because some prefer not to share the experience with friends to avoid feelings of embarrassment or pity towards them. A similar experience was described with school as some schools provided support and adolescents found someone there to talk to but for others the support was not existent and they would have liked the school to at least acknowledge their experience.

Age and gender seem to have an impact on adolescent experiences of parental cancer; however the knowledge seems to be limited as not all studies in this synthesis analyzed their results according to these variables (Forrest et al., 2009; Hilton & Elfert, 1996). Adolescent age can contribute to their understanding of the implications of parental illness and the possibility of death (Hilton & Gustavson, 2002); however this could also lead to denial of parental illness as a coping strategy and a way of responding to developmental demands such as identity separation (Issel et al., 1990). Males and females seem to cope with parental cancer in different ways, girls seem to worry and boys block the situation (Hilton & Elfert, 1996). There is no clear evidence to suggest this but it may be that social gender roles are responsible for differences in experiences; females seem to

be more involved with caring duties with their ill parent, particularly mothers. Further research is needed to identify if there is an interaction between parent gender and differences with adolescent experiences. This finding suggest the importance of adopting a developmental perspective when trying to understand an experience of parental cancer in a young person, as it has been suggested that it is not the same the experience of younger children (Pedersen & Revenson, 2005; Kornreich, 2008; Aldwin, 2011).

Recommendations

Interventions designed for adolescents experiencing parental cancer need to take the phase of maternal illness (diagnosis, treatment and post treatment) into account as adolescents appear to have different needs and challenges at every illness stage. Adolescent adjustment should not be understood as a single 'outcome' but instead, it seems to be a process of continuous adjustments across illness stages; some adolescents may adjust successfully at a specific stage but may struggle in a different one. It is important to screen adolescents throughout maternal illness to identify those that may be struggling independent on the illness stage of their mothers.

This meta-ethnography identified the need to adopt a Family Systems approach and understanding of adolescent adjustment experiences, as family and environmental factors can improve or challenge adolescent adjustment experiences. There seems to be a need for developmentally appropriate communication interventions for parents, adolescents and health care providers to deal with the experience of young people who have a parent with cancer. Health practitioners need to adopt a family centred approach when they are dealing with cancer patients, as their families are affected, not just the ill person.

According to the findings of this meta-ethnography, adolescents need factual and honest information about cancer to help them understand the illness and overcome preconceived ideas such as the immediate association with death. Adolescents may benefit from emotional support as parental cancer can be associated with a wide spectrum of negative emotions. It is important, however, to understand that not all want or require this type of support.

This meta-ethnography identified that age and gender may have an impact on adolescent experiences of adjustment but there seems to be a lack of research on this specific topic that should be addressed in future research to fully understand adolescent experiences.

Future research may also benefit from more longitudinal designs as these could provide additional insights into how adolescents develop over time, most studies had a cross sectional design that provide insights into adjustment but it is limited to a specific stage or moment in time, particularly diagnosis and not other illness phases.

Summary

The meta-ethnography (Noblit & Hare, 1988) provided a detailed synthesis of the state of current qualitative research focused on the experiences of adolescents facing parental cancer. This meta-ethnography described maternal cancer as a significant challenge at a life stage with developmental demands for identity formation and independence. Maternal cancer is an intrusion in adolescent normal lives, relationships and responsibilities. The experience changes them, their environments and their worlds in general. Adolescents experience a juxtaposition of positive and negative outcomes and changes from maternal cancer. The meta-ethnography includes a description of adolescent perception of cancer, emotional reactions to diagnosis, family experiences and coping skills. The analysis also identified the main factors found by previous research as important determinants of adolescent adjustment: cancer knowledge and challenges along different illness stages; family and contextual supports and adolescent coping abilities. This finding is important as it provides an insight into the possible variables that may lead to positive outcomes or negative ones for adolescents at the time of parental cancer.

CHAPTER 4

RESEARCH RESULTS

Study1 (a) Thematic Analysis of Adolescent Interviews.

Introduction

The experience of parental cancer can be challenging and stressful for adolescents and some can experience psychosocial difficulties (Su & Ryan-Wenger, 2007; Dehlin & Reg, 2009; Rosenfeld et al., 1983) at a time when they are facing developmental tasks such as individuation and identity formation (Sieh et al., 2010). Opposite to this, some studies have suggested that adolescents can have positive experiences even in difficult circumstances, for example, enhancing their skills and psychological resources (Pedersen & Revenson, 2005) and some adolescents show normal levels of emotional and behavioural adjustment (Howes et al., 1994; Welch et al., 1996). Overall, analysis of previous research has suggested that there are conflicting findings on the experience of adolescents when adjusting to maternal cancer and there is a particular paucity of research in an Irish context; therefore the objective of this study is to identify from an adolescent perspective the circumstances that may facilitate or challenge adolescent adjustment. This will contribute to the knowledge of practitioners on how to navigate a multifaceted and contradictory experience where adolescents face distressing challenges but also identify positive gains for their lives from the experience.

Method

Design.

The AMC study has a mixed methods approach, this study is part of the qualitative data collection and analysis.

Recruitment.

Women who had a cancer diagnosis in the previous 24 months and who had a teenage child were recruited from The Irish Cancer Society affiliated Cancer Support Centres, the Symptomatic Breast Centre (University Hospital Galway) and University students from NUI Galway. Mothers who were going to these centres were contacted personally or with a letter via post. The researcher called then on the telephone a week later to explain the research further and determine the level of interest in taking part

in the study. University students were contacted through media and official collective university emails for all registered students. All potential participants received online information or an information package (with SAE) which included information sheets and informed consent forms.

When consent forms were completed, adolescents were asked to take part in a semi structured interview (Appendix E). Interviews were carried out at a time and place that was selected by the adolescents and they were given the choice of completing interviews face to face, by telephone or online. Interviews were recorded, transcribed and analyzed using Thematic Analysis. The analysis was carried out by the researcher and an external adviser, specialized in qualitative research.

Analysis.

Thematic Analysis.

Braun and Clarke (2006) defined thematic analysis as a method to identify, analyze and report patterns (themes) in data and reveal core consistencies and meanings in a text (Buetow, 2010). It organizes and describes elements of the research data but can also be used for interpretation. Thematic analysis emphasizes the content of the text, specifically what is being said and not how it is being said (Katz, 2013).

Boyatzis (1998) described thematic analysis as a process to encode qualitative information. It is also a way of 'seeing', as different people may agree or disagree, even if they are dealing with the same data, events and situations. Salmon and Rapport (2005) suggested that the essential principle of thematic analysis is to identify more and higher levels of abstraction in the data.

Thematic analysis can be an essentialist (realist) method, a constructionist method or a contextualist method (Boyatzis, 1998). In this research, thematic analysis will be approached from an essentialist/ realist perspective which is used to describe experiences, meanings and reality of research participants that will help to inform health practitioners with knowledge of how adolescents can be supported when they face maternal cancer, it will help to understand their responses to this challenge and the possible implications this has on their adjustment.

Themes

Boyatzis (1998) explained that a researcher needs to be able to identify and 'sense' themes by being open to all information and having a fundamental knowledge of the field of inquiry. The second phase of thematic analysis is the ability 'to see' or 'to see as' which is the ability to use codes and themes reliably. The researcher then develops a code to process and analyze the essence of their data to finally interpret the data and contribute to the development of knowledge.

Braun and Clarke (2006) described that a theme includes an important aspect in the data which relates to the overall research topic. Thematic codes can be theory driven, prior research driven or inductive (data driven). Codes that are closely related to the raw data increase the likelihood that data will be encoded in a similar way by different people and reduce potential contamination factors. Thematic codes, according to Boyatzis (1998) need five basic elements: a label (name), a definition of the theme, a description of how the theme occurs (indicators), qualifications or exclusions to identify a theme and positive and negative examples to eliminate confusion when identifying a theme.

Analysis

According to Braun and Clarke (2006) thematic analysis can have an inductive approach or thematic approach. Data analysis from a thematic approach is driven by theoretical and analytical research interests. Analysis would be focused on a specific aspect of data and requires engagement with the literature prior to analysis. According to Boyatzis (1998) the wording of the themes corresponds to the researcher's construction of meaning, communication style and theory this, however, also means that the researcher may be at a greater risk of projecting their personal and theoretical assumptions.

Themes according to Braun and Clarke (2006) can be identified on a semantic/explicit level or a latent/interpretative level. In this research, themes will be identified from a semantic level which means these will emerge from the explicit meaning of the data. Katz (2013) described that in semantic themes the researcher is not identifying anything beyond what was said. In this study data was first described and then interpreted to allow

theorizing of the significance of patterns, meanings and implications of data. Braun and Clarke (2006) provided methodological guidelines for thematic analysis.

1. *Familiarizing yourself with the data*

This phase involved becoming familiar with the data. This was achieved by repeatedly reading the data in an active manner to identify possible meanings and patterns.

At this stage notes and marking ideas emerged to identify possible codes in subsequent phases of the analysis.

2. *Generating initial codes*

Codes represent semantic or latent features of the raw data. Information can then be addressed in a meaningful way according to the research topic. Coding can be data driven or theory driven, which is an approach to the data based on specific questions that will determine the coding process. In this research this process was driven by the research objectives. This stage involved coding for potential themes and patterns.

3. *Searching for themes*

Codes identified in the previous step were sorted into potential themes. This phase also involved identifying the relationship between codes, themes and different levels of themes. Some initial codes became main themes, sub themes or were discarded.

4. *Reviewing themes*

This phase involved refinement of themes. Data extracts for each theme were revised to determine if they formed a coherent pattern. Those extracts that didn't seem to fit were relocated to a new theme, an already existing theme or eliminated.

Themes were included in a potential 'thematic map'. Individual themes were reviewed to determine their validity compared to the data set and to decide if the meanings included in the thematic map were accurate.

5. *Defining and naming themes*

This phase required a satisfactory thematic map of the data, the essence of each theme was identified and the specific aspect of the data that were included in each theme compared to the others. Sub themes are themes within a theme that provide structure and hierarchy of meaning in large complex data sets.

6. *Producing the report*

The report is a validity of the analysis in a logical, concise, coherent, non-repetitive and interesting manner. Analysis went beyond a descriptive level but built an argument in relation to the research question. Katz (2013) additionally suggested that vivid examples of the children's narratives had to be included to capture the essence of the themes identified. In this phase initial themes were reviewed and interpreted further to make sure that the challenges for adolescents were identified but also their responses to the challenges and the implications these had on their overall experience of adjustment to maternal cancer.

Limitations of Thematic Analysis (Boyatzis, 1998).

Projection can be a limitation of thematic analysis as projection may lead a researcher to 'read into' or 'attribute' the researcher's characteristics, emotions, values and attitudes to the data. Projection, however, is improved by developing explicit codes, a reliable and consistent judgement of the data, using different people to encode the same data and sticking close to the data when developing themes and codes.

Sampling may also be an issue as data collected may be contaminated with factors and variables that the researcher is not aware of which can affect analysis and interpretation. This can be avoided by reviewing the unit of analysis on which the study is focused and the unit of coding can be assessed in a meaningful way in relation to the unit of analysis. Units of analysis and coding should be reviewed from different perspectives and possibly by other researchers.

Another possible limitation of Thematic Analysis is mood and style, as qualitative research may be subjective and the source of the data can have

an effect on the researcher, their cognitive style and the drive to find a clear, definite and correct answer. Researchers may also have periods of atrophy of skills and accuracy during periods of stress, fatigue and distraction.

Participants.

Fifteen adolescents completed semi structured interviews with the main researcher, twelve interviews were face to face, two interviews were over the phone and one through video conferencing. Adolescents had a mean age of 17. Five males and ten females took part. The average time since maternal diagnosis was 18 months.

Table 6 Irish Adolescent Interviews- Sociodemographic Data

Interview*	Interview type	Gender	Age	Cancer type	Time since diagnosis (months)	Interview length
Evan	Telephone	Male	18	Breast	12	13:32
Claire	Telephone	Female	16	Breast	24	19:47
Ella	Face to face	Female	18	Breast	24	47:16
Ryan	Face to face	Male	18	Breast	23	24:37
Shiloh	Face to face	Female	17	Breast	18	31:08
Ethan	Face to face	Male	15	Breast	18	19:35
Fiona	Skype	Female	17	Breast	24	40:53
Connor	Face to face	Male	16	Colon	10	18:05
Derek	Face to face	Male	14	Colon	10	13:03
Sophia	Face to face	Female	16	Colon	10	29:00
Barbra	Face to face	Female	20	Breast	25	34:21
Caroline	Face to face	Female	19	Gastrointestinal	14	56:18

	face						
Naomi	Face	to	Female	17	Breast	14	29:24
	face						
Elaine	Face	to	Female	17	Gastrointestinal	11	22:36
	face						
Anne	Face	to	Female	17	Gastrointestinal	29	28:30
	face						

*Participant names have been changed to preserve anonymity.

The length of adolescent interviews varied from 13 minutes up to 56 minutes. The average length of male interviews were 17 minutes and the average length of female interviews was 33 minutes, which may suggest a possible gender imbalance in the amount of information that was obtained and suggesting a possible limitation of the study, as the knowledge of male experiences may be more restricted.

Results

The analysis identified three themes: The challenge of maternal cancer, Building back my broken world, My vision of the future.

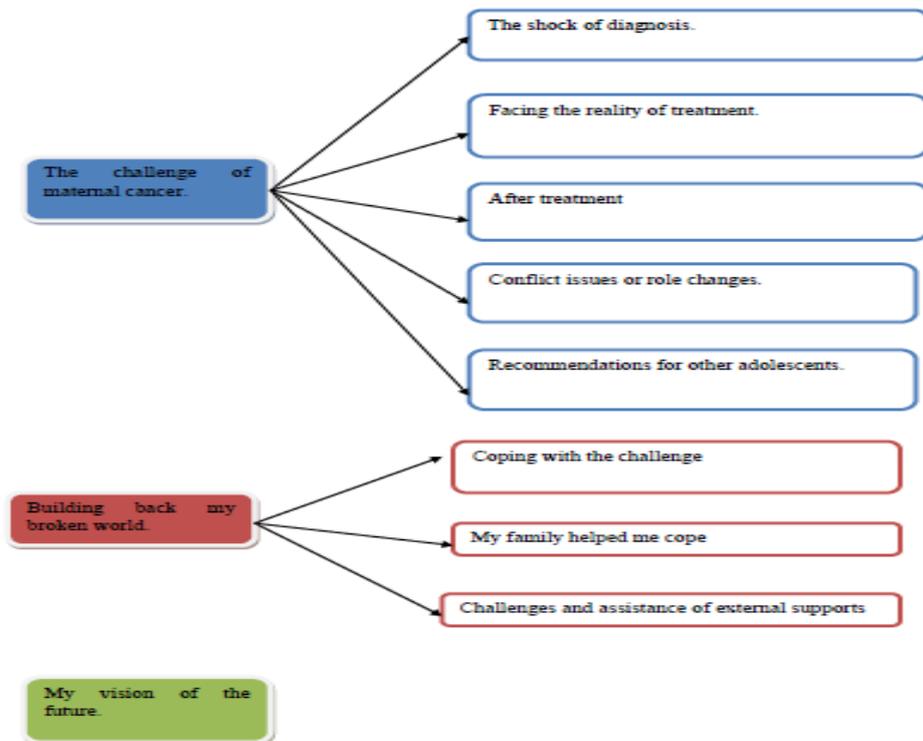


Figure 8: Summary of themes in adolescent interviews.

1. The challenge of maternal cancer

This theme describes how adolescents experienced maternal cancer as very challenging, particularly because at different stages of maternal cancer new challenges arose and adolescents found it difficult to adjust to them. Adolescents, however, attempted to minimise the threat of a frightening and unknown illness by finding resources and skills in themselves. They also experienced new and unexpected challenges and sometimes their attempts to cope with the challenge were not successful, increasing their distress further.

The shock of diagnosis

A cancer diagnosis is an unexpected experience for any young person that can lead to upset, worry, confusion and fear. Adolescents attempted to minimise this threat by communicating openly about a topic that was frightening and difficult for them.

Adolescents used a variety of adjectives to describe their emotions at the time of cancer disclosure including upset, worry, denial, guilt, confusion, shock and surprise (Ella, 18; Anne 17). All of which describe a very distressful experience.

I didn't believe, I was like no , no, stop messing, stop messing, it's only a joke and I was like no, no, no, this can't be happening and he was like it's going to be fine it's just like it's going to be tough for a while and I didn't want to believe it I just started crying... (Anne, 17).

The disclosure process seems to have an impact on adolescent's response to the diagnosis. For the majority, cancer was usually disclosed to adolescents by their mother except for three adolescents, Connor (16), Derek (14) and Sophia (16); whose mum was hospitalized by emergency and was very ill for several days before the cancer diagnosis. Mothers usually decided to tell their children in person except for one case where she was told by phone (Ella, 18). Some families sat down to deliver the news (Clare, 16; Fiona, 17; Evan 18) but in other cases it could have happened in other more informal scenarios such as in the car (Ethan, 15; Sophia, 16).

I talked to my mum about it she always said to me, if you had any questions, like all the doctors have told her everything about it, she knows what's involved and she knows what's happening, and if I had any questions just talk to her and not be afraid to talk about it (Ella, 18).

Here we see an example of the approach taken to minimise the challenge not being successful. Two adolescents found out about the cancer diagnosis before it was properly disclosed because other people accidentally talked about it or assumed they already knew (Naomi, 17, Barbra, 20).

I went for lunch with my uncle, who lives in (name place) and he asked me ...he was like 'oh did your mum get the results of the diagnosis?' And I was like 'Oh God' and my sister kind of mentioned something to me as well ...as there were little mentions the entire time (Barbra, 20).

Another difficulty faced by adolescents (Connor, Derek and Sophia) was that their parents struggled to say the word 'cancer' and only gave adolescents hints of the diagnosis like tumour or chemotherapy so they had to figure out the situation themselves.

I think my dad told me that like she had a tumour but he didn't use the word cancer he said that they just had a tumour and they needed to remove it so and then, I don't now, just later, when he said that she had chemo then eeemm...I knew that it was cancer (Connor, 16).

Talking about cancer was a challenging experience for adolescents themselves. They were aware of people they could talk to but were afraid that the reaction of other people might instead make them feel worse and not better.

I had people that I know I could talk to about it but I didn't really want to talk to anyone about it because I felt like their reaction would make me feel worse like I felt like they would scare me more. For ages even the idea of talking about it or saying it out loud I just couldn't do it (Ella, 18).

Adolescents not only had difficulties talking about cancer but also expressing their emotions but this had the purpose of protecting their parents. Adolescents described having to 'stay strong' for their mother's sake and this meant hiding their emotions and reassuring the parent that they were okay even if they were struggling (Caroline, 19; Anne, 17, Barbra 20, Elaine, 17).

We'd always be good like she does everything for me, but then when she got sick I think I became more upset than she was, she was very strong when she had it and like I cry a lot more, I'd never seen her cry and she was very strong and I should have been the strong one for her (Anne, 17).

Even if disclosure was difficult, adolescents identified ways in which the process can be improved. Adolescents appreciated openness towards the topic but most importantly appreciated being informed honestly about what to expect.

And she is very open, she will discuss it like, she doesn't have this big taboo around talking about it whereas I don't either to the extent that I would have... (Ella, 18).

Previous cancer experiences seem to also have an impact on adolescents at the time of diagnosis, some had experienced cancer in a family member before (Sophia, 16; Barbra 20, Elaine, 17), in a member of their community (Ella, 18), a friend, (Ryan, 18) or a school classmate (Sophia 16). Sophia (16) and Shiloh (17) had friends that were going through maternal cancer close to the time of diagnosis of their own mothers and this experience reassured them that their own mothers could overcome cancer. Ryan (18) knew a friend of his that had been through cancer himself some years before.

Cancer has affected like a good few people around me so it wasn't like a new thing that had happened but eemm...like my granddad is old so it wasn't like a big thing, he had like more years to live but he is 85 now so it's not a big thing but mum was only...she was 45 or

something when she got her cancer which is young enough so... (Barbra, 20).

Other adolescents, however, mentioned that they were unfamiliar with cancer before the diagnosis of their mothers and were completely unfamiliar with hospital environments, apart from checkups adolescents had never been inside a hospital ward (Connor, 16; Derek, 14 and Sophia, 16). “I went onto the websites and I just went on to like breast cancer in particular because I know well I was ignorant of it before” (Ella, 18).

Adolescents also struggled with preconceived ideas about cancer, usually directly associated to death (Ella, 18; Anne, 17).

People just presume straight away that, like if you have cancer then that would be the end, they just think in one thing when they think about it. And I think that the reason people have that view on it is that because they always hear the bad things (...) and it's like if you hear that someone dies and if you ask oh what or how did they die and someone says they died of cancer like if you have cancer people just like ‘oh yeah I should have known that... (Ella, 18).

Overall, cancer diagnosis was challenging for adolescents as this was unexpected and difficult to cope with. The style of disclosure had an impact on adolescents, the majority were told face to face but some were told by phone and this caused difficulties, some even found out from changes sensed in their context, which was more challenging. Adolescents explained that open and honest information was important and improved their coping ability at the time of diagnosis. Some adolescents had previous cancer experiences from family members or friends and this was helpful because it reassured them that a cure was possible. Adolescents also struggled with the lack of factual information about cancer which could lead to preconceived negative ideas that increased fear and anxiety.

Facing the reality of treatment

Maternal treatment was also a challenging time for adolescents as this was a time where they experienced the ‘reality’ of the illness and were faced with the physical and emotional changes and side effects of the illness

and treatment in their mothers (Ryan, 18; Barbra, 20). *“That was the hardest like visually seeing her sick and like maybe understand that it is a serious disease”* (Ryan, 18).

Adolescents (Connor, 16; Sophia, 16) mentioned being very worried and stressed at the time of maternal surgery.

I worried about the surgery, like right before, in case anything went wrong and...like during the chemo it was okay, it was just kind of different round the house but it wasn't too difficult, like once the surgery is over, like once it went well, I just looked forward (Connor, 16).

Changes in the physical appearance of their mothers were also identified as difficult for adolescents as suddenly their mums had no hair or were wearing a scarf instead; adolescents, however, got used to the changes.

... she didn't show that she was upset but I am sure that she was a bit sad that her hair was going (...) But over time I just got used to it, I didn't even notice like after a while because it became normal (Shiloh, 17).

Another incident described as challenging was looking at their mother with tubes and other medical equipment after the surgery.

Oh well the worst time was the day after her surgery, she had like a million tubes coming out of her and she just looked disgusting, she had like lots of IVs in her neck and tubes coming out everywhere. (...) I didn't like seeing her like that at all (Sophia, 16).

Another aspect of the treatment phase was adolescent contact with medical staff. Adolescents mentioned that nobody talked to them directly or offered them any kind of help or support. Some adolescents (Shiloh, 17 and Ethan, 15) had no contact with medical personnel at all during maternal illness which means no support was provided to them, even if some were interested in it.

Maybe give numbers or something to the person with them (...) I can't not be worried for her at that time cos she needs support or maybe like numbers or you give them information or anything like that but I wouldn't like

anyone to come and start asking me stuff in front of my mum (Barbra, 20).

Fiona (17) and Naomi (17) mentioned having a tour of the hospital facilities and machines that her mother would be in contact with. At first this was described by Fiona as an upsetting experience but later it was described as reassurance that her mum would be well taken care of, but it was a positive experience for Naomi.

I would have come up the first time and the nurses took me in and showed me where they were giving her the radiotherapy, where they were giving her the chemotherapy, I liked that (Naomi, 17).

Some adolescent felt very strongly about not wanting to be involved in the hospital setting in any way, although they still went and waited for their mothers (Elaine, 17; Naomi, 17; Anne, 17). “*I have phobia of blood so I’d be useless if I had gone to the hospital*” (Elaine, 17).

One adolescent instead described a particular interest in the treatment and medical aspects related to her mother’s illness, “*I would have been particularly interested in her treatment, more so than my brother and sister, I suppose being interested in a medical point of view*” (Caroline, 19).

Overall, the treatment phase, particularly maternal treatments like chemotherapy and surgery caused worry and stress on adolescents, but these emotions were temporary as adolescents were fine once the treatments were successful. Adolescents described a lack of contact with medical staff and contexts and this restricted their opportunities to talk or ask questions. Adolescents that were given tours of the medical settings were reassured that their mother was taken care of. Individual differences were identified in adolescents’ interest in medical settings, some disliked it and tried to avoid it but others were interested in treatment and medications and tried to be more actively and happily involved.

After treatment

The time after treatment was also challenging for adolescents and some adolescents described that their mothers were still dealing with the long term physical and psychological effects of cancer and this had an impact on them too (Barbra, 20). “*She is still very tired ...kind of like, she*

can't really like...even if people came over for a cup of tea or something she'd be like wrecked after it from like just talking'' (Elaine, 17).

Another challenge faced after treatment was dealing with the fear of recurrence. Some adolescents (Ella 18, and Fiona, 17) described that this was constantly in their minds.

... I think reassurance, like you need constant kind of reassurance I don't know how long for because I still feel like I need that, so I don't know at what time that feeling goes away or if it does go away (...) I just want someone to say like 'yeah it happened and but it's not something you have to worry about again (Ella, 18).

Adolescents were also scared about the possibility of having cancer themselves in the future. They were also more aware of self check but were also very alert and concerned.

...it is like happening so much more now so I do think that's scary and my younger sister got a breast cancer scare herself, she had to go to the place and get a biopsy. I think we are on high alert now, if I feel a lump anywhere I am like 'Oh my God its cancer mum!' Take me to the doctor (Barbra, 20).

Adolescents had to deal with other issues in their families after treatment. One adolescent described that after treatment there was some tension in her family due to financial issues and other stresses.

My mum and dad yeah they became close but I think there was a bit of pressure financially as well as you know, keeping on top of work, as well as looking after mum, like dad had to keep working and then looking after her, justlike they were all fine....but there was a bit of anxiety with work, finance, social...you know just different things like that (Anne, 17).

Overall, the time after treatment was influenced by the experiences of their mothers and their families after treatment and how much time had passed since the completion of treatment, if mothers were still struggling with fatigue and secondary side effects of treatment adolescents struggled.

Family issues such as financial issues were also challenging for adolescents. Adolescents were also struggling with the possibility of recurrence. At an individual level, adolescents struggled with the possibility of having cancer themselves but they seemed to deal with the challenge by checking themselves.

Conflict issues or role changes.

Adolescents experienced disruptions in their daily lives which were related to increased labour requirements and additional responsibilities which added to the challenge of maternal illness.

Some adolescents had to take over more household chores and responsibilities and just having extra activities to do such as hospital visits (Sophia, 16; Anne, 17). “...*there was a lot more responsibility expected of me for her, like she'd be like can you do this, cook the dinner, bla, bla, bla...*” (Anne, 17).

Overall the perception of these changes was positive and they knew it was due to their mother being ill or the side effects of treatment, in this sense, none of them were upset but they definitely noticed these changes in their lives (Ryan, 18; Clare, 16; Evan, 18; Derek, 14; Sophia, 16).

No, not really. I knew that whenever she was getting chemotherapy that I would definitely do some more house work and just so she wouldn't be so tired, but it was never really expected of me it was just something I wanted to do you know to make sure she got more rest (Ryan, 18).

Some adolescents experienced significant role changes, becoming supporters of their parents. Adolescents provided emotional and tangible support for their mothers during the illness process (Barbra, 20, Ryan, 18, Caroline, 19). This role improved the relationship adolescents had with their mothers and brought them closer together (Elaine, 17; Barbra, 20; Ryan, 18, Anne, 17), “*So I was just the listening ear I suppose*” (Ryan 18).

Gender may have also determined differences in the way adolescents experienced this role. One boy mentioned becoming ‘protective’ of his mother but none of the girls described this (Ethan 15). One girl instead described that she became a ‘carer’ for her mother (Caroline, 20).

I guess actually I kind of became more protective over her (...)...I don't know, I take it upon myself to do more stuff(..) so I guess I just...anything that involves lifting or anything like that I don't really let her do it ...(Ethan, 15).

Overall, maternal cancer required additional demands and responsibilities for adolescents, which increased the magnitude of the challenge they were dealing with. Adolescents described this as difficult but they also actually perceived it as a positive experience as it was a way of helping their ill parent and a way of improving family relationships. Some adolescents, however, had to live up to the expectations of the parent and these standards were difficult to achieve, which complicated the challenge even more.

Recommendations for other adolescents

Adolescents were able to identify strategies or recommendations that would have helped them face the challenge of maternal cancer at the time.

Adolescents would have liked to talk more about the experience they were going through and advised this to other adolescents in similar situations (Ryan, 18 Claire, 16, Fiona, 17, Connor, 16, Caroline, 19 and Barbra, 20).

Well I think that once you get to the stage when you feel comfortable talking about it I think it is very important to do that. I don't think I did enough of that. But when I did do it I felt that it helped a lot... (Ella, 18).

Adolescents also suggested that talking to someone going through a similar experience would have been of benefit to them, however, this was not available for all, although some had a friend or boy friend that had experienced parental cancer previously. Adolescents encouraged others to try to continue with their normal lives.

You have to get on with your normal life and study, that was something that I had to do and I did it (...) make sure that it is not going to affect your life more than it has to (Naomi, 17).

One adolescent described that taking care of themselves and reassuring the ill parent that they were doing okay was important.

...maybe let your parent know that you are okay, that you are getting lots of support, that you understand what is going on and you are coping with it... (Caroline, 19).

Overall, adolescents identified that talking more and specifically talking with someone who had a similar experience to them was a helpful strategy when facing the challenge of maternal illness. Taking care of themselves and keeping normality in their lives were other strategies suggested by adolescents.

2. Building back my broken world

Maternal cancer was challenging for adolescents and implied a combination of drastic changes and adjustments in their worlds but adolescents were able to use their own resources and coping strategies to deal with the challenge, even if they did have some particularly difficult days (Naomi, 17; Anne, 17, Fioma). Adolescents seem to have individual ways and preferences for coping with the changes in their worlds, however the account of their experiences seem to agree that their environments have an impact on their experiences, facilitating adolescent efforts or making them more difficult.

“I thought I was fine, you just keep your balance really. You would have the odd day where I’d be like ‘I can’t do this anymore (...) but you just have to keep going really’” (Anne, 17).

Coping with the challenge

Adolescents used different strategies that helped them cope through maternal illness. These strategies were varied for every adolescent; some used more personal strategies such as spending time alone but others preferred more group activities to help them cope such as playing sports.

Having a positive outlook and not worrying were strategies used by several adolescents (Ryan, 18; Shiloh, 17; Ethan, 15 and Sophia, 16).

Don’t worry about it. It never really got to my head, it wasn’t like ‘oh my God, my mum is going to die’ or it was never like that it was just like, she is going to be home for a while (Sophia, 16).

Some adolescents mentioned they needed more private moments like spending time alone in their rooms when they were upset (Naomi, 17, Elaine, 17). Other individual activities were listening to music, walking the dog or horseback riding. Being alone, however, worked for some and not for others, Ella (18) described that it was a bad idea to be alone and isolated as this made her think more about the situation, *“So just kept going, listen to music, went for a walk, did something to clear my head like rang a friend something like that...”* (Anne, 17).

Adolescents also expressed that trusting the treatment and the medical team was useful to them as it helped them deal with fear and made them think of more positive outcomes for their mums. (Ryan, 18, Evan, 18 and Ethan 15) All the adolescents that used this coping strategy were male, *“I guess if it was the exact same as what my mum had I guess not to be afraid....just to let her get on with it and the doctors know what they are doing so ...”* (Ethan, 15).

Adolescents were also concerned about keeping normality in their lives and to keep doing the activities that they usually did before maternal illness. (Evan, 18, Ryan, 18, Anne, 17). This sense of normality was kept also in adolescent's extracurricular activities such as sports, drama school, and piano, *“I just kind of put my head down and started working again, we just got on with everything. I continued on normally”* (Ryan, 18).

Supporting their parent was also perceived as an important part of the experience that facilitated coping (Barbra, 20; Elaine, 17, Anne, 17).

...it's only when they are sick that you realize how much they actually do for you and now is your turn to step into their shoes if you like and do as much as you can for them... (Anne, 17).

Information was handled in different ways by adolescents, they seem to need information in different amounts but if this was exceeded it was experienced as frightening and unpleasant.

Information needs were age determined as adolescents, particularly those that were in University, were the ones interested in doing research themselves using different sources, for example, Google and Wikipedia.

One tried to read scientific articles, however they perceived that judging the reliability of such information was not easy.

I researched a lot on the internet. I looked up all I could find on breast cancer and stuff yeah (...) Yeah I found it was more useful it kind of was the less I knew the more scared I would have been but it was not as serious as it could have been (Claire, 16).

Ella (18) perceived that the information available had a negative approach and it was difficult to find information with a realistic and positive outlook, for example, survival statistics, so she decided to stop searching.

Yeah I did a bit of research on it but then I found after a while the information that I got I didn't like it like. I think a lot of information like, the statistics a lot of people see cancer like a terminal illness (Ella, 18).

Overall, adolescents used a variety of coping strategies, none of which were described as more effective than others, instead it may be suggested that adolescents cope with the challenge of maternal cancer by actually doing what they need, which may be at completely opposite ends of the spectrum, for example, being alone or not being alone. Adolescents also mentioned that trusting the medical team and supporting their ill parent provided reassurance to them and allowed them to cope with the challenge.

My family helped me cope

Families were important sources of support for adolescents and had an impact on how adolescents coped with the challenges of maternal cancer. The challenge of maternal cancer had an impact on family stability and structure, maternal cancer increased closeness and expression of affection but in other cases it could drive the families further apart.

All adolescents that took part in this study mentioned a desire to be closer to their families, particularly their mothers and younger brothers and sisters (Ella, 18, Anne, 17).

(...) when second semester came then I wanted to go home, I wanted to be more involved I wanted to do as much as possible because even though there were such small things that I could, I just wanted to do anything I

could to relieve some of the distress my mum was going through and I wanted to be there for my little brother ... (Ella, 18).

The expression of affection in families also improved. One adolescent described that her family would now be more open to expressing love and were more comfortable with physical expressions of affection.

(...) we were quite sentimental while she was ill and we were saying these things to her, now it's like it's okay to continue to do that and I do, I continue to say it to her (...) It opened things up to talk about emotions more, about being more sentimental and it has made us closer, very much so, yeah... (Caroline, 19).

One adolescent, instead, described how the cancer experience separated their family.

I'd get upset and mum was sick and dad wasn't too happy either so there was always...there was a strain on the family. There was nothing to do about it really just what it was (Naomi, 17).

Adolescents also explained the importance of sibling relationships in the process of maternal cancer as they perceived they shared the same experience in a way that nobody else was able to understand. Siblings were also important to balance and accept their emotions, if they were upset together it was a validation for their own feelings. Older brothers and sisters adopted an attitude of protection with their younger brothers and sisters, a duty of care and support through the process (Ella, 18 and Ryan, 18).

My brother and my sister, my two siblings. We were kind of, we were on the same page and were, you know, trying to help her and stuff, they were the easiest to talk to I think then... (Ryan, 18).

Younger siblings also supported older adolescents regarding household chores, although their actual level of support was limited by their age.

They didn't do an awful lot like my sister would have done more than my brother, my brother just not, nothing

but if I asked can you help me set the table and whatever, they would have helped me... (Anne, 17).

Not all siblings, however, had open communication about maternal illness because they did not have a close relationship to begin with (Fiona, 17, Clare, 16) or they were always together when they were provided information so there was no perceived need for talking with each other (Connor, 16, Derek, 14 and Sophia, 16).

We didn't really discuss it that much. We like most of the time it would be like if I was giving out to them for being too loud or something. You know, we really didn't talk about it (Clare, 16).

Maternal coping was an example for adolescents on how to cope themselves. Maternal illness was a perspective changing experience for adolescents in terms of the perception of their mother before and after diagnosis. Adolescents developed a sense of admiration towards their mothers and the way they dealt with their illness and diagnosis (Anne, 17). Adolescents mentioned maternal positivity as important (Ryan, 18, Fiona 17), as well as maternal sense of humour (Fiona, 17) and how these helped them cope with their own illness.

(...) talking to your mum helps a lot because it showed me that like she was so strong and she just like I really admired how well she was coping (...) and how she still balanced that with her everyday life and to be able to talk to her about it made me feel it just really reassured me ... (Ella, 18).

One adolescent, instead, described how her mother was struggling to cope with the situation and was focusing mostly on negative aspects instead of positive.

To be honest she really doesn't really see much of the help that she was given most of the time I think, she's just focusing, she focuses on all the bad that happened from the situation, I don't think she is over it. I think she is really angry so (Barbra, 20).

Some adolescents made reference to the relationship they had with their fathers before and after maternal diagnosis, Dads from supportive families had a positive contribution in adolescent lives and helped the adjustment processes.

Fathers were described as very important sources of information and in charge of answering adolescents questions or were even in charge of disclosing the diagnosis to adolescents (Evan, 18, Connor, 16, Derek, 14, Sophia, 16, Caroline, 19, Anne, 17, Ella, 18, Caroline, 19), *“I suppose he was the stronger one, he had to be strong for us and mum so if I had a question I’d ask him...”* (Anne, 17).

Some parents, however, worked far away from the household and they had fewer opportunities to be actively involved in the process of illness (Ryan 18 and Clare, 16). In some cases the father was not involved, as the relationship with the mothers was already damaged before the diagnosis, *“(...) there was a lot going at the time, but I think you just get desensitized after a while hearing about everything like when my parents were fighting...”* (Barbra, 20).

Overall, family support was important for adolescents dealing with the challenge of parental cancer. Families that had strong and supportive relationships before the diagnosis grew closer together and adolescents enjoyed spending time together. Some families instead grew further apart because they could not withstand the pressure of the challenge. Strong sibling relationships were helpful to adolescents because they could share a common experience. More communal families shared the burden of care and different members provided help and support according to their age which contributed to sharing the burden. Maternal coping also influenced adolescent coping, if mothers were positive and had a sense of humour adolescent coping was facilitated, the opposite occurred when mothers were negative. Fathers that were present and had good relationships had a crucial role providing support for adolescents and their families, sharing the burden of care and providing information and care. Fathers that were distant or absent instead increased the burden on adolescents.

Challenges and assistance of external supports.

Nuclear families had to develop more permeable boundaries because due to the experience of maternal illness they required support from external sources. Adolescents described the role of other family members and the community in the process, as they provided tangible support such as information, preparing dinners, taking over household chores, or providing other favours, for example, lifts (Clare, 16, Shiloh, 17, Ethan, 15, Connor, 16, Derek, 14, Sophia, 16, Barbra, 20).

Yeah, we live in a very kind of close community so all the....specially my younger brother is still in the local primary school his friends mothers are always at the house or are always coming over for birthdays and dinners ...one of them would have...there was always a person (...) she never has to drive up for treatment on her own (Naomi, 17).

Friends were important as they provided support and were available to talk to (Shiloh, 17, Anne, 17).

No, my boyfriend and then my friends, they would be the main ones. I don't talk to family that much. My sister travels a lot. My brother, he is married with his own kids so I don't think he has time (Naomi, 17).

Adolescents, however, faced an important challenge because they were sometimes concerned about disclosing maternal illness to their friends to avoid them feeling uncomfortable, being 'careful' around them or giving pity. Adolescents responded to the challenge by selecting specific friends to share the information with (Ella, 18, Evan, 18, Shiloh, 17, Derek, 14, Sophia, Naomi, 17, Ryan 18, Barbra, 20, Elaine, 17).

I definitely wouldn't want pity. That was my one big thing that I didn't want like people saying 'oh you poor thing like going home cleaning, going home cooking'. That is why I didn't tell that many people because I didn't want them to treat me differently (...). That's I think, it was my thing (Clare, 16).

Regarding support provided from school, adolescents felt that they did not want their school to be informed about maternal illness as they did not want to be treated any differently to other young people. In other cases school support was welcomed and appreciated (Ryan, 18, Anne, 17).

I think my mum told my Principal I think but I didn't want anything to change, I didn't want to be treated any different I just wanted to be left alone, let them get on with it I suppose...I didn't want anyone treating me like I was a baby, I could deal with it myself (Ethan, 15).

Some adolescents described that they were offered help or given information about counsellors but they never availed of it (Claire, 16, Fiona, 17, Shiloh, 17, Ethan, 15, Connor 16) Adolescents were also aware of the possibility of attending a support group at the time but they felt like they would not have enjoyed the experience or didn't really need it. One adolescent was in therapy at the time (Evan, 18) or was aware of the possibility of going to a School Counsellor (Connor, 16).

(...) it never would have crossed my mind to go to some sort of group situation where everyone is talking about it I even now like I just, even if a lot of people do that and it is like the kind of thing to do I would still not want to do that (...) I prefer to talk to someone that knows me and that knows my mum and that can be there on a constant basis (Ella, 18).

Two adolescents described that they required the intervention of professional support which they looked for on their own or with the support of a friend.

I did crash when mum started to go to chemo and I had to go to therapy and...but I think it was really the best thing for me because I just cried and talked about everything. I think it really did help me being able to talk to someone that was really objective to the situation... (Barbra, 20).

Overall, external supports were available for adolescents but they wanted to make decisions about the extent of involvement and the types of supports they wanted. Some adolescents chose to tell their friends but others

preferred to avoid stigma or deferential treatment. The same occurred with other sources of support, for example, Schools and Counsellors, some adolescents wanted to share their experience in these contexts but others did not. External supports could facilitate the experience when they were wanted but instead could have made the challenge more difficult if adolescent's needs or desires to involve other people were not respected.

3. My vision of the future

Adolescents described maternal illness as a challenge but also a life changing experience. Adolescents coped with the difficult challenge at the time but described how the experience has a long term impact on their lives that will have an influence on the way they deal with life and possibly deal with other challenges faced in the future.

The experience of cancer in the family was described as completely different from just knowing or hearing about cancer, a more human experience of cancer emerged from this personal experience (Caroline, 19, Barbra, 20).

(...) it gave a lot of meaning to it that this isn't just some illness that is listed in a book, that this is something that people go through, this is something that changes people's lives...this is a very scary illness to people and from what I have seen from what happened to my mother this is what happens to people with an illness like this (Caroline, 19).

Experience of maternal illness can also help adolescents identify and appreciate what was positive in their lives and even make decisions about how to spend their time, set priorities for their life and appreciate their mothers more. Some adolescents refused to get involved in stereotypical 'adolescent' behaviours like partying and drinking and instead focused on their studies. (Ryan 18 Fiona, 17, Shiloh, 17)

I suppose you don't realize what cancer is about until it knocks on your doorstep and when it comes to your house you really appreciate everything, like it's changed me and it's just made me think in a different light... (Anne, 17).

Maturing and growing up was another of the consequences adolescents identified in the process of maternal cancer (Clare, 16, Naomi, 17), “*No, definitely made me like grow up...*” (Clare, 16).

Adolescents in this study seem to have developed empathy, they recognized that not all cancer cases have positive outcomes and it is important to take this into account before providing any kind of advice to others as their individual circumstances may vary and this could upset them. (Ryan, 18, Shiloh, 17).

(...) it kind of depends on the situation, as in how serious the illness is. Like I think we were fortunate that although mum had cancer it wasn't so bad that there wasn't a possibility of her being like clear of it (...) I was able to have a more positive outlook but maybe for some people, it wouldn't have ended so well (Shiloh, 17).

One adolescent, however, described that her family history of cancer has been very negative and her perception of cancer, even after maternal treatment and survival, was very negative.

(...) cancer is just bad like, not really care you just have to get rid of it (...) I don't actually have any scientific...about it but like...It just got kind of scary I suppose (...)Yeah it just kind of terrifies me (...) I suppose that besides granddad everyone has kind of come out of it. So I don't want to hear it again kind of but then like my family... (Family history of breast cancer, three other family members had cancer previously) (Elaine, 17).

Overall, the challenge of maternal cancer did not only have an impact in the present moment for adolescents, the experience had a long term impact in their lives and the way they will cope with challenges faced in the future, including changes in their perception of life, their decision making and priorities. Adolescents described themselves as more mature, grown up, empathic and appreciative of positive aspects and people in their lives. The perception of cancer was now more positive and humanized for some except one adolescent who claimed that her family history of cancer

was so bad that it was impeding any possibility of her having a positive outlook.

Discussion

The objective of this thematic analysis was to gain insight into the subjective experiences of adolescents dealing with maternal cancer.

The challenge of maternal cancer

Previous cancer research (Davey et al., 2003; Hilton, 1993; Sales, 1991) has described that the time of diagnosis is particularly challenging for young people. The ‘challenge of maternal cancer’ is a detailed description of the struggles and distress that adolescents had to cope with at different stages of maternal illness.

At diagnosis adolescents struggled with the shock of the news but other factors can contribute to making the challenge more difficult. Adolescents that are told face to face seem to report more trust and credibility than those that found out by phone or that found out by mistake, without being told directly by their parents or their ill mother. Adolescents struggled with communicating about cancer, particularly regarding their own emotions, however, they explained that open and honest communication would help them at this time, therefore, practitioners should encourage this type of communication among family members to reduce the distress of adolescents at diagnosis. In line with this study, previous research suggested that adolescents tried to hide their real feelings and fears to avoid anxiety in other people (Gabriak, Bender & Puskar, 2007; Visser et al., 2007; Rosenfeld et al., 1983; Hilton & Gustavson, 2002; Osborn, 2007; Huizinga et al., 2003). Other studies also described that talking about their emotions made adolescents feel guilty and selfish (Maynard et al., 2013) or they thought it was a burden for the ill parent (Clemmens, 2009; Stiffler et al., 2008; Forrest et al., 2009). Similar to the current study, previous research has described the importance of open communication to enhance adjustment and improve adolescent coping skills (Maynard et al., 2013; Costas-Muñiz, 2011; Osborn, 2007).

Adolescents seem to struggle with lack of factual information about cancer and also by being unfamiliar with hospital settings. Health practitioners may help adolescents by providing them with factual and realistic information. Previous research has identified the negative effect that preconceived ideas about illnesses can have on the way young people perceive illnesses at a time of diagnosis, Michielutte and Diseker (1982) carried out a study on the perception of heart disease, diabetes, cancer and mental illness in children in seventh grade. Children perceived cancer as higher in severity, higher in susceptibility and lower in benefits of treatment than other chronic illnesses. Cancer was stigmatized and described as a fearsome chronic illness with little hope of a cure. This negative perception could probably lead to a very negative approach to a cancer diagnosis. Similarly to what this study described, previous research has identified that the ill mother was usually the main source of information (Bradburry et al., 2012) but there seems to be a lack of emphasis in the existant literature on the impact that different ways of delivering the information has on adolescent responses and adjustment processes.

Treatment was particularly difficult as maternal physical and behavioural changes made adolescents realize how real and serious the illness was. This finding is supported by previous research which identified that the effect of the treatment stage was to materialize or make the illness experience 'real' for adolescents (Hooper & Marcus, 1998; Davey et al., 2011; Finch & Gibson, 2009). According to Davey et al. (2003) watching a strong parent become ill and weak is a challenge for adolescents which could lead to fear. Adolescents struggled to deal with changes in the physical appearance of their mothers such as hair loss but particularly struggled to look at their mothers with tubes and surrounded by medical equipment. Parental changes have been investigated previously and described as challenging. Davey et al. (2011) found in their research that adolescents were sensitive to changes in normal parental behaviour. Previous research suggested that adolescents were concerned as they watched their mother's illness, her fatigue and changes in physical appearance such as hair loss (Kennedy & Lloyd- Williams, 2009; Finch & Gibson, 2009; Davey et al., 2011; Thastum et al., 2008; Hilton &

Gustavson, 2002; Clemmens, 2009). Stiffler et al. (2008) identified that adolescents mourned the loss of their mothers as they were before the cancer.

Adolescents described that they responded to the challenge by getting used to the changes, which shows their ability to adjust even to difficult circumstances. Adolescents experienced stress and worry in relation to maternal treatments but these seem to disappear once the procedures were successful. Previously, Rosenfeld et al. (1983) reported that their participants had higher levels of stress at the time of their mother's mastectomy and chemotherapy. Practitioners may help adolescent by being in contact with them and providing them with opportunities to ask questions, when possible, hospital visits seem to be reassuring for adolescents that their mothers are well taken care of. Practitioners should also be aware of individual differences as some seem to be very interested but others dislike hospital settings, these differences should be respected and at least adolescents should be allowed to decide themselves. Previous research has suggested that adjustment and the needs of children seem not to be part of routine clinical care (Turner & McGrath, 1998) but these needs should be taken into account by health personnel (Hilton & Elfert, 1996). Finch and Gibson (2009) reported that adolescents did not perceive a role for themselves in hospitals. Some preferred not to talk about their experience with a 'stranger' or a person that seemed 'unfamiliar' to them (Huizinga et al., 2011).

Adolescents' experiences after treatment are determined by the long term effects of the illness and treatments in their mothers, those closer to the end of treatments were still worried about their mothers being tired from simple tasks. Adolescents also had to deal with family issues, particularly financial difficulties post treatment. Adolescents also faced the fear of recurrence and the possibility of getting cancer themselves. They seem to respond by being more mindful of their own health and doing more health checkups. Previous research has also identified that adolescents and their families struggle with the fear of recurrence. According to Sales (1991) fear of recurrence is almost universal in patients and families. Davey et al. (2011), Stiffler et al. (2008) and Northouse (1984) described that the

recurrence of cancer may create uncertainty in the patients and the families. Several research studies have described that adolescents were concerned about their greater risk of developing cancer themselves, as in their mothers (Huzinga et al., 2005; Hilton & Elfert, 1996; Visser et al., 2004; Davey et al., 2011, Kissil et al., 2010; Clarke, 1995). Adolescents may benefit from factual and honest information from health practitioners regarding what they can expect after treatments are completed and also from factual information about the real possibilities of recurrence or getting cancer themselves.

Previous research described that adolescents facing parental illness go through a process of adaptation, for example, they had to let others be more important than themselves, adapt to new conditions and take more responsibilities with, for example, household chores (Davey et al., 2005; Dehlin & Reg, 2009). In this study, maternal cancer could lead to conflict or role changes because adolescents took over more household chores and responsibilities. In general, their response to these changes was very positive identifying that this improved the relationships with other family members and increased closeness. Health practitioners may help adolescents by making sure that the adolescents can deal properly with the additional responsibilities. Health practitioners may also be more able to understand the adolescents' experiences by taking account of gender differences as adolescent boys seem to assume a protective role and girls a caring role.

Adolescents provided recommendations for other adolescents which revealed alternative ways in which they would have responded to the challenge of maternal cancer, all of which are very useful for health practitioners as these are suggestions from adolescents themselves on how they can be supported during this difficult time. Health practitioners may help adolescents by providing them with opportunities to talk and meet other adolescents in similar situations. Adolescents also mentioned that it was important to keep normality and take care of themselves.. Previous research has described that adolescents are concerned with being understood by their peers, they doubt that someone who has not experienced parental cancer would be able to truly understand (Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Davey et al., 2011; Davey et al., 2003; Giesbers et al., 2010).

Building back my broken world

The second theme includes adolescents' description of how maternal cancer disturbed their environments but still they managed to find their own resources and coping skills to find stability and adjust more successfully to the challenges faced.

This thematic analysis provides important information on methods used by adolescents to cope with the challenges posed by maternal cancer. It suggests to health practitioners that they can expect adolescents to cope in very different ways, some cope on their own while others prefer group activities. Previous research also reported that adolescents may have a need for privacy and used coping strategies such as staying in their room, taking long walks, writing a journal, watching TV and playing video games (Maynard et al., 2013; Stiffler et al., 2008; Issel et al., 1990; Hilton & Gustavson, 2002; Davey et al., 2011; Clemmens, 2009; Adams- Greenly et al., 1986). Thastum et al. (2008) reported that being optimistic was a coping style used by adolescents when facing parental cancer. Adolescents also mentioned other coping strategies that were effective for them at the time which may also benefit other adolescents facing a similar challenge: Having a positive outlook, not worrying and keeping normal routines. Family routines should be kept as normal as possible throughout parental illness (Asbury et al., 2014; Turner & McGrath 1998; Maynard et al., 2013; Davey et al., 2003; Issel et al., 1990; Adams - Greenly et al., 1986; Nelson et al., 1994). There may also be gender differences in the way adolescents cope as only male adolescents mentioned that trusting the treatment and the medical team was one of their coping strategies. Taking these methods and differences into account may help health practitioners to encourage the use of effective coping strategies.

Seeking information was another coping strategy used by adolescents but it is important for health practitioners to understand that adolescents may need and want information in different amounts and from different sources. Some differences seem to be determined by age, older adolescents were more interested and actively involved in seeking information themselves. Health practitioners may help adolescents by providing them with age appropriate information or providing a critical

approach to the information, however, this would only be possible if they established a relationship and provided a safe environment for adolescents to express themselves. Previous research has suggested that information was important for young people when a parent had cancer but also agree with the findings in this study that there are individual differences in the information needs of each adolescent (Patterson et al., 2011; Fitch & Abramson, 2007; Davey et al., 2011; Hilton & Gustavson, 2002; Thastum et al., 2014; Lewandowski, 1996; Maynard et al., 2013; Hymovich, 1995; Kennedy & Lloyd-Williams, 2009). Hilton and Gustavson (2002) identified that some young people were active seekers of information but others were not interested in finding out anything beyond what they were told.

Adolescents described how their families helped them cope with the challenge of maternal cancer. This subtheme in particular is characterized by strong contradictions. Some families became closer and more affectionate but others grew further apart. Close sibling relationships helped adolescents to balance their emotions and support each other but not all relationships were described as open or supportive, but were instead conflicting. Maternal coping also had an impact on adolescent coping, mothers that were more positive and had a sense of humour helped their adolescents but mothers that were more negative increased the burden. Healthy fathers that were close and present were important sources of support and information but some fathers were not physically present at the time and did not get involved in any way. Previous research had also identified that families that experienced parental cancer spent more time together and this increased cohesion and sharing (Clemmens, 2009; Kissil et al., 2010) and this had a positive impact on young people (Issel et al., 1990; Maynard et al., 2013; Finch & Gibson, 2009; Clemmens, 2009, Hilton & Elfert, 1996; Kissil et al., 2010; Issel et al., 1990). Hilton and Elfert (1996) described that young people from well adjusted and flexible families were more satisfied with the way they coped with cancer as they were able to handle problems, provided mutual support and managed to shift their roles to fit the demands, those from poorly adjusted families grew further apart instead. This finding is important as adolescent coping needs to be understood in the context in which it occurs, as family coping can help

adolescents or instead increase the burden. Health practitioners may be able to identify adolescents at higher risk of poor adaptation by taking into account of the family environment.

Adolescents also described the challenges and assistance of external supports in their experience of maternal cancer. Adolescents described positive sources of support including friends, boyfriends and the community, however adolescents specifically selected who they wanted to tell as they wished to avoid being treated differently or receiving pity. Previous studies have also described the importance of friends in adolescent coping, (Clemmens, 2009; Stiffler et al., 2008; Issel et al., 1990). Huizinga et al. (2011) and Dehlin and Reg (2009) reported that friends provided an illness 'free zone' where adolescents could continue with their normal activities without thinking about the illness. Opposite to this, previous research identified that some adolescents decided to not tell their friends about maternal cancer because they did not want to be pitied, (Rosenfeld et al., 1983), stigmatized, (Clarke, 1995) and did not like when people overreacted, treated them differently or said hurtful jokes to them (Kristjanson et al., 2004).

Some adolescents in the current study appreciated school support, others did not want this. Some adolescents had positive experiences with Counsellors that helped them but the majority did not think they needed it or even if they were given the information, they did not avail of it. External supports can be important sources of support as long as they match adolescents' needs. Health practitioners can help adolescents by making sure these decisions are respected and supported so that adolescents obtain a benefit and avoid upset. Kristjanson et al. (2004) identified that adolescents appreciated health professionals that treated them 'as adults' and provided information in clear and simple language, adolescents liked having access to a professional's phone number but few mentioned actually having direct access to a Nurse, Social worker or Physician.

My vision of the future

Thoits (1995) suggested that negative life events, in general, do not always have a negative impact on health and mental health, as people tend to try to solve the problems they face and will grow and learn from negative

experiences. Adolescent's vision of the future was shaped by the experience of maternal cancer. The majority of adolescents described positive gains, for example, more appreciation for their mothers and the good things in their lives, they had a more empathic and humanized experience of cancer and described themselves as more mature. Several research studies found that adolescents who experienced parental illness perceived they were more mature than their friends and that the experience also changed their values about what is right and what is wrong and even their choice of occupation for the future, their appreciation for life and their understanding of life (Dehlin & Reg, 2009; Wong et al., 2009; Davey et al., 2005; Kissil, et al., 2010; Hilton & Gustavson, 2002; Karlsson et al., 2013; Fitch & Abramson, 2007; Davey et al., 2011).

One adolescent continued to have a very negative view of the experience which may suggest difficulties in adjustment and health practitioners may be able to intervene in such cases to help facilitate long term adaptation and positive growth where possible.

Recommendations and limitations

It is important for health practitioners to understand that adolescence is a critical developmental stage that will have an impact on the way young people respond to and adapt to maternal illness. Adolescents have a highly developed and complex cognitive capacity to handle honest and open information and deal with the emotions associated with the news of having a cancer diagnosis in their mothers. In this study it was suggested that age and gender can have an impact on adolescents' experiences and, therefore, developmental characteristics may need to be taken into account to fully understand adolescent adjustment to maternal cancer.

Adolescents need to be aware of support services or counselling services that can provide help but it is necessary to recognise that not all of them will need or avail of these services. Adolescents seem to be able to make that decision and do look for help when they consider that they can't cope anymore. It is not clear from this study what the underlying reasons are as to why adolescents chose not to avail of the support available; but it

could be useful to make sure there no barriers or difficulties for adolescents in access to these services, particularly at a challenging time like maternal cancer.

It is important to respect and take into account individual experiences and individual needs of adolescents, particularly in their coping styles, communication styles, needs and emotions. Differences exist in the way adolescents cope, the level of information that they want to have and the levels of contact they wish to have with medical settings and staff. Some adolescents are very private about the experience of maternal cancer and want to have the choice of who in their social circle is informed about it and who is not. Adolescents should be allowed to make these informed decisions themselves as not doing so may make the adjustment experience even more difficult.

Health practitioners could be more concerned about the experiences of other members of the families and not just the ill patient as a cancer diagnosis affects the whole family but at the same time different family members provide models of coping and adjustment to other members. Adolescents seem to want to approach medical staff to obtain information but consider that this is not possible and they have no place in the system, which leaves them with unanswered questions.

Future research needs to focus on gender balance in this type of research as still the knowledge of experiences of male adolescents seem to be lacking. This study has a small number of male participants and the length of their interviews was also shorter than female interviews, supporting this existing gender disparity. Other methodological approaches such as participatory research methods might be more suitable to attract this population or having male researchers might provide a sense of identification that would help male adolescents to be more open about their experiences. The findings of this analysis are limited by the fact that more adolescent girls than boys wanted to take part and so the experiences reported are more pertinent to adolescent girls.

Summary

This thematic analysis was focused on the subjective experiences of adolescents dealing with maternal cancer. The study indentified three themes: (i) The challenge of maternal cancer, (ii) Building back my broken world (iii) My vision of the future.

The first theme identified different illness related challenges that adolescents face and have to deal with such as the shock of diagnosis, stress and worry of maternal treatments, maternal physical changes, family financial difficulties after treatment, role confusion, and additional responsibilities. These challenges are improved by having open communication, access to information, contact with medical staff, talking and willingness to do chores as a way to help the family and the ill parent. The second theme describes skills and resources that adolescents use to deal with the challenge of maternal cancer such as individual coping strategies, contact with external supports (friends, school, extended family) and information levels congruent with their needs and desires. This theme also identifies how family and maternal coping can decrease or increase the burden for adolescents. When close relationships and co-operative systems share the burden, this reduces the demands on adolescents. The third theme describes positive gains for adolescents arising from a challenging experience such as maturity, closer relationships, empathy and clear priorities and shows how this contributed to their lives and to potential future challenges they may face.

Study 1 (b) Interpretative Phenomenological Analysis of Adolescent Interviews (IPA)

'...witnessing cancer in a family member may have a more profound impact on a child than being a cancer victim oneself'

(Huizinga et al., 2005, p.293)

Introduction

An Interpretative Phenomenological Analysis was conducted, focused on three adolescents interviews that were purposefully selected (from Study 1a) to carry out a deeper analysis of adolescent adjustment experiences to maternal cancer and to further understand adolescent strengths, difficulties faced and how they deal with them.

Method

Interpretative Phenomenological Analysis (IPA) was defined by Smith, Flowers and Larkin (2009) as a qualitative, experiential and psychological research approach which is committed to examine how people make sense of major life experiences in their 'own terms'. It examines in detail human lived experience. It also has an idiographic commitment where participant are situated in their context and their personal perspectives are explored, providing a detailed account of each case before making more general claims.

According to Finch and Gibson (2009) IPA differs from other qualitative methods because it recognises the interactive nature of data collection between the participant and the analyst. Data interpretation is also an interactive process between data collection and the analyst's interpretation. Finch and Gibson (2009) suggested that there is extensive support in literature for the use of IPA in social science research but not extensively in research focused on young people experiencing parental cancer diagnosis.

Smith et al. (2009) proposed a series of steps to carry out an IPA analysis.

1. Reading and re-reading.

This stage involves becoming familiar with the original transcribed interviews by reading them, focusing on the data to begin the process of entering the participant's world.

2. *Initial noting*⁸.

This step involved examining the semantics and language of the interviews at an exploratory level, including participant use of repetition, emphasis, descriptions and metaphors to identify patterns of meaning in participant's interviews by looking at the language used and the context of their issues but also the depth and detail included in their attempt to accurately share their experiences. For example describing maternal illness as '*a slap on the face*'.

Content was divided into three different groups: descriptive, linguistic and conceptual. Descriptive comments mainly included content, facts or themes in the interviews that helped identify things that mattered to participants and objects which structure their thoughts, experiences and worlds, for example, University experiences, moving away, family traditions, Christmas, separations, marriages and friendships. Linguistic comments included the specific use of language by the participant and how the transcript reflected the way in which the content and meaning were presented like laughter as a way to lighten difficult topics and release tension, crying to express emotional upset. Conceptual comments involve a more interrogative and conceptual level, moving away from the explicit claims of participants towards an overarching understanding of the topics discussed, supported by the text. This involved identifying conflicting ideas for participants for example expressing concern for maternal illness but also being upset by maternal illness being disruptive to normative teenage experiences such as partying and having fun with friends in the first year of University.

3. *Developing emergent themes*.

This task involved reducing the volume of detail (transcript and initial notes) but still conserving the complexity of interrelationships, connections and patterns between the exploratory notes. Initial exploratory

⁸ The initial noting and emergent themes are available by contacting the main researcher.

comments become emergent themes also supported and informed by theory and research.

4. Searching for connections among emergent themes.

Chronologically identified themes in each interview were organised in a way in which they fit together with relevance to the research question which was concerned with describing the experiences of adolescents adjusting to maternal cancer.

5. Moving to the next case.

This step involved analysing the next transcript and repeating the previous steps in the analysis conserving the individuality of each of the experiences of the three girls.

6. Looking for patterns across cases.

This is a compare and contrast process which allows the identification of similarities, discrepancies and patterns across the three transcripts. Emergent themes were reorganised to produce super-ordinate themes.

Initial phases of this Interpretative Phenomenological Analysis suggested a strong tendency of the data to be focused on the mother child relationship at a difficult and challenging time of maternal illness. This relationship seemed particularly close and based on a caring dyad characterized by polarities and contradictions. This initial phase of analysis and iterative coding and reflection suggested the use of a theoretical interpretative frame which became the source of organisation for the emergent themes and patterns of the data in this IPA analysis. The theoretical frameworks chosen were Young Carers Theory (Aldridge & Becker, 1993; Abraham & Aldridge, 2010; Aldridge & Becker, 1999) and the Family Ecology Model (White & Klein, 2008; Bronfenbrenner, 1979; Pederson & Revenson; 2005). These theories contributed to the understanding of adolescents experiences in context by identifying the different systems adolescents interact with including their families, University, hospital setting, friends and other significant roles they fulfilled while they experienced maternal cancer.

Young Carers Theory.

Young Carers Theory has focused on exploring the experiences of young people who live and provide support to an ill family member (Ireland & Pakenham, 2010). It is mainly concerned with the developmental impact that caring for an ill parent has on the young person. ‘A young carer is a child or young person [...] whose life is affected in a significant way by the need to provide care for a family or household member who has an illness, disability, addiction or other care requirement’ (Fives, Kennan, Canavan & Cairns, 2010, p.16).

Aldridge and Becker (1999) suggested that most children are involved in caring for others, within and outside their families and this is part of normal childhood development. Intergenerational caring can be part of reciprocity and interdependence within the family and it enables the family unit to survive. Fives et al. (2010) suggested the importance of taking into account the level of caring, as caring can have positive consequences but when this level is exceeded it can lead to impairment in the child’s health, development and welfare. Aldridge and Becker (1993) suggested that caring can have long term repercussions in children’s emotional development, as the levels of stress produced by caring can lead to depression, anxiety and fear, but still young carers manage to show remarkable levels of resilience.

Previous research has suggested that adolescent girls are a particularly vulnerable population at the time of parental illness. Visser et al. (2005) described that daughters are more sensitive to interpersonal concerns and stressful life events than sons and also explained that adolescent daughters seemed to be more vulnerable due to increased identification with their mothers and additional role responsibilities. From a Young Carers theory perspective, Aldridge and Becker (1993) identified that the majority of caregivers are usually female and in an exclusively Irish study, Fives et al. (2010) identified that 62% of young carers are female.

Family Ecology Model.

‘Human Ecology is the study of the surroundings of human beings in the effects they produce on (other) lives’ (Richards, 1907, cited in White &

Klein, 2008). Tudge, Morkova, Hatfield and Karnik (2009) described the four elements that make up this model: process, person, context and time.

The person component consists of the biological, genetic and individual aspects that the person brings to any situation. The context component is divided into four aspects: (i) The microsystem is the environment where people spend the majority of their time (school, home), (ii) The mesosystem are the interactions between microsystems, (iii) The exosystem are indirect influences that have an impact on development even if the person is not actually situated there (for example, maternal work causing stress on the child) and (iv) The macrosystem is the extended culture or social group that determine beliefs, patterns and lifestyle. Time is another important component. It is divided into three: (i) Micro-time occurs during a specific activity (ii) Meso-time includes activities that consistently occur in the person's environment, (iii) Macro-time refers to the way historical events can affect a developing person at a specific age.

The bioecological model defined human development as progressive processes that are increasingly more complex and interacting between an active, evolving and biopsychosocial human organism and other people, objects and symbols in the immediate external environment. This interaction need to occur on a fairly regular basis over time. These interactions are known as proximal processes. These processes can vary as a function of the individual characteristics of a developing person, contexts and time periods in which the proximal processes occur (Bronfenbrenner & Morris, 2007).

Pederson and Revenson (2005) designed a family ecology model to explain the interrelationships between parental illness characteristics, family functioning and adolescent wellbeing. Illness affects adolescent and family functioning and has an impact on stigma and threat, physiological stress responses, distribution of roles and responsibilities in the family and daily routines. Contextual variables such as parental and adolescent gender, family attachment style, and cultural norms are related with emotional responses to stress. This is, however, a theoretical model.

Pedersen and Revenson (2005) included proximal processes in their family ecology framework of parental illness. Proximal effects are defined as the individual and family- level mediators that can affect family

functioning and adolescent well being at a time of parental illness. Parental illness severity is hypothesized to impact appraisals of stigma and threat, physiological stress responses, the distribution of roles and responsibilities in the family and daily routines. These processes can interact with each other and have an impact on family functioning and adolescent well-being (family and youth outcomes).

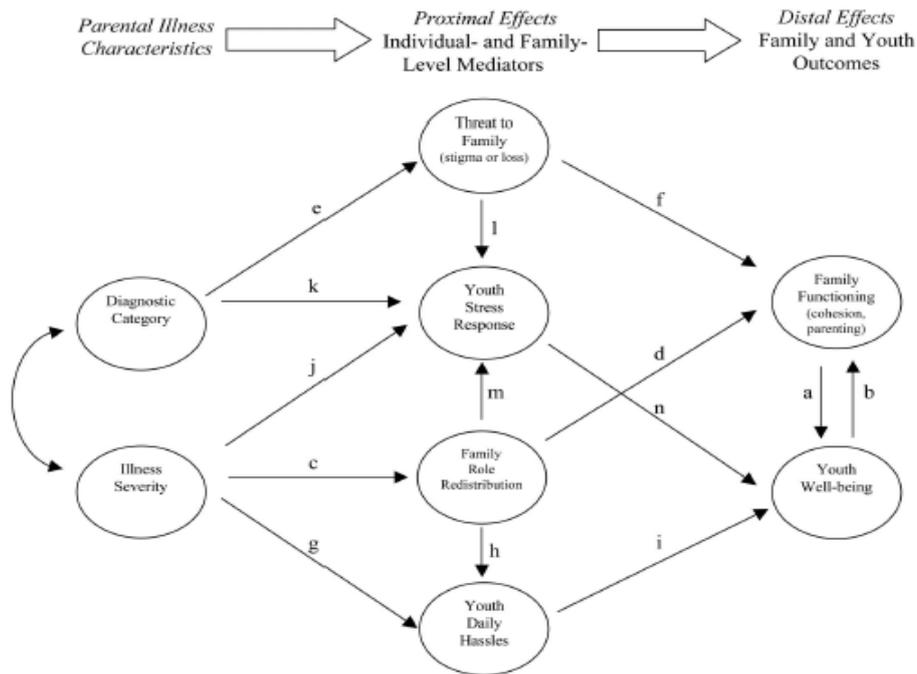


Figure 9: Family ecology framework for research on parental illness (Pedersen & Revenson, 2005, p.405)

Results

Description of participants.

Three adolescent girls between 17 and 20 years of age were purposefully selected (Fiona, Caroline and Barbra). Fiona is a 17 year old adolescent who had to move away from home to begin her University experience almost at the same time she found out about maternal diagnosis. She went to University, as this was the wish of her ill mum, but she struggled to adapt to her new life and her new friends while feeling guilty for being away from her ill mother. She experienced some difficulty dealing with her own emotions and is the only one who cried during the interview, so she appeared to be still struggling to cope with her feelings, even two years after

her mother's diagnosis. She has a close relationship with her mother, although she described her family as being close but not overly involved with each other, and this was functional for them. She found comfort in spending time on her own and trying to think but also she described being supported by friends. Fiona's account lacks detail on her mother's illness process as such because she is physically separated, but it provides a descriptive account of how she struggled with the guilt of not being able to be there for her mother, this is why Fiona was included as it provides a different perspective of the experience of caring.

Caroline is 19 years old. She was going through the developmental transition of moving away from her family home to attend University when her mother was ill. Caroline's experience is a complex combination as she had to deal with her mother's mental and physical illness simultaneously. Caroline has a very strong family system, where communication is open and this flow of information provided her with a feeling of trust and security. The role of her father is particularly significant as a provider of information about maternal illness but also as a person who shows validation and respect for her as a young adult and not a child anymore. Caroline takes on a caring role towards her mother and other family members but she is supported by other family members.

Barbra is 20 years of age and her experience is very unique because she becomes her mother's closest carer and assumes the responsibility of taking care of her and also of her younger sister. Barbra struggled to continue with normal adolescence demands such as attending University as she was so busy at home. Barbra's family is not cohesive, in fact she described that the cancer experience pushed them further away. Barbra had a close relationship with her mum but could not speak to her about the cancer, she found support in her friends mostly and sporadic support from a neighbour and an aunt.

Table 7 Irish Adolescent Interviews-Sociodemographic Data

Interview	Type of interview	Gender	Age	Cancer Type	Time since diagnosis	Interview length
5	Video chat	Female	17	Breast	24 months	40:53
11	Face to face	Female	20	Breast	25months	34:21
12	Face to face	Female	19	Gastrointestinal	14 months	56:18

This IPA identified two major themes. Becoming my mother's mum is mainly focused on the impact that maternal illness had on the mother-daughter relationship. Theme two is Illness: A family experience. This theme describes the impact of maternal illness from an ecological approach, understanding the impact that maternal cancer had on the individual but also on the context that they were in, including the illness itself, family, friends, University, external supports and the hospital setting.

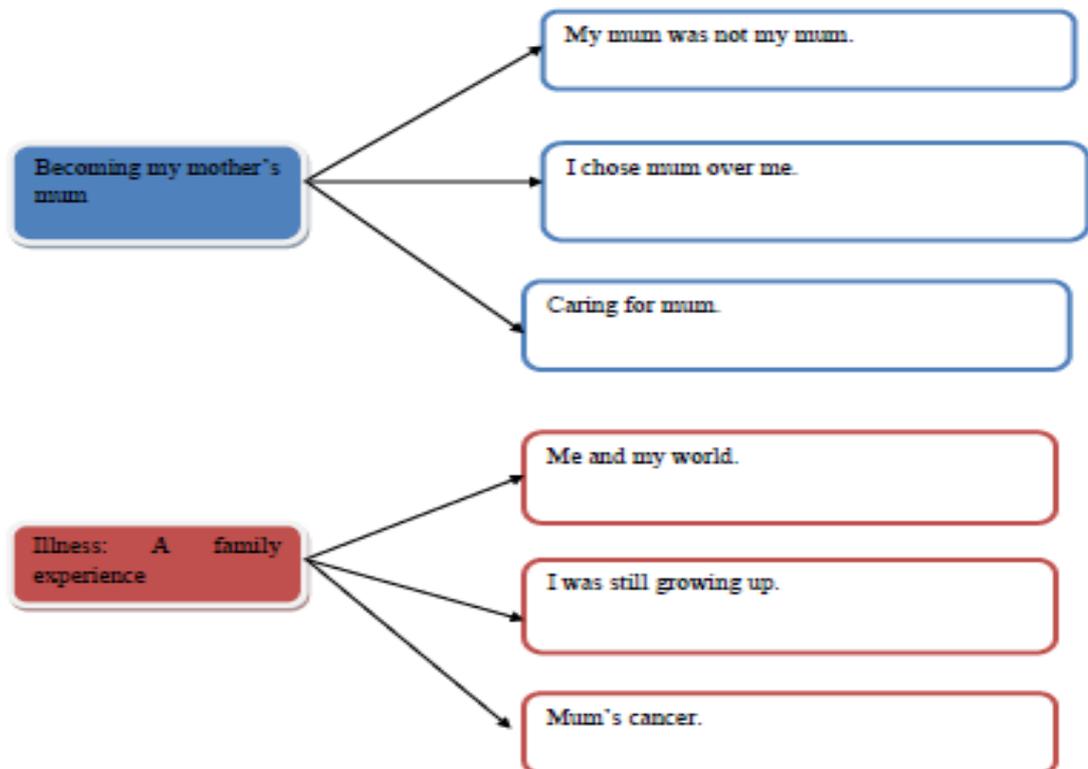


Figure 10: Summary of themes identified in the Interpretative Phenomenological Analysis.

Becoming my mother's mum.

This theme describes the complexity of the mother child relationship at the time of maternal cancer and the specific relationship built between a caring daughter and their ill mother. The first sub theme 'my mum was not my mum' is a description of drastic changes in their mother, mum vs. sick person is the main polarity identified. Mum was not recognizable in their minds as this sick person. 'I chose mum over me' is focused on the way adolescents dealt with the realization that their mother was ill which was mainly denying their own feelings and their own needs to prioritize their mother's emotions and needs. 'Caring for mum' described how adolescents assumed a caring role for their mothers, instead of being cared for by their mothers, as would be expected in a relationship between a mother and her adolescent child.

My mum was not my mum.

One of the challenges faced by Caroline and Barbra was having to see the emotional and physical changes that their mothers went through due to illness, to the extent that their mothers were no longer the people they knew before. These changes were less drastic for Fiona.

Barbra used the metaphor '*slap in the face*' to describe her experience of seeing her mother sick, which suggests an unexpected and painful realization for her. Barbra repeated the adjective 'sick' three times, which may suggest her struggle to come to terms with the fact that her mother became defeated and sick. In her mind, mum and 'sick person' seem incompatible ideas.

The hospital setting and treatment made the experience of maternal illness more real for Barbra. She described that she had difficulty dealing with it, she was upset and she felt helpless as there was nothing she could do to help her sick mother.

I think when she was at the hospital and I saw her with the mastectomy, I was really upset when I saw that cause it was just like, you know, a slap in the face cause she had the drain and the blood and she was so sick like I've never seen her that sick before and I don't know I just don't like her being so upset or defeated in any way (...)

it's just like it's so real when you are surrounded by all this sick people and it's just hard to deal with like that you can't help them but you just sit there with them (Barbra, 20).

Similar to Barbra, Caroline also struggled to deal with the changes in her mother due to the illness. Caroline, however, had a particularly challenging experience as her mother was diagnosed with a mental health illness, almost simultaneously with the cancer diagnosis. The mental health issue was taking over her mother and was impeding her from taking part in important family events like her brother's graduation, '*...it was her anxiety that was holding her back*'. Caroline described that she felt concerned but mostly she seemed confused and this is expressed through the questions and doubts she seems to have surrounding her mother's diagnosis.

I was very concerned when this happened, what exactly is going on with my mother (...) where is this stemming from, is it because of the cancer and the related operation, is there something I don't know about, have you gotten I suppose, have you gotten any other information in relation to the cancer that is more worrying than what I'd been told at that point (Caroline, 19).

Caroline also provided a detailed account of how her mother experienced a drastic change in her normal behaviour, she became scared, vulnerable, in a state of desperation, trapped, claustrophobic, which suggests drastic and significant changes. Caroline emphasized the phrase 'really suffering' twice to describe the severity of her mother's state. This was very upsetting for her.

...it was very upsetting to see your mother in such state like I mean that she was so vulnerable, she felt...I suppose she felt so trapped, claustrophobic...her behaviour was like someone that was really suffering, it seemed like she was really suffering and she...I suppose I felt very helpless like there was nothing I could... (Caroline, 19).

Compared to Caroline and Barbra there is no evidence in Fiona's interview to suggest major changes in Fiona's mother. Fiona describes that: *“My mum was really great she was just so like methodical she was like yeah yeah absolutely fine”*. Fiona only described that her mother has a permanent change in the function of her arm due to secondary effects of treatment: *“she's got a bad arm now because they had to take the lymph nodes out of her right arm”* but no other changes are mentioned.

Fiona expressed that remembering the experience still makes her cry but her mother's jokes and sense of humour facilitated the experience for her. Laughter in Fiona's account adds a completely different tone to the descriptions of Caroline and Barbra. Fiona was also the person with the longest time since diagnosis at the time of the interview and, therefore, the experience of maternal cancer could have been dealt with or perceived in a different way by then.

But now it's like, if I think about it a lot then I start to cry but as far as I joke with my mum about it 'cause one of them is like one of them is slightly small now (...) we watched this thing some programme about Angelina Jolie got the double mastectomy (...) my mum was saying that she should have both of them cut off and get a nice new pair (*laughter*) like whatever she actually wants and stuff (Fiona, 17).

I chose mum over me.

Adolescents dealt with their own emotions by leaving them aside or silencing them to avoid being a burden or causing distress on their mothers and other family members. Adolescents were very accepting and open to maternal feelings and emotional needs but did not grant themselves this same permission.

Caroline described that she put her feelings aside and focused on her mother's wellbeing over her own emotions, not being able to put personal feelings aside was understood as being selfish: *“We just felt that if we were to let our feelings be the main reason rather than what was best for her, that would be selfish of us (...) her wellbeing needed to come before our feelings”* (Caroline, 19).

Adolescents experienced a duality in their emotions, what they felt versus what they thought they were allowed to feel. Barbra described feeling upset and helpless but did not share this with anybody and instead pretended to be strong and have a sense of humour around her mother.

I feel that I have to be the strong one for her, I need to make jokes and I need to make light the situation like I can't be worried for her at that time cause she needs support (Barbra, 20).

Fiona also struggled with her own emotions because she was not sure if she had a right to be sad or get help, as she was not the ill one. The guilt and confusion surrounding her emotions still seems to remain over time as she began to cry during the interview.

...cause you feel like, it's a combination of feeling crap because it's such a bad thing and then you feel guilty cause it's not really happening to you, so like 'okay I feel bad but should I feel this bad, how bad am I allowed to feel?' because it's not me. It's confusing like that because you don't want anyone's sympathy because you feel you don't really deserve it... (Interviewee begins to cry) Sorry (Fiona, 17).

Adolescents struggled to disclose their real emotions with other people and minimized their true feelings to appear 'normal'. From Barbara's account it is very significant to notice how she tries to normalize her experience but it seems that she is instead trying to minimize it by using adjectives like *okay* and *fine* and thinking she was '*milking it*' to people, looking for pity or sympathy from others not because she actually deserved other people's support and understanding, as she was genuinely going through a difficult moment. Barbra described that maternal illness was difficult for her and used a strong metaphor to describe how she felt: *I couldn't breathe* and she struggled to handle and come to terms with seeing her mother sick.

...well the first stage is just, I couldn't breathe at all and all the time like there was no room for it because it was bad news and more bad news and hard time and like you

don't know just how much more you can take at that point like I just couldn't handle seeing my mum like that, then the second stage (...) you nearly get used to the fact that your mum has cancer and it's like 'okay, yeah my mum has cancer, its fine' and you like milking it with other people and they are much nicer to you (that's good, laughter)...got a lot of free stuff (Barbra, 20).

Fiona's description of her mother usually included a perception of her being positive, strong for other family members, joking and coping quite well; however there was reference to a telephone conversation where maternal fears of possible death became clear to Fiona and she struggled to deal with this. She described that she '*freaked out*' and went away to cry by herself, but firstly she finished the conversation with the mother. This also shows how adolescents dealt with their emotions on their own and kept their honest emotions from their mothers.

...she said something like that she was hoping to get to my graduation and I just, she said that was her next marker in life and I was like. 'cause she never mentioned like life span or anything or chances or anything it was always 'we are going to be fine, we got it like really early, I am going to be okay' and then I mentioned that and I was like you are really expecting...in my head she was only expecting to live like four years and I was only like 19 and I freaked out. I remember like I just calmed down and finished the conversation and just walked straight past my friends to the toilet and burst out crying... (Fiona, 17).

Adolescents also chose their mum's needs over their own needs, denying their own need for care, the same way they did with their emotions. Fiona understood that the medical staff had to concentrate on her mother and not on her own needs "*...they were lovely but obviously it was like medically for my mum but there was never anyone who came and said 'are you okay?'*" (Fiona, 18). Barbra described that even though she spent a long time with her mother in hospital, she was never offered any kind of help for

herself but she was not really expecting anything. She used a strong metaphor to describe the state of her mother: '*A woman broken both inside and out*'.

I don't think it's about me when I go into the hospital, it's about my mum and how she is feeling and how to make her feel more comfortable like I can't expect people to be asking me like how I am feeling when there is you know a woman broken both inside and outside, you can't think that (Barbra, 20).

Caring for mum.

The level of maternal change was drastic, particularly for Barbra and Caroline, and this led to adolescents assuming more of a maternal role with their mothers during illness; they were the ones providing care instead of receiving it.

Barbra made a very strong decision at the time of her mum's diagnosis; she assumed the responsibility of her mother's care completely. Barbara's account is the one which provides the most detailed information about maternal treatment because she was the only one involved as a full time carer: '*I didn't really think anything like that could ever happen but it did and I was like okay and I took it on my shoulders more than anything 'cause there is nothing else you can do than to deal with it*' (Barbra, 20).

Barbra's described herself as being more *mature, organized* and *clean* than her other two sisters, therefore the correct person to take over the caring role of her mother. This, however, can also be a justification and assumption of why she becomes the sole carer of her mother, excusing her two sisters from their lack of support and involvement in maternal care.

I am the middle child so I think I've always kind of been really mature compared to my other sisters.(...) I think I have always been like the child that helps the most, it's probably because I am the cleanest, my other sisters are really dirty (...) and I can't handle dirt ... (Barbra, 20).

Caroline described that her caring role was activated by the state of illness and vulnerability in her mother. Caroline described that her mother was unable to recognize her as the daughter and enact her usual maternal

role. Caroline used the metaphor of a '*vulnerable child*' to describe her mother's current state, which was accompanied by the possible emotions her mother was experiencing like being scared and out of control and this suggests the level of identification and connection she had with her mother at the time but also her duty of care towards her mother.

I think it felt like the mother child relationships had reversed (...) I felt like I was the one kind of caring for her, I was the one making her feel better, she was the one crying onto my shoulder (...)it wasn't so much that she became me, it was more that she became a young child, a very vulnerable young child...scared vulnerable child...and I just had to (...)I suppose make her not feel so scared, I had to comfort her (Caroline, 19).

Fiona's account is very different to the other two because as she was physically separated from her mother and, therefore, was not able to become her mother's carer. This resulted in her feeling very guilty, which may suggest that she would have voluntarily taken on the role as her mother's carer: "*I felt guilty for being away, I felt guilty for not even, I'm away so I am not even fulfilling what I am supposed to be doing while I was away*" (Fiona, 18).

Fiona described her mother as the strong one of the family; making decisions and helping other family members cope, including herself and her dad.

...like my mum is so calm and like she rarely loses the rag but my dad is just like short tempered and like he doesn't cope well with change with stuff and he can stress out himself quite a lot, just like me (*laughter*). She told me that he didn't cope well like he, she was really like 'right what do we do now?' (Fiona, 18).

Although mothers need care there were some moments when they returned to their maternal roles and were concerned and worried for their children. Caroline described that her mother had '*flickers of normality*'. These were specific moments when she showed concern for her children as an instinctive behaviour. Caroline added that her mother was being caring,

comforting and sentimental towards her children even though this was not her normal maternal behaviour, she was not as emotional before and this reminded Caroline again that her mother was not her usual self.

...there were times when the flickers of normality came through...it was when she was worried about my sister and I being upset at the state she was in (...) She was very caring and comforting and sentimental maybe which she wouldn't have been before. (...) there wouldn't have been a lot of emotional closeness (...) she was trying to emotionally look after us...even though emotionally she couldn't look after herself (Caroline, 19).

Barbra and Caroline also described a sense of maternal guilt related to the fact that mothers were aware that they could not fulfil their regular maternal roles and duties of care.

It was very hard cleaning because my mum was not as clean before but suddenly when she got cancer I think she got ...because she was kind of feeling bad that she wasn't a good enough mum so it was really hard to like help her cause she felt that she had to do everything cause she was a really bad mum so she was struggling but she couldn't do everything... (Barbra, 20).

Overall, adolescents described that caring for mum was not a negative experience but could identify very positive aspects brought about by it. Caroline, Barbra and Fiona agreed that the cancer experience improved the relationship with their mothers, by increasing the intimacy and closeness in their relationship.

...we were really really close, like we were talking to each other every day, we were texting each other. Like I'd talk to her about anything and she'd do the same for me so it really brought us closer together (Barbra, 20).

In the case of Fiona, she described that she was already close to her mother and the experience did not change that, as the closeness remained, *'I'd be very close with my mum...it didn't really change anything*

permanently but...I don't know. It changed it a bit but nothing really drastic" (Fiona, 18).

Illness: A family experience.

Caroline, Fiona and Barbra struggled through maternal crisis on their own. This was a time of demands that were difficult to cope with when they were burdened with concerns and lacked supports. They found it difficult to find someone to communicate with and also had reduced social networks. This theme focuses on the different challenges that adolescents faced and the different roles they had in the different contexts they were in including their families, University, friends and hospital setting. The analysis in this theme is supported by the Family Ecological Model which will provide an understanding of the four different elements that interact: process, person, context and time.

Me and my world

Fiona, Barbra and Caroline had different family systems at the time of maternal illness and this had a different impact on their own experience. Barbara's family system was the most dysfunctional and the parental dyad was separated shortly before cancer diagnosis, the separation process seems to have been difficult for a long time before the cancer diagnosis, to the point that she described feeling '*desensitized*' from listening to parental arguments.

...you just get desensitized after a while hearing about everything like when my parents fighting (...) I don't know, my mum and dad have a very complicated relationship which is like they are together but they are not together, they don't sleep in the same room, they don't talk to each other they don't really like each other. My mum and dad have a very complicated relationship (Barbra, 20).

Barbra described that she had a 'maternal role' with her younger sister, both before and after maternal cancer diagnosis because her younger sister has a specific psychological condition and was not able to deal with change as she was a witness of war when she was younger. During maternal illness, Barbra had to take care of her younger sister instead of finding

support in her. It is possible to see how she would be more maternal to her younger sister given family problems experienced at the time. Her older sister got married during maternal treatment and moved away, which reduced further the supports available for Barbra and increased her demands and responsibilities: “...my older sister didn't help in the end because she just couldn't deal with it so we never really hear from her, she didn't come over” (Barbra, 20).

Maternal illness had a different level of impact on family systems themselves. Barbra described that cancer had a negative effect on her family and separated them even more, “...we were a close family and now we are like less close definitely, I think the cancer diagnosis definitely split us more apart, unfortunately...” (Barbra, 20).

Opposite to Barbra, Fiona described her family as ‘good’ yet not ‘traditionally close’ before the cancer diagnosis, yet she described that the illness brought them closer as a family, even though it was a ‘bad’ way to achieve that. She also described that she didn't have a particularly close relationship with her sister and the illness didn't bring them closer.

It brought us closer a little bit like to be more supportive of mum and dad a bit but me and my sister really didn't change anything. (...) I knew I could talk to her if I needed to but we didn't particularly really bond together or anything... (Fiona, 17).

Opposite to Barbra, Caroline had the closest family system and it was supportive and co-operative so her caring role was not solely focused on her mother but also included other family members.

...just generally looking after, keeping things going from all round and just being there for her, my father and I suppose my siblings, even to some extent and I suppose her parents, my grandparents just keeping an eye on them too for her cause she would be a carer for them a lot too. They live next door to us at home so you know, while she was not able to look after them as much” (Caroline, 19).

An important element of Caroline's description is that she refers to her mother as a ‘carer’ which may suggest an identification of Caroline with

her mother as carer, or the source from which Caroline learnt to become a carer for others, following the example of her mother.

Family communication can also be challenging as adolescents struggled to speak openly about cancer, particularly Fiona and Barbra's families. Fiona avoided talking about her own experience, mainly because she did not have anybody to talk to, as she did not have a close relationship with her sister or her dad. Fiona also filtered the information she shared with her mother to avoid worry in her. The interview was the first opportunity for sharing her experience with somebody, two years after.

I've never spoken to anyone about it properly apart from my mum but I wouldn't tell her half of this so like (yeah) I didn't want to worry her more and I don't talk to my sister much yeah and my dad is nothing like an emotionally open person so I wouldn't really haven't talk this much with anyone (Fiona, 19).

Barbra explained that communication was difficult because there was a significant level of maternal *sensitivity* and *upset* towards the topic and *family fear*, she said she did not talk about it to avoid grief, this however, changed over time and she was able to talk with her mother but not until after the treatment was completed. Barbara described herself as her mother's '*listener*' but this was not reciprocal, "*She is highly sensitive about the whole subject so I try not to cause any grief about it. I just listen to her if she needs to talk about it...*" (Barbra, 20).

Caroline had a completely different experience as her family took many decisions about maternal illness and treatment together. She explained that her father did not want to make decisions without the consent of other family members. "*...he didn't want to make any decisions about my mum without consulting...you see none of this was against her will*" (Caroline, 19).

The relationship with the healthy parent can also be a challenge for Fiona and Barbara because they are described as being distant. Caroline's dad instead is a central figure in her narrative and is crucial in her experience of maternal cancer.

In Barbara's case her father had recently separated from her mother and moved away, he was absent. "*My dad was already gone at that stage*" (Barbra, 20). Fiona described her dad as '*stressful*' and not being emotionally accessible for her or supportive of her "*...my dad is just like short tempered and like he doesn't cope well with change with stuff and he can stress out himself quite a lot*" (Fiona, 18). Fiona mentioned twice in the interview that her father struggled to cope himself, which may suggest she empathised with him as they both found it hard to cope with maternal cancer.

Caroline's father instead was a very important figure of support for Caroline and her mum during maternal illness. Her father was in charge of diagnosis disclosure as she described: "*I don't think my mother was able at that stage to explain what was going on*" (Caroline, 19). Caroline was able to identify paternal emotional struggles and reactions, she described that her father felt anxiety and fear. It was also the very first time that he had seen her father cry, "*I remember there was tears from us all, I remember it was the first time I had seen my father crying but you know, we all felt very sorry*". Caroline also said that she appreciated an adult-like treatment from her father, as it showed respect and recognition of her maturity:

...my father would have treated me with a lot of respect, he used to tell me that he was very proud of me, that I was very mature so I feel like any discussion that he had with me he was treating me like I could comprehend as if I was an adult (Caroline, 19).

Adolescents also mentioned other external sources of support. Barbra mentioned three sources: Neighbour, aunt and friends. Support provided from the neighbour was focused at the time of diagnosis disclosure but then she mentioned that she lacked support at the time of diagnosis. Barbra particularly appreciated her aunt's help, as she flew from another country to help them. Barbra's best friend and roommates were essential as they supported her and let her express herself. Barbra also had a boyfriend but could not talk to him about maternal cancer because he had struggled with his own cancer experience previously.

...my aunt came over from (name place) to help us out and that was the best thing in the world because I didn't drive so I couldn't drive mum to the hospital or anything like that so it was really like the best thing happened to us (...)at the time when she was diagnosed I didn't really have many people ...my friend (name) was like amazing ...but when my mum went through chemo I had a lot of support through like my roommates and stuff, they were very good with it. Cause obviously like I just said random things and I just started talking about it and I didn't realize I was talking about it (*laughter*) (Barbra, 20).

Like Barbra, Fiona also described her friends as essential in her coping process. Fiona was going through a transition between her old and new friends. Support provided by her University friends was appreciated, mostly when they understood her. Fiona decided not to inform all of her friends, only some as this would avoid having people constantly asking her how she was doing all the time, but this allowed her to identify which friends were genuine.

I'd made really good friends last year theythey told me that they would come like they would all be going out they would be in halls and they would come up to my room and knock on my door and see like I remember there were lots of times when they knocked and I just stayed in bed and pretended I wasn't in (...) They said we knew and I was like well how did you know? Sometimes we heard the radio or the music being switched off and I was like yeah well, they understood totally but that's how it sort of affected the first part of University (Fiona, 18).

Other sources of support for adolescents were more formal, such as Counsellors. Barbra described that during maternal treatment she went to a therapist in the University to get help. Caroline also decided to seek

professional support when she identified the ‘warning signs’ in herself that the experience was becoming difficult to handle on her own.

I think I kind of recognised in myself that ...I would have an awful lot of emotions to deal with and that I would need that extra bit of support so my mother going through this experience made me go and seek that support from student counselling (...) I kind of recognized the signs in myself and I took the steps... (Caroline, 19).

I was still growing up.

Fiona, Caroline and Barbra had to face challenges specifically related to their age and developmental stage. Adolescents were all starting their first year in University when maternal cancer diagnosis happened so they doubted whether they should leave the family home at a time when they were needed.

Fiona explained that her mother wanted her to go to University, as it was planned before the cancer diagnosis. Fiona, however, was still not sure if that was the correct choice to make.

...it wasn't really mentioned about me not going (...) I dunno if it was the right thing to go away or not um for me it was the right thing and I think whatever was the right thing for me was the right thing for my mum (...) I think I was so busy trying to pack (...) I think the main sort of distraction...it was good and bad to go away (Fiona, 18).

Fiona described that she struggled to balance her social life with University during the first year. Fiona probably perceived that first year students had fun in University, but instead she spent time by herself, hiding from her friends and trying to cope with her emotions about her mother's illness. She used the metaphor ‘*domino effect*’ to describe how the effect of maternal illness had long term consequences on her University life.

... it really affected like my whole first year at least as if as domino affect it affected my second year but like in my first year like freshers and all that stuff we were supposed to be

just having fun and meeting loads of people and getting drunk and stuff...(Fiona, 18).

Fiona also showed concern for changes in her personality/ behaviour to the extent that she did not feel 'like herself' anymore, she described herself as social and outgoing but she was instead spending more time on her own. She described herself as a '*bipolar disorder*' which is a metaphor of the sudden changes in her mood but also suggests other people may have perceived her as a person with a mental health issue.

...before I was always up for going out or if there is anything like a party or going out for the night or something I would be always first in line straight away...After, sometimes I just wanted to be by myself for a bit (...) I wasn't myself socially or personality wise (...) I felt I had to explain a bit more so that they [friends] didn't think I was like a bipolar disorder (*laughter*) (Fiona, 18).

Fiona also described how the cancer experience interfered with her University duties and this made her feel very *guilty*, which she mentioned twice in the same sentence, as she was not at home caring for her mother and yet she was not being able to keep up with University either.

I wasn't going to class so that made me feel even worse cause I was falling behind with school (...) My (...) teacher was getting very frustrated with me and I just felt like everything was going wrong and this is not how it is supposed to be. I felt guilty for being away, I felt guilty for not even, I'm away so I am not even fulfilling what I am supposed to be doing while I was away (Fiona, 18).

Barbra, like Fiona, also struggled with University. She described that she felt unprepared to go to University and was facing many other demands at the same time. As maternal treatment advanced she could not attend anymore.

I was going through a lot when I first went into University, I don't think I was prepared for it at all but I didn't really talk to my mum about that anymore, like I really just tried to help her (...) 'I missed a lot of

University to go home and go with her to chemo, I didn't like not going to chemo with her (Barbra, 20).

Caroline also described her experience in University. Compared with Fiona and Barbra, there is only evidence of one day that she was not able to attend University, the day after maternal mental illness was disclosed. There is no more evidence in Caroline's interview of any other struggles faced in University, "*...that Thursday I went home with my parents and I didn't feel able to go to University the next morning cause I was so alarmed at the state that my mother was in...*" (Caroline, 19).

Mum's cancer.

One of the initial challenges that Caroline, Barbra and Fiona had was to cope with the diagnosis, starting with the way cancer was disclosed. Fiona found out about maternal cancer diagnosis from her parents, family communication of serious events was not familiar to her and the seriousness of the ritual made her realize how significant the news was.

...they called us into (...) the front room and sat us down and they never like in my whole life they've never sat us down to say we need to tell you about something and then I was just like, like a relative has just died or something... (Fiona, 18).

Caroline described that her mother knew about cancer some time before it was disclosed to her but she had to tell them because the surgery was going to happen. They were told by her mother, gathered together as a family.

Barbara found out about maternal diagnosis by accident. She had noticed changes around her house and also her sister and another family member had accidentally mentioned something about maternal illness before. It can be seen that the days before having a definite disclosure of the diagnosis, her feelings and emotions were building up around the uncertainty of what could be happening. Barbara was then told by her mother, she was just emptying the dishwasher and that is when and how she was told in a very informal way, compared with Fiona and Caroline.

...it was like a change in the house (...) my mum was more stressed out'. I think I kind of knew at that point

because my sister just had said something to me, I think a few nights before but it was like a thinking feeling that it wasn't just something small anymore it was something bigger (...) my uncle (...) asked me ..he was like 'oh did your mum get the results of the diagnosis?'(...) there were little mentions the entire time...but I was home for the weekend and emptying the dishwasher she told me... (Barbra, 20).

Barbra's experience at diagnosis was particularly difficult as her mother had a type of cancer described as 'spider' which meant that it could spread more easily but there were also accidental diagnosis and uncertainty, which she described it as being '*kept on their toes*' permanently and she also describes that there was not a lot of good things happening at the time.

...they told us...accidentally (...) they read a scan wrong going for the mastectomy and they told us that they had spread everywhere and it hadn't, they thought it had and ...it was just weird stuff happening the whole time like they kept telling us that her type of cancer is called spider cancer or something so it spreads really easily and it was just like keeping us on our toes the entire time (...) the good stuff wasn't a lot (Barbra, 20).

From these accounts it is possible to suggest that the beginning of their experience of maternal cancer was marked by an attempt by the parents to manage the disclosure, which was not successful in Barbra's case and seems to have elicited more uncertainty. But even when the disclosure was managed, it was a difficult and unnatural moment for all adolescents.

Adolescents seemed to agree that the time of diagnosis was particularly difficult for them to assume and cope with. This could be supported by the fact that each of them seemed to recall the circumstances of that time but the specific details are vague, which may have happened due to the overwhelming shock of getting these news, "*It's so easy to explain but my mind is gone blank*" (Barbra, 20). "*I can't remember 100% percent now...I think what happened was...*" (Caroline, 19). "*I don't really*

remember anything; I can't really remember the rest' I just kind of blanked" (Fiona, 18).

Barbra described that the time of maternal diagnosis was very difficult for her as many things were happening at the same time, it was a 'mess'. She had difficulties listening and understanding and coping with the disclosure which can be seen when she emphasized three times that it was 'hard to believe' what was happening to her nuclear family, although illness would have been more expected in other elder members of her family like her grandparents and not the younger ones like her mother.

...the first stage was just a mess of things cause there is just so much going on, diagnoses and wrong diagnoses just everything was muddled together... I don't know I wasn't really listening ... (Barbra, 20).

Fiona also identified that the first two months after diagnosis were the most difficult but she not avail of the help from a counsellor that her mother suggested. Fiona was not sure if that would have made a positive difference or not which suggests she doubts the decisions she made at the time.

I can't know if it would have made a big difference at the time because now I've had enough time like to gather my thoughts about the whole thing and try and understand it a bit more and how I feel and it's a fact that everyone, for my own well being it probably would have been good but at the time, in those first two months or so mmm... like I don't know (Fiona, 18).

Caroline, Barbra and Fiona were all somehow familiar with the term cancer, they had heard of it before or had previous experiences of a cancer diagnosis in their families (Barbra) but this did not make the experience easier to deal with. Caroline's immediate reaction to cancer was feeling worried and anxious. She used the adjectives *horrible* and *completely catastrophic* but she wanted to be informed and not judge the situation from these pre-conceived perceptions that she had of cancer.

I suppose I was a bit worried or anxious, I wanted to know as much as possible as I could about it eeemmm I

didn't want to be like 'Oh it's, you know, it's the end it's...horrible, you know, it's completely catastrophic, I wanted before I decided how I felt about it I wanted to hear all of the details (Caroline, 19).

Maternal diagnosis was difficult but adolescents not only struggled at this time, illness related demands remain over an extended period of time, even beyond the completion of treatment, especially for Barbra. Caroline's account instead shows that illness demands came to an end for her after maternal treatment was completed.

Barbra continued to perceive illness demands beyond maternal treatment because she described how other people seem to think that once the treatment is over, the cancer is over and that is the end. '*then after treatment I think it's like people expect, people do better but they are not, they are still so sick and so upset about everything, you know, they are not better, I don't think*' (Barbra, 20). Mothers experienced drastic changes due to the illness and would probably never be like they were before, including changes in their physical appearance as secondary effects of mastectomy. Barbara described that her mother's hair and eye lashes have not grown back as before and this makes her feel '*self conscious*'.

...she is really self conscious and I think that she feels like her womanhood is gone like cause its not only that like your pushed into menopause and you lose your hair and your eyelashes, your eyebrows and it's still not growing back for her like her hair won't really grow properly and her eyebrows are gone completely now and her eyelashes aren't growing back so it's not gone back to normal for her at all... (Barbra, 20).

Caroline instead believed that her mother was getting back to normal and was '*back to herself*'. Fiona did not describe major psychological or physical changes in her mother, except for a secondary effect on her arm due to lymph node removal surgery. Fiona's major concern seems to be the possibility of recurrence because her mother is older than the mothers of other adolescents her age, and this means that she might not overcome the cancer again. Fiona used '*terrified*' twice in the same sentence to emphasize

her current state but also she seems to have a negative outlook to the possibility of her mother having cancer: '*It's going to go wrong*'.

It's going to go wrong, it's going to go wrong...I am terrified of it coming back, I am terrified of that phone call, she is old, she is 63 now so...I know in my heart that that would be it (Fiona, 18).

Barbara's concern seems to be the possibility of having cancer herself in the future. She explained that she was aware and scared of the increasing number of cancer diagnoses and she felt scared towards the possibility of getting a cancer diagnosis herself. '*it was so scary*'. In her case, however, this fear led to awareness to self check for lumps and prevent her from eventually having to go through an experience like her mother's. Barbara also uses her sense of humour as a way of coping with her fear.

...the kind of cancer my mother has it was likely that all of us would have had it too so we all had to go to a geneticist and get checked out and everything...thank God none of us have it but now mum is like 'check your boobs' for lumps and stuff it's the worst, lymph nodes are very confusing for lumps (laughter) so if I am sick I am like 'Oh my God (Barbra, 20).

Barbra, Fiona and Caroline described cancer as one of the most difficult experiences in their lives but they could also identify positive gains in their families from it. Caroline explained that the experience of cancer changed the perspective of things, she appreciated her mother and the people she loved even more. Her expression of love and care towards others also improved.

Maybe we just put things back into perspective and I suppose....maybe the whole thing that you know, life is so short and something like cancer can happen at any time and just take your loved ones away from you so thankfully it didn't happen in my mother's case...but that I supposeappreciating your loved ones while they are there (Caroline, 19).

Caroline also identified positive effects of cancer for her family, as now there was more openness towards talking about mental health issues in the family “*There is definitely a more open attitude towards mental illness and looking after your mental well being, very much so*” (Caroline, 19).

The expression of physical and verbal affection between members of the family also increased and she perceived this as positive.

I think beforehand there would have been a little bit of discomfort and being too sentimental and because it wasn't the norm too, you know, maybe say things like, oh thank you, I love you, you know and be close and give each other hugs as we might have done when I was a younger child (...) I think those two things combined have made us emotionally closer, if that makes sense. Its opened things up to talk about emotions more, Its open things up about being more sentimental and it has made us closer, very much so (Caroline, 19).

Fiona said that maternal cancer allowed her to appreciate more the time available she had with her parents and now wants to spend more time at home.

I've had enough time like to gather my thoughts about the whole thing and try and understand it a bit more and how I feel (...) I am more appreciative of my mum and my parents because they are older than most people's parents that are my age so I know like I am not going to have another forty years with them (Fiona, 18).

Fiona, Caroline and Barbra agreed that after their experience of maternal cancer they know had a more ‘*humanized*’ approach to cancer.

...it definitely increased my interest in it because it just added that human element to it and eeemm it gave a lot of meaning to it that this isn't just some illness that is listed in a book, that this is something that people go through, this is something that changes people's lives... (Caroline, 19).

Discussion

This Interpretative Phenomenological Analysis (IPA) described adolescent adjustment to maternal cancer by analysing the role they had as caregivers and the emotions, challenges and difficulties they faced in the caring process. This caring role was also described in the context of adolescent lives including their families, friends, University and the illness itself.

Mothers and daughters: The profound caring bond.

The IPA Analysis identified deep and profound relationship between adolescent mothers and daughters at the time of maternal cancer. Adolescents struggled to come to terms with the shock of maternal illness but developed a deep sense of care for their mothers above and beyond their own needs, emotions and lives. Mothers became the priority in their lives. Previous research, including Carers Theory has identified that young people dealing with parental illness seem to make a sacrifice for the welfare of their ill parent and thus they cope by themselves with the fears and anxieties they may have (Aldridge & Becker, 1993; 1999; Fridriksdottir et al., 2011, Hilton & Gustavson, 2002; Davey et al., 2003, Huzinga et al., 2003). Aldridge and Becker (1993) described that when both carer and the ill parent were female, the caring experience consolidates a very strong bond of commitment and affection that was evident in the relationship between mothers and daughters in the AMC Study.

Maternal cancer caused drastic changes in maternal usual behaviours and physical appearance to different extents for adolescents who had to deal with a 'new' mother who was not the usual mother. This is similar to previous research, which described that adolescents were concerned when they witnessed changes in maternal physical appearance and levels of fatigue (Kennedy & Lloyd- Williams ,2009; Finch & Gibson, 2009; Davey et al., 2011; Thastum et al., 2008; Hilton & Gustavson, 2002; Clemmens,2009).

Parallel diagnosis, particularly in the case of mental health issues could exacerbate changes in maternal normal behaviour and this was an additional challenge for adolescents. The deterioration of parental mental health has been described in previous research as a traumatic event because

the onset is not associated with a clear precipitating event as physical illness usually is (Ireland & Pakenham, 2010).

It is possible to suggest that perceiving maternal drastic changes may be the reason why adolescents were motivated to assume a caring role. Adolescents described that facing the reality of maternal illness and dealing with maternal changes made them feel upset, concerned confused and helpless but they could not deny maternal illness as they had reminders of it, for example, the hospital setting and being surrounded by sick people. Previous research has also identified upset and helplessness in adolescents at the time of maternal cancer diagnosis (Clemmens, 2009; Finch & Gibson, 2009; Fitch & Abramson, 2007, Forrest et al., 2009, Davey et al., 2011, Kissil et al., 2010; Stiffler et al., 2008; Davey et al., 2003, Hilton & Gustavson, 2002). Similar to the AMC Study, previous research by Davey et al. (2005) described that adolescents perceived their mothers as more emotional and vulnerable and they made the decision to be more affectionate and got more involved in chores and caring duties.

Adolescents seem to approach maternal cancer differently which may come from their own coping abilities and personalities but it may also be linked to the time since diagnosis. As time since diagnosis increased, adolescents had a different approach to the experience and included laughter and sense of humour in their accounts, however it is controversial within existing research if time since diagnosis could be suggested as the origin of these differences. Sigal et al. (2003); however, identified that young people (12 to 18 years) with mothers diagnosed with breast cancer who had the greater elapsed time since the last hospital treatment had lower levels of psychological symptoms.

In this study, choosing their mum over themselves led to a duality in adolescent's emotions between what they felt and what they thought they allowed themselves to feel, particularly in front of their mothers. From the Carer's Theory perspective, a possible developmental risk for young carers is the lack of expression of their emotions (Aldridge & Becker, 1993). The problem with this lack of emotional expression is that this can increase adolescent vulnerability and lead to invisibility and isolation (Aldridge & Becker, 1993). Rosenfeld et al. (1983) described that girls who hold in their

suffering regarding parental cancer may be predisposed to psychosomatic illness or depression. This emotional denial did not mean that adolescents did not have emotions, instead they pretended to be strong and have a sense of humour in front of their mothers, as a way to protect their parents and they were also seeking validation for their emotions (Davey et al., 2003; Visser et al. 2007; Clemmens, 2009; Stiffler et al., 2008; Forrest et al., 2009; Adams - Greenly et al., 1986; Kristjanson et al., 2004).

Adolescents' denial of their own needs and emotions may have also been reinforced by the contexts they were in at the time of maternal illness as adolescents seem to agree that they were not given any support in hospital settings, adolescents were not expecting any support either as they believed the focus should be on their mothers. Previous research has described this phenomenon, Finch and Gibson (2009) reported that adolescents did not perceive a role for themselves in hospitals and some even preferred not to talk about their experience with a "stranger", i.e. medical health staff. Some adolescents seem to feel anxious and fearful of the hospital setting (Finch & Gibson 2009) and perceived the hospital as frightening and boring (Thastum et al., 2008) which might have distanced them from the setting even more.

In the Carer's Theory perspective, it has been described that sometimes parents seem to keep their parental status in the household, despite their temporal inability to fulfil such a role (Aldridge & Becker, 1993). This study described that the level of involvement that adolescents had as carers was different, for some the burden of care was greater. It was identified that several contextual factors had an impact on adolescent involvement: Maternal coping resources and skills contributed to those differences. Mothers that seemed stronger and used coping resources such as sense of humour allowed adolescents to be less involved in caring duties. Adolescents also described specific moments where mothers tried to assume back their mothering roles and care for her children which again would have reduced the caring burden on adolescents (Clemmens, 2009; Stiffler et al., 2008; Issel et al., 1990).

In this study, adolescents felt guilty if they could not provide care for their mothers; this has been explored in previous research. Wolf (2015)

carried out research on breast cancer and family coping and described that physical separation was an important variable in marginalization of other family members. Family members have a need to provide support in line with cultural expectations whether these were actual demonstrations or only offers of support. Stiffler et al., (2008) identified that daughters were conflicted between anger and guilt, they knew that they needed to help their mothers but also needed to protect themselves by getting out of the house but this made them feel guilty when they were not there to help their mothers. Mothers also felt guilty when they realized they were not providing care for their children and families, therefore the caring dyad may be characterized by reciprocal guilt associated to a sense of duty of care. Fitch et al. (1999) described that women felt tense because of their need of self care and knowing their children were still in need of care themselves, which they were not providing for them. Some women felt insecure about their parenting skills.

Overall, adolescents seem to have voluntarily taken over caring roles and do not perceive it as a burden since they instead identified positive gains from their caring role including an improvement in closeness and intimacy in the mother-daughter relationships. Strong relationships remained strong. Abraham and Aldridge (2010) determined that carers can have positive benefits from caring including enhanced parent-child relationships. Caring, although hard, was also described as a way of coping with maternal illness. Research by Rosenfeld et al. (1983) suggested that taking over household chores may have been used by adolescents as a coping strategy which could have a positive impact on their autonomy and sense of personal worth.

The context of care.

Adolescent caring roles were shaped by family structures, those adolescents that had less cohesive families or were facing family separations and difficulties at the time had a bigger burden than other families that were able to communicate more openly with each other and also shared the caring burden. Faulkner and Davey (2002) concluded that the diagnosis and treatment of cancer is a stressful situation for patients and their children, the condition of one family member influences the condition of the others. Hilton (1993) and Huizinga et al. (2011) found that the emotional impact of

one person affected the whole family. Su and Ryan-Wenger (2007) suggested cancer is a 'family affair' as all members are influenced by the illness. Hilton and Elfert, (1996) described that children from well adjusted and flexible families were more satisfied with the way they coped with cancer as they were able to handle problems, provided mutual support and managed to shift their roles to fit the demands. Poorly adjusted families, instead, grew further apart.

Adolescents who had caring roles in their families previously just extended it to include their ill mothers. This may suggest that sometimes adolescents may not have been given the choice but to assume a caring role. Carers theory has described that adolescents that have been socialized into their caring role usually just assume the role without distress or complaints (Aldridge & Becker, 1993). Adolescents in the AMC Study described particular characteristics that made them suitable to assume a caring role including maturity and cleanliness; however this could have been a way to justify other family members' lack of involvement and commitment. Aldridge and Becker (1993) identified that the responsibility of care may fall on a single child either because she cares deeply for the adult, has a strong sense of loyalty or they feel that they are the 'elected' ones.

From a Family Ecology perspective, Pedersen and Revenson (2005) have suggested that social support enables young people to use coping strategies more effectively by reducing emotional stress, increasing understanding of the problem and increasing motivation to take instrumental action. Analysing in more detail specific relationships within nuclear families, adolescents explained their relationships with their siblings and their healthy fathers. Siblings were not always helpful or supportive; those that were distant from the beginning remained as such. A similar situation happened with the healthy parent; those from more dysfunctional families were absent, not emotionally available or distant. The crucial role of fathers has been previously described; fathers tried to keep the family system by taking over roles and responsibilities; as well as provide emotional support for partners and children (Forrest et al., 2009; Thastum et al., 2008 & Wolf, 2015).

Regarding the extended family, adolescents mentioned that they were involved in taking care of other family members like their grandparents or had to deal with issues related to them, for example, illness and even death at the time of maternal cancer which may suggest that the extended family may not provide support for the adolescent and may be an additional burden instead. Research on young carers, for example, identified that grandparents seem to not provide a network of support for young carers (Aldridge & Becker, 1993).

Adolescents also had external sources of support including neighbours and friends. Friends were crucial for adolescents in more dysfunctional family systems. Friends provided support and listened, in a way they supplemented the lack of family support. Previous research described that friends were a relief for adolescents, as they were a “protective zone” where adolescents did not have to think about the illness anymore (Dehlin & Reg, 2009; Huizinga et al., 2011; Finch & Gibson, 2009). Research with young carers in Ireland (Fives et al., 2010) also identified that friends were crucial support providers for young people in caring roles. Although friend support seems positive, Feiske, Taska and Lewis (1998, cited by Bal et al., 2003) suggested that adolescents who rely on their friends as their major source of support are at a higher risk of poor adjustment, relying on friends at a time of high personal vulnerability suggests that the person doesn't have family resources for protection.

Counsellors were essential sources of formal support for some adolescents as they were able to express their emotions with someone, as was described above adolescents couldn't generally do this. It is also significant to notice that they looked for this help themselves which may suggest a great deal of insight into their own emotional states and needs but also a sense of self care that may have saved them from long term difficulties or problems. All adolescents, however, did not avail of these services which may suggest that there may be barriers that need to be identified and overcome to facilitate access. Gates and Lackey (1998) identified that young people were aware of the help available but they did not seek that help themselves but it was not clear if they don't need it or if they lack the skills to ask for it. Visser et al. (2007) suggested that seeking

support might be important in situations of parental cancer, however shy and anxious children tend to withdraw and hesitate to seek the support they need from their surroundings.

Adolescents were also dealing with illness demands. There is a shared perception that the time of diagnosis was the toughest for adolescents, as it may have been an overwhelming shock for them and they also found it hard to believe. Previous research has identified this time of diagnosis as the most stressful (Davey et al., 2003; Hilton, 1993; Northouse, 1984). Sales (1991) described that in the initial diagnostic phase, family members shared the common belief that a cancer diagnosis is a death sentence; it disrupts the continuity of all family members and threatens hopes for the future.

At the time of the interviews, adolescents were still struggling with long term consequences of cancer, even though all mothers had completed their treatments. The extent of these consequences varied. One adolescent was still dealing with maternal difficulties to cope with physical and emotional changes, this again suggests how adolescents were not the ill ones but maternal illness was so close to them that it had an impact on their lives. Other adolescents described that mothers were on the way to recovery and normality. All adolescents described that they shared the fear of recurrence, irrespective of how much time since diagnosis and treatment had passed. Different research studies have described that fear of recurrence is almost universal in patients and their families (Sales, 1991; Davey et al., 2011; Stiffler et al., 2008; Northouse, 1984). Clarke (1995) described that young people can be hyper vigilant to body signs and symptoms associated to cancer as they expected to get cancer themselves.

Based on the Family Ecology model (Tudge et al., 2009), the experiences of adolescents in the AMC Study were accommodated to this model. Adolescent microsystems were composed of their friends, nuclear families, extended families and friends. The mesosystem, the interaction between adolescents and their microsystems, seems to play a crucial role in adolescent coping and adjustment. Overall functional and open relationships allowed for more open communication, more co-operations and a shared burden of care but interactions that were more dysfunctional, closed and problematic caused more difficulties and challenges for adolescents. Less

supports were available and overall the experience of maternal cancer was more difficult. It is possible to suggest that adolescents had a very similar composition of their microsystems but it is the quality of interactions (mesosystem) that caused differences in their experiences. In the exosystem adolescents identified more external sources of support such as neighbours and counsellors that were perceived as more distant and therefore sources of objective support. The exosystem also included developmental demands and social expectations for young people at this particular age. A graphical representation of adolescent ecological family systems models is included in Appendix I.

Overall, adolescents shared the perception that maternal cancer was one of the most difficult experiences in their lives but they were also able to identify positive gains from it including more appreciation for life, their mothers and their families. They also mentioned changes in families' verbal and physical expression of affection, closeness and also more open communication towards topics like mental health issues. Adolescents initial perception of cancer was also changed and they described having a more humanized approach to it. Aldwin (2011) described these as 'tertiary appraisals' which can occur after a situation has been resolved but it involves long term appraisals of the impact and meaning it had. Positive consequences may include clearer values, increased spirituality and better relationships with family and friends. Thoits (1995) suggested that 'negative' life events do not always have a negative impact on health and mental health, as people tend to try to solve the problems they face and will grow and learn from these 'negative' experiences. People may decide to change their situation and improve it, enhancing their well being in the process. Thoits (1995) suggested that it may well be that positive and negative life events are just as important to a person's health and well-being.

Developmental approach of adolescent experiences.

Adolescents in the AMC Study were also dealing with developmental demands at the time of maternal illness. From a Family Ecology perspective it is important to mention the concept of time as adolescents were in a transition period from childhood to adulthood (Tudge, et al., 2009). Pedersen and Revenson (2005) suggested that when adolescents adopt

additional family responsibilities or roles due to parental illness these can compromise adolescent normative development of social relationships and competencies outside the house. Sears and Sheppard (2004) identified that adolescents struggled when their role in the family went from child to adult and they were expected to 'shoulder' adult roles prematurely.

Adolescents in this study were starting to go to University and they had to move away from the family home, at a time when maternal illness instead was pulling them back to the family. Previous research also identified that this is not uncommon that young people in caring roles are sometimes denied their right to education because they had to take time to care for their ill parent (Aldridge & Becker, 1993; Fives et al., 2010). Adolescents described that they found it difficult to balance all the demands at the same time including their social life and University while coping with maternal cancer. Coleman (1980) described that young people would usually pace themselves through the transition from childhood to adulthood; they would usually concentrate on one issue at a time and this allowed successful coping. At the time of maternal illness it seems that adolescents have no choice and cannot really pace themselves, they have to deal with many issues at the same time and this could lead to difficulties. Adolescents still need care and support at this age, Sears and Sheppard (2004) suggested that parents needed to encourage the individuation of adolescents, mostly when family demands were interfering with their normative developmental tasks. At this age, specific feelings, decisions and responsibilities need to be managed by adults so adolescents can continue to help at home and not be burdened (Sears & Sheppard, 2004).

The fact that all participants in this analysis were female and the fact that they were purposefully selected due to difficulties described in their interviews, may suggest that gender could be contributing factor to increased vulnerability of adolescents. International and Irish research has suggested that daughters have a particular identification with their mothers and may be socially expected to take over more caring roles than males (Litchman et al., 1984; Welch et al., 1996; Visser et al., 2005; Aldridge & Becker, 1993; Fives et al., 2010; Gazedam-Donofrio et al., 2011).

Recommendations

The analysis revealed that adjustment is a very personal experience as adolescents may share similar experiences but will deal with them in very different ways according to their personalities, families, adaptability to change, abilities to cope and their overall perception of maternal cancer at the different stages of the illness. It is important that health care professionals are open to differences in adolescent coping styles and their unique or particular experiences.

Professionals need to evaluate different aspects of adolescent lives in a holistic manner. This analysis has identified that many aspects and layers of adolescent lives are affected by maternal illness. Maternal cancer needs to be understood within a context (Microsystems) looking at family structure, family communication, family cohesion and family adaptability. This also includes adolescent contact with extended family, friends, School or University and through extracurricular activities.

The methodology of Interpretative phenomenological analysis can provide a very detailed insight into participants' experiences from their own perspective but one of the innate limitations of the method is that it does not achieve generalization and, therefore, the findings can be restricted to a very specific cohort. Overall different aspects of adolescent adjustment were outlined but it seems that the experience of adjustment can be personal and unique, which may pose a difficulty for policy development or actually designing guidelines for health professionals.

The analysis was limited due to the theoretical definition of a carer as defined by Carers Theory. This theory has mostly focused on caring roles that have a long duration where 'carers' may have been involved in parental care since they were very young. This theory, therefore, needs to address the experience of caring for a parent over shorter periods of time, for example for one or two years in the case of parental cancer.

Summary

This study described the experiences of three female adolescents, between 17 and 20 years of age, adjusting to maternal cancer, focusing specifically on the role they had as caregivers and the emotions, challenges

and gains they had from this caring process. These interviews were purposefully selected because they provided more detailed information about adolescent experiences. The interviews were analyzed using Interpretative Phenomenological Analysis (Smith et al., 2009). The analysis is supported further by Young Carers Theory (Aldridge & Becker, 1993) and the Family Ecology Model (Bronfenbrenner, 1979; Pedersen & Revenson, 2005).

The first theme is focused on the mother child dyad, which was in essence a caring dyad. Adolescents describe how they had to face the reality of maternal illness when drastic side effect of cancer and treatment almost left their mothers unrecognisable. The state of their mothers motivated them to voluntarily take care of their ill mothers but by doing so they denied their own feelings and needs. The second theme looks at the caring dyad in the context in which it happened and described the impact that maternal cancer had on every aspect of adolescents' lives including their nuclear families, extended families, friends, University and hospital settings. Adolescents also described the challenges they faced by dealing with maternal cancer and trying to balance the developmental challenges and needs of being an adolescent while responding to the illness demands of maternal cancer.

Study 1 (c): Thematic analysis of maternal interviews.**Introduction**

Parenting at a time of maternal cancer can be a very challenging experience (Semple & McCance, 2010) Parents experience significant feelings of guilt and sadness associated with not being able to be a ‘good parent’ as they struggle to keep routines and activities as normal, but still experiencing illness demands and changes. Asbury, Lalayianni and Walshe (2014) suggested that women experiencing breast cancer were concerned with protecting their children and the main way they achieved this was by maintaining normality, managing information disclosure to the young person and minimising their own emotions, they told the truth but in a way that the young person would not be scared or think the worst. Wolf (2015) also described that female cancer patients tried to remain as responsible wives and mothers during the illness to reduce the cancer burden on other family members. Other research studies, such as Huizinga et al. (2011), found that mothers, fathers and children influence each other during the experience of parental cancer, even if only one member is ill. Fitch et al. (1999) explained that women may feel tense because of their need of self care and knowing their children were still in need of care themselves, and some women felt insecure about their parenting skills. Elmberger et al. (2000) described that facing cancer had a strong impact on family life, with the women in this study saying that they lacked information regarding expected reactions in their children. Participants also suggested that cancer caused family disruptions but, at the same time, this led to closer bonds between family members.

Parenting young children may be more physically demanding but parenting adolescents may be more emotionally demanding, Ares Lebel and Bielajew (2014) described that having adolescent children increased perceived stress and illness intrusiveness in young mothers with breast cancer; however, this study was restricted to this specific subset of women only. Mother and adolescent relationships are also challenged at the time of maternal illness. Lewis et al. (1985) described the experience of maternal cancer as the ‘ultimate test’ for an adolescent as they are attempting to withdraw from their mothers, and instead they are needed at home. Davey et

al. (2005) identified that adolescents had the need for separation and a continued connection with their mothers at this developmental stage. Compass et al. (1994) identified that adolescents experiencing maternal cancer showed strength, resilience and hope to face challenges of the illness but they still needed limits, nurturing and security provided by their family, therefore maternal illness seems to have contradictory demands to adolescent developmental demands.

The objective of this study is to explore maternal experiences of motherhood in the context of cancer, particularly focusing on the impact that the 'sick person' and 'cancer patient' status has on maternal identity and maternal perceptions of their adolescent adjustment process. The 'biographical disruption' framework (Bury, 1982; 2001) provides the analytical framework for the analysis which will provide an understanding of how maternal experiences of illness can have an impact on adolescent experiences, as this can be a major additional stress for the mother and it can potentially impact on the relationship with the adolescent and impact their adjustment experiences.

According to Bury (1982; 2001) chronic illness is a major 'biographical disruption' in which the relationship between body, mind and everyday life are threatened. This disruption leads to a re-examination of personal, family and work-related issues associated with the onset and unfolding of the illness, parallel to becoming familiar with the current medical condition. "*There is rarely anything in the individual's biography which provides an immediate basis for recognition of the illness as illness*" (Bury, 1982, p.171), which means that people lack the experience in their lives to assume a serious illness diagnosis and, therefore, have difficulties identifying resources and coping skills that are necessary to respond to the challenge fast and efficiently.

In the context of chronic illness, Wilson (2007) described maternal illness as a 'biographical disruption' to maternal identity, as it can be fundamentally threatened by illness, while paradoxically forming a reason for the continuation of maternal identity and self-worth, determined to protect their children by surviving until their children reach adulthood or experience a 'normal' childhood. Participants in this study had children

between seven and 22 years of age, all but four were minors. Seven mothers had one child, four women had two children and one had three children. This suggests that adolescents were part of the sample but not necessarily all mothers had adolescent children.

In the context of cancer research the biographical disruption framework has not been used extensively previously. Fisher and O'Connor (2012) applied the biographical disruption theory to understand the experience of motherhood in women diagnosed with breast cancer, however the children ranged from new born babies up to eight years of age. That study described maternal cancer diagnosis as a life changing experience that can precipitate complex changes in a woman's identity as a mother. Mothers constructed and reconstructed their identities as mothers in the context of living with breast cancer, the mothering role was modified but was maintained in constant tension between the mother identity, the "breast cancer patient" and the "breast cancer survivor". Mothers argued that they were not recognized as mothers but only as patients which disrupted their responsibilities for the well being of their sons and daughters (Fisher & O'Connor, 2012).

Method

To further understand adolescent experiences of adjustment to maternal cancer, ten Irish mothers were contacted and interviewed. Interviews were audiotaped and transcribed. A thematic analysis was conducted on the interview data. Braun and Clarke (2006) defined thematic analysis as a method to identify, analyze and report patterns (themes) in data and reveal core consistencies and meanings in a text (Buetow, 2010). It organizes and describes elements of the research data but can also be used for interpretation. Thematic analysis emphasizes the content of the text, specifically what is being said and not how it is being said (Katz, 2013). Further detailed description of this methodology is included in Study 1 (a). The interview schedule consisted of twelve questions to explore maternal perspectives of adolescent adjustment (Appendix E).

How did your adolescent(s) find out about your illness?
What do you think your adolescent(s) knows or understands?
What or who was your adolescent(s) source of information?
What changes have you noticed in your family since diagnosis?

Figure 11. Example of maternal interview script.

Results

Description of participants.

Ten mothers completed semistructured interviews. Their ages ranged from 38 to 60 years (mean age of 48 years). Six mothers had a breast cancer diagnosis, two experienced colon cancer, one cervical cancer and another non Hodgkin's lymphoma. Mothers were contacted from cancer centres and cancer support groups nationwide and were invited to take part even if their adolescent children were not involved in the study. The majority of interviews (60%) were done by phone to keep the interruption to maternal routines to a minimum. The length of the interviews ranged between 30 and 53 minutes.

Table 8 *Irish Maternal Interviews- Sociodemographic Data*

Interview	Adolescents in AMC Study	Type of interview	Age	Cancer type	Time since diagnosis	Active treatment ⁹
Katie	1	Telephone	60	Breast	12 months	No
Violet	1	Email	47	Breast	23 months	No
Ivy	2	Face to face	52	Breast	18 months	No
Vivien	0	Face to face	41	Cervical	17 months	Yes
Molly	1	Telephone	51	Breast	7 months	Yes
Emma	3	Face to face	46	Colon	10 months	Yes
Jasmine	1	Telephone	38	Breast	12 months	No
Linda	0	Telephone	49	Non Hodgkin's lymphoma	11 months	Yes
Miriam	1	Telephone	53	Colon	14	No
Melissa	3	Telephone	45	Breast	8	Yes

⁹ Receiving treatment at the time of the interview.

Themes

Maternal cancer is an unexpected and life changing experience for mothers; this affects their normal functioning and has an impact on their role as mothers. The analysis identified that cancer is a biographical disruption to mothers that can have an impact on their identity as woman, but particularly to their perception of how to be good mothers as cancer patients. Mothers main concern is the impact of the illness on their family and particularly their adolescent children; this leads them to protect their families and prioritize their children's needs over their own, even at a time when they are facing a critical and debilitating health condition with physical and psychological demands of its own. Mothers refuse to be defeated and won't allow themselves to be 'sick' as a way of protecting their children above and beyond anything.

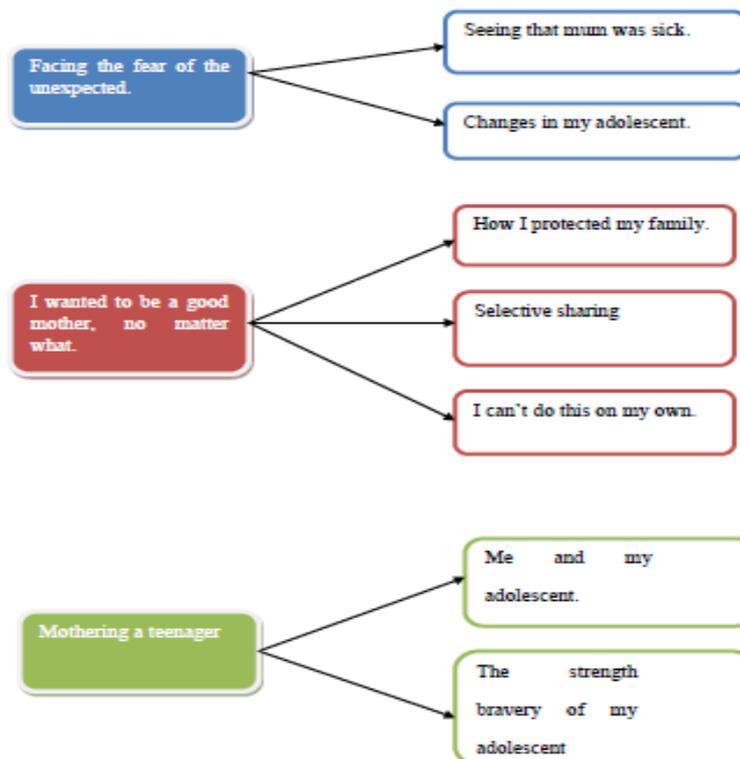


Figure 12. Summary of themes in maternal interviews

Facing the fear of the unexpected.

As previous literature has suggested (Wilson, 2007), a cancer diagnosis is a shocking and unexpected experience which can lead to a combination of difficulties, changes, challenges and emotional reactions

such as fear and uncertainty. Similarly, it is possible to suggest from maternal accounts in the AMC Study that the mothers' main fears and concerns were not focused on the illness itself but on the impact that this could have on their adolescent children and their families.

Mothers described that one of the main challenges was disclosing the information to the adolescent and their brothers and sisters, possibly because this is not a usual conversation and mothers may have never imagined they would have to deliver such information in their role as mothers. Disclosure of the diagnosis was usually done by the mother herself, except in a few cases the father was in charge because the mother was in hospital (Emma, 46, Ivy, 52, Melissa, 45). Mothers usually discussed with their partners when, where and how they would disclose the information to their adolescent children but even if they tried to plan the best way possible they could not prevent the distress experienced by the children due to the shock of the diagnosis. *“oh we were having great fun and then now and then it would just hit me mum, just hit me, what you told us”* (Description of adolescent quote by Linda, 49).

Mothers expressed doubts around the topic and how to deliver it, for example they were not sure about how much information to disclose (Vivien 41). Some mothers looked for professional advice on how best to approach it. This advice was provided by a cancer care nurse who recommended being truthful (Vivien 41, Jasmine 38, Molly 51):

Now...at first we weren't sure how much detail to give them... but we spoke to my cancer care nurse and she asked me the age of my kids and I said 15 and 19 and...she said it was better to be truthful with them and tell them as much information as I was given (Molly 51).

Death was described as another difficult topic for mothers to deal with. They expressed having specific conversations with their children about the possibility of death due to the illness, mothers reacted by reassuring their children that they would get better (Vivien 41, Jasmine 38, Miriam, 53):

...well obviously the first question that came to mind was, was I going to die? And then I had to explain to her

that no, I won't die, you know I will have the treatment and everything to go with it and after that I will just get the all clear you know ... (Jasmine, 38).

Seeing that mum was sick.

Mothers were aware of the challenge that maternal illness imposed on their adolescents and how they struggled to see their mothers become a 'sick person'. Mothers described how seeing them ill was one of the biggest challenges for adolescents (Katie 60, Emma 46).

I think it was the first time he saw me being sick, he saw me being ...you know, that I could die (...) I think that was an eye opener for him, that he ...up to that day I was just his mother giving out (...) (Katie, 60).

Adolescents were exposed to unexpected and unfamiliar experiences that other adolescents may never have to experience in their lives, as part of assuming the 'sick person' maternal identity. Two mothers took their adolescent children along with them the day they got their hair cut and got their wigs (Molly 51 and Ivy 52).

What else was challenging for them was...losing my hair because I involved them in it which was good because I was losing my hair anyway so I got my head shaved and you know, they came with me to the clinic where I had it done (...) they were a bit emotional but they wanted to be with me and then they were also with me when I tried different wigs you know (...) so the challenge is coming to grips and seeing their mummy looking different... (Molly, 51).

One mother expressed concern regarding her son as he was very scared of seeing her lose her hair from previous experiences with the topic.

His friend's mum had had breast cancer and his friend had told him that he got a fright the first time he saw his mum without a wig and I think this has been in his head. And the other thing was a little boy in school, second year in school, had had chemotherapy and when he came

back he got a fright to see him without hair so there was a little...concern, anxiety about the hair (Linda, 49).

Mothers described that besides changes in their physical appearance, they experienced mood changes associated to treatment and side which caused changes in their personality and adolescents were aware of these changes in their mothers.

Changes in my adolescent

It is important to notice that maternal main concern was not focused on the impact of the illness on themselves but on the effect that these changes had on the adolescents. Some mothers noticed changes in their adolescents as a result of maternal illness, some adolescents became more quiet, irritable or temperamental (Molly 51, Emma, 46).

I think when I got ill I have been very temperamental as I would be short tempered or irritable or I don't know how to explain it I'd get easily upset or angered about something you know (...) and I did some times without realizing and they were like 'mommy, why are you so angry? (Molly, 51).

Mothers described specific issues that adolescents struggled with during the process of maternal illness like changes in adolescent behaviours and personality including increased anger and irritability (Vivien 41; Emma, 46; Molly, 51, Linda 49; Melissa, 45) and they were concerned about the impact this could have on them.

...it's hard to know (...) is maybe a little bit of anger about the whole issue..sometimes he would even say a nasty thing to me like 'oh for goodness's sake you need more attention now that you're sick' you know, he'd comment you know the way he is angry about it... (Linda, 49).

Mothers were aware of the emotions that their adolescent children experienced at the time of diagnosis including anxiety, worry, upset, shock, fear, loneliness and anger.

...the children bless them! Were you know, they were anxious and waiting and wanting to know and I suppose they could read me, they knew, I mean...and again

[daughter's name] I can just remember sitting next to her on the couch and said to her (...) she just said 'mum you have cancer haven't you? (Ivy, 52).

Another mother noticed that at the time of diagnosis there were behavioural changes in her daughter but these stopped over time.

...at the beginning she kind of spent more time in her room, you know, listening to her music, I think that was her way of relaxing or keeping her thoughts away ...but I think she is coming out of that she is more confident now maybe (Jasmine, 38).

Anger was also perceived by three mothers as possibly a direct reaction to them and not to the illness itself. Mothers felt their children were angry at them. (Emma 46, Vivien 41, Linda 49).

Yeah, I'd say the younger guy was more distant and maybe a little bit angry at me, not particularly at me but he was angry (...)I think he was probably more distant and maybe, probably he still is a little bit... (Emma, 46).

Adolescents may have also seemed distant or not concerned at all in the process. In other families, some adolescents might have become closer to the mum but others became angry and more distant (Vivien 41, Emma 46).

I get the impression that she is, she's trying to distance herself from me and I think that's because she thinks I am going to die and she is preparing for it because that is how I would react (Vivien 41).

This theme provides evidence for the impact of maternal cancer as a biographical disruption for mothers, as the cancer diagnosis was experienced and described as 'unexpected' and this generated fear and concern in the mothers, particularly associated to the impact that the diagnosis could have on the lives of their adolescent. Mothers were aware that even if they wanted to protect their adolescents, they still had difficulties adapting to maternal physical and personality changes and they

described changes in the adolescent that they associated with their illness including increased irritability and anger.

I wanted to be a good mother, no matter what

In line with the biographical disruption framework, maternal accounts show that at the time of maternal cancer, mothers were mainly concerned about protecting their families and keeping normal family everyday routines, as this was a measure for them of their identity as ‘good mothers’, being able to protect their families from adversity (Ivy 52, Vivien 41).

...you will embark on this journey and you are not on this journey on your own, your family are with you...meaning immediate family, my children...so she said you know....you are in this together so they are on the journey with you...(Ivy, 52).

Mothers described that the cancer diagnosis was a disruption to the plan they had for their children and their families. Even if they could have not foreseen the situation and could not be suggested ‘guilty’ of it, mothers felt they had failed their adolescent children somehow with the diagnosis.

Oh my God, the poor children, why do they have to go through this now, you know, how are they going to deal with it and (...) oh my God, how am I going to protect the children? (Ivy, 52).

Mothers were also concerned about the secondary effects of treatment in their maternal duties as being tired and sick would not allow them to carry on with their lives as usual and they thought this could have a negative impact on their families (Ivy, 52).

I didn’t want days when if I had to stay in the bed I had to but thank God, I mean I would be very tired in the mornings(...) I just didn’t want again for the children to have this feeling of mum is sick and she is just in bed, you know, in bed all day, so....I thought that could not be good for the children, you know, it could affect them (...) I just wanted them protected...(Ivy, 52).

Some mothers expressed not being aware of how adolescents really coped with the situation themselves; one had been hospitalized over a long period of time (Emma, 46). In general they were not aware of how their own coping mechanisms could have an impact on their adolescent children at all, “(...) whatever way they coped, they...did it their way I think” (Ivy, 52).

Yeah, I am not really sure how he dealt with them. There was probably more going on than I was aware of at the time, ‘cuase I was very sick in hospital for about three weeks (Emma, 46).

One mother expressed feeling guilty when family plans and fun times were not possible because of the cancer diagnosis and treatment. Not being available for the children was a source of guilt for this mother.

I have to be here and have my treatment (...) I was here on the summer holidays and I wasn’t there and we had originally planned to go to the (...) mountains and stay in a caravan for two weeks(...) I had to be here instead and I cried more times than I’ve ever cried in my life because I just felt so guilty ...I love my kids, they didn’t have mum, there was no holiday there was no family thing going on...(Vivien, 41).

How I protected my family.

Mothers were very concerned about the impact of cancer on their adolescents and they wanted to protect them by trying to keep normal family routines and everyday functioning; however this was very challenging as the illness was demanding and mothers sometimes struggled to balance maternal and illness demands.

Mothers suggested it was important to keep routines as normal as possible and allow adolescents to continue to be involved in any activities or routines that they would normally have (Ivy 52, Molly 51, Emma 46, Melissa 45)

...keep routines not only for when they are babies I think it’s so important cause any disruption in that I think can have adverse effects maybe on their lives (...) so they wouldn’t be thinking ‘God this is worse than we thought

about (...) they didn't stop doing anything because of it
(Melissa, 45).

Mothers described that small changes were also very hard for adolescents to deal with, particularly when it involved changes to their normal routines or activities, adolescents could become very upset and angry.

One day I was so fatigued and I said ...[husband name] called and said he couldn't make it to pick him [adolescent son] up, so if I was going to bring him [adolescent son] I was going to have to wait for him [adolescent son] and I said I just can't do it ...He went into a tantrum about it ...you know banging doors, and I was taken aback by his anger (...) (Linda, 49).

Another strategy that mothers used to protect their families was to turn the treatments and hospital visits into family activities or achievements so adolescents would not associate the cancer treatment with a negative experience.

One mother described how her treatment was purposefully planned as a 'day out' for the family.

She did, she did, she came with me, actually the oldest a couple of times, we tried to combine that with you know, building up a better relationship you know so the purpose of us going into Galway would not be necessarily just to go for my treatment ...we would go to the movies or something together so they all did (Jasmine, 38).

In another family, each stage of treatment completed was celebrated as a family achievement (Ivy 52, Jasmine 38).

I kept it very simple for them (...) chemotherapy was over, we celebrated, we were jumping around the kitchen the night I came home (laughter) I didn't have to come back in you know it was so such such a relief and funny again (...) it was like we really had achieved something, you know something wonderful... (Ivy, 52).

Keeping everything as normal is not an easy task for mothers as sometimes they would be sick or tired because of the treatment and still they felt they had to keep up with adolescents' normal routines themselves (Ivy 52, Molly 51).

I try to keep everything as normal as possible so that their dinners are always there when they come home from school, whether I am feeling really sick or not... (Molly, 51).

Maternal behaviours and coping strategies were purposefully used to protect adolescents and help them cope. One mother described how she used sense of humour to distract and reassure her adolescent, however the humour was not natural, it was a way of disguising her real feelings and emotions.

He asked me was I going to die and I said no, I am not. I am not going to die. You went get rid of me that easily, trying to make a joke out of it for his benefit. I had to fight how I was feeling at the time... (Vivien, 41).

Mothers expressed being concerned and worried about the sources of information that their children used. Vivien asked her children to explicitly stay away from the internet as it was not a reliable source. Others were happy to let adolescents do research on their own (Molly) or giving them suggestion on other people that could answer their questions such as grandparents (Katie). Linda was convinced that her adolescents had not done any type of research on their own.

They've Googled it, which is a big mistake because the internet does not give you the right information (...) I did that in the beginning myself, (...) but it wasn't giving me the right answers so I decided I would never look at it again, I wouldn't google again. If I didn't know something I would ask a cancer care nurse that I have called (name) or I'd ask my consultant, and that's what I told my children do not bother with the internet (Vivien, 49).

There were also specific circumstances in which mothers could not protect the adolescents, for example recent experiences of death from cancer in family members. One family in particular had experienced a death from cancer very close to the time of diagnosis and this caused additional distress for the adolescent when they found out about the diagnosis. The mother knew that this made the disclosure of diagnosis more upsetting for her child.

...she had an encounter with cancer just the year before because her aunt had just died from cancer the year before so the funeral was somewhere I don't know May or June last year and then in October I was diagnosed with it and you can imagine the shock was considerable for her (Jasmine, 38).

Selective sharing.

Mothers made conscious decisions of having open and honest communication with their adolescent children and considered it was important to inform adolescents early on the treatment as the process could become more complex or involve more procedures that would make it more difficult to disclose in the future. (Vivien 41, Molly 51; Jasmine 38; Linda 49; Melissa 45).

The first thing they said to me was 'thank you mummy for being honest' and truthful and chat to them and everything. I was actually honest with them and I told them all the necessary details you know so obviously they were very very upset for me and they were worried for me (Molly, 51).

Maternal honesty, however, had certain limits. Mothers described the limits in different ways. It was important to avoid presenting the truth in a way that could upset or alarm them. Mothers described being "economical" about the truth (Ivy, 52).

...you need to find a balance because you don't want to tell them everything but you want to make sure that they don't think that they are holding anything back and I think I would say to someone just be as honest as you can

and present it just in very simple terms and answer whatever questions they have... (Jasmine, 38).

Mothers also filtered the type of information they provided, communication was focused on factual information about the illness and treatment but this excluded maternal feelings and emotions. Mothers felt they had to hide their emotions as a way of protecting their children because these could harm them (Ivy 52, Katie 60, Vivien 41, Emma 46). Only Jasmine expressed that she would cry and find comfort in her 15 year old daughter.

I didn't even have to say anything you know, she can tell if there is something wrong, (...) sometimes we'd just cry together but, you know. I suppose because there was always very good connection between me and her...(Jasmine, 38).

From a biographical disruption perspective it is particularly interesting the Vivien does a personification of herself as 'mum' separated from 'I' suggesting that mothers were simultaneously dealing with different identity roles at the time of illness. 'Mum' is not allowed to be upset or scared, 'I' is brave, fights tears back and laughs despite being scared.

Mothers also described that their children might have been scared to speak with them to avoid upsetting them, therefore, even if there was a sense of honesty and openness towards communication this was not necessarily really the case, both from the mother to the children and from the children to the mothers (Vivien 41, Linda 49).

I think my children are scared of speaking to me about it cause I get upset very very easily and they are scared that I am going to turn around and start crying and then that's not going to help them, they would probably be more scared (...) I can cry when I am not with my kids but as soon as I see the kids it's like no, I fight the tears back I can only laugh and joke and say mum's going to be fine (Vivien, 41).

Another mother also suggested that her children might have also protected her from their own possible negative feelings and reactions;

however she was convinced that she would have noticed this in her children, even if communication was not verbal.

I just (...) going back to the children, I hope (...) like if there were ever any negatives, I never sensed it, any frustrations ...maybe they had them but they protected me from them, maybe they phoned one of their aunties and said oh! But I would have sensed it as well you know there... (Ivy, 52).

Mothers were usually understanding and respectful towards their adolescents and did not try to push them to talk (Vivien 41, Violet 47).

It's very much emotionally difficult and it can be hard to get a teenager to talk to someone they have never met before but it's a good thing that we open up and speak to somebody but you can't push them (Violet, 47).

I can't do this on my own.

Mothers developed a series of strategies to continue 'normality' in adolescents lives; however keeping normality and routines was not always possible on their own as sometimes activities that they carried out, such as providing lifts, was restricted by secondary effects of treatments or fatigue. Mothers realized that they could not continue all on their own and decided to allow other people to provide help and support to them with the objective of protecting the family and adolescent children. This motivated them to open the boundaries and let external supports contribute or even take over roles that they were exclusively in charge of previously.

Partners had a very important role as providers of support for mothers but also in their role as fathers. Husbands were described as very important sources of support, strength and reassurance by five mothers (Katie 60, Vivien 41, Molly 51, Miriam 53, Melissa 45).

He talked to them, he had to do housework, he had to do shopping, he had to do cooking, he did cleaning, he had to do anything University related for them, any questions they had about me, any prescriptions, any appointments all that, he had to take care of all that (Miriam, 53).

Fathers would also get involved in activities that the mother would have done exclusively, like supervising homework, attending school meetings and other meetings ,for example, religious confirmation (Linda, 49).

...my husband was excellent, he reassured me every time and he helped me get through it because he was strong and he really did take good care of me and...because I am a weak person generally and for the most I am not a strong person so when the illness came it hit me quite bad... (Molly, 51).

Mothers relied on their partners mostly for honest emotional disclosure. Partners were usually the only ones mothers cried with and who they talked with about what they truly felt: “The only one who has ever really seen how I feel is my husband” (Vivien, 41).

Another important aspect of family support was sibling relationships between their children. Mothers also described the importance of sibling relationships as a way to cope with maternal illness. Siblings would talk to each other and help each other. A special emphasis was put on the role of elder siblings in supporting their younger brothers and sisters (Emma, 46: Jasmine, 38). “Oh I’d say she was very close to her sister as well and they would spend a lot of time together watching DVDs and you know, chatting to each other, you know” (Miriam, 53).

Nuclear families were not the only ones which provided support for the ill mother, extended family and other external supports were also important for families during this time (Ivy 52, Emma 46, Vivien 41, Linda 49, Miriam 53, Melissa 45). Other supports were crucial providers of support for mothers but also for their children, mostly in families where adolescent children lived far away from the family home.

I shared with my siblings and I included my brothers too so that they knew, all my family knew I was going in on the [date] for results and the indicators aren’t good. I suppose I was more honest with...not that I was dishonest with my children, I wouldn’t be but I was more open with my siblings... (Ivy, 52).

Other family members were also key providers of tangible support for families as they were in charge of house chores such as cooking dinners, shopping, lifts, organize daily school routines and talking to the adolescents (Ivy 52, Melissa 45).

...actually my cousin's wife who lives in (name place) came, she would have known the children when they were tiny(...)she was my guardian angel, she came and she just moved in with us and did the food shopping and cooked the meals and was up to get the children out to school... (Ivy, 52).

One mother, however, also perceived that having other people taking over specific activities might have contributed to making the cancer experience more real for adolescents, although this was not confirmed by them.

People are very very willing to do it but I was inclined not to ask before but I am asking now (...) my brother in law is taking them into music lessons and I am getting a little bit more help this time, this programme, and I think maybe they realized that the last time it seemed to be just 'business as usual' I practically did everything that I always do but I am taking the help and I think maybe that has made it more real to them (Linda, 49).

In Vivien's family, family members who had gone through the experience of cancer themselves were particularly helpful for mothers as they appreciated their knowledge and how they could become a reliable source of information and reassurance for their adolescents:

They do talk to her quite a lot about it and if I say (name son) I have a PET scan, they ask their Nana what's a PET scan and Nana can explain everything like a CT scan, she's taught them through the different types of scans that we have to go through during cancer. She knew about the chemo drug she knew about that much and she knew how they all worked... (Vivien, 41).

Mothers were also supported by health care professionals including cancer care nurses, social workers and GPs that could answer their questions (Molly 51, Vivien 41). Mothers also described the importance of cancer care centres throughout their illness.

I could make a phone call to my cancer care nurse, they worked in a team, they were job sharing and they were fantastic, they would phone me back and give me details you know, in the same way my own GP, my own doctor, if I had any concerns I could speak to him or my husband could go in and have a chat and he'd come back with the information you know (Molly, 51).

Mothers (Linda 49, Miriam 53; Melissa 45) also described some other sources of support that their adolescents had at the time. One of the sons was actively taking part in a therapeutic process and this was a support at the time of diagnosis and another was in close contact with her counsellor. Other important sources of support mentioned were school teachers and counsellors (Linda 49, Melissa 45).

...he was told there was a counsellor, (...) but they said they didn't want it, that they didn't need to so and...eeemmm....(daughter's name)'s teacher had been through the same experience about 20 years ago so she said 'look if you ever want to talk to me, let me know' and she can talk to me and she was very good at the time and made sure she was okay... (Melissa, 45).

Mothering a teenager

Mothers in the AMC Study showed great sensitivity to adolescent developmental stage and the developmental demands that adolescent needed to solve but could not due to responding to the demands of her illness. This was a source of worry and concern for them.

Adolescence was perceived by mothers as an important developmental stage where young people were meant to enjoy themselves and have fun (Vivien 41, Molly 51).

She goes off a lot with her friends sometimes there would be a disco or something and she would want to go to that.

I find that exciting for me too because she's never really been a girly girl she's been a tomboy (laughter) and now there's all this discos and she's got to that age, she's a girly girl now, so all the makeup and the dresses and high heels it's exciting for me 'cause I get to be a teenager again (Vivien, 41).

One mother described that her adolescent was starting to spend more time away from the house with their friends at the time of her illness.

...in fairness both of them are very good socially and they get great pleasure from their friends (...) they go out for their play dates and (older son) has started to go out you know, with his friends, just go off on a Saturday afternoon to play football with them or go to the cinema (...) so they are starting to do a little bit of socializing on their own ... (Linda, 49).

Mothers also expressed that adolescents were happy to spend time at home and do regular activities like watch TV or watch a DVD.

They met up with their friends and would go with them to the cinema and do other fun activities. We also watched movies together in the house and made sure the family always had quality time. My adolescent really enjoyed these activities and helped them relax (Violet, 47).

Mothers also tried to understand the situation from the adolescents' perspectives, taking into account the developmental issues they might be dealing with simultaneously at the time of maternal illness. Important academic demands were identified as additional stressors for adolescents (Molly 51, Miriam 53).

We asked her not to tell her older brother and sister for the only reason that on (date) they were both heading back to college in (name place) for their first semester exams and there were also assignments due as well... (Miriam, 53).

Mothers had some preconceived ideas about the impact of hormonal changes in adolescence and their reactions to maternal diagnosis.

...it's hard to know, I suppose what is natural teenage hormones and what is maybe a little bit of anger about the whole issue...sometimes he would even say a nasty thing to me like 'oh for goodness's sake you need more attention now that you're sick' you know... (Linda 49).

Me and my adolescent.

Even if mothers were concerned about the impact that cancer may have on the normal development process of their adolescents, they identified consequences that the illness had which could have a positive impact on their adolescent's lives.

Mothers described changes in the relationship with their adolescents but these were usually perceived as positive: "Well if anything it just brought us closer ...you know, it wasn't a deciding factor but it was a contributing factor" (Jasmine, 38).

Relationships became closer and this made mothers realize the importance of their maternal role in their adolescents' lives (Ivy 52, Vivien 41).

"...my experience proved to me how I suppose how important I am, one is, how important mum is in their lives, it didn't take this really, of course we all know we are valued and we are loved" (Ivy, 52).

Mothers noticed that these changes, spending more time together and closeness had a positive impact on the adolescents.

"I am at home, I used to be at work you see, that is another thing they love having me at home whereas before I would be working, up to 5 or 6 o'clock, so they are really happy for that" (Jasmine, 38).

Adolescents were described as more affectionate and also one mother described how her adolescent went to a service to support her.

"Well I think...(young son) was always affectionate to me but (young son) is a little bit more cuddly (...)He came to the hope ceremony and after that I said were you all right yesterday and he said 'yeah yeah, It was a bit long he said' it was nice but it was a bit long. I think he

said he did it for me, he said to me on the way home on the car, ‘were you happy with that mum?’ I think he was doing it for me... to support me, you know’’ (Linda, 49).

One mother described that the relationship with her children was already good before the diagnosis and the experience did not cause changes. Melissa’s description of the experience seems to suggest that maternal cancer was not a drastic biographical disruption for her and her family and this may be why relationships were not drastically changed. A serious and threatening illness was described as ‘a bit of a blip’ or it may also be that she was trying to minimize the issue as a way to reduce the disruption it caused.

‘‘...we didn’t want to change anything in any way we wanted...we were really happy with our lives and we just thought it was a bit of a blip...get over it and back to normal’’ (Melissa, 45).

The cancer experience, however, did not always have a positive impact on the mother-adolescent relationship. Sometimes a cancer diagnosis generated further tension in already difficult relationships and the absence of the mother due to treatment reduced her availability and so deteriorated relationships further, but this was only mentioned by one mother. This mother was separated during the week days from her family as she required specialized treatment that was not available in her local hospital. She considers this geographical separation had a strong deteriorating effect on the relationship with her adolescents, particularly her daughter.

‘‘Me and my daughter didn’t really have a good relationship in the beginning anyway but I feel that it has added more pressure on the relationship it’s kind of we are growing further and further apart so I am not only worried about my cancer but about losing my daughter (...) I’m not there for her (...). Like before me and her could go for a walk and then she could talk to me, she can’t do that now, mum’s not there’’ (Vivien, 41).

The strength and bravery of my adolescent

Mothers seem to be very aware and sensitive of the developmental stage of their adolescents, yet it seems that they were still surprised at the level of maturity that adolescents showed at the time of their illness and the way they responded to it by caring and supporting them (Ivy 52, Molly 51, Miriam 53). This may suggest that mothers were expecting their adolescents to respond as younger and more dependent children, still in need of care and protection, but this was not the case, they instead provided care and support.

‘‘Em I have to say they were brilliant they really now I don’t know, they were so helpful all the time, they did everything for themselves, they did a lot more around the house than they probably would have done before and I don’t know they were really really good (...) they were really brilliant through it...’’ (Melissa, 45).

Mothers agreed that adolescents matured and grew up from the experience of maternal cancer. This is relevant in the context of the biographical disruption framework as mothers realized that their adolescents did not require as much care and comfort from their mothers and were instead more independent, although it was not explicitly mentioned, this may have helped mothers deal with the role identity conflict associated with the biographical disruption as this may have reduced the tension between their illness (‘sick person’) and the maternal demands experienced.

‘‘They were very loving and very caring and very wanting to help, very mature, you know, I thought she handled it absolutely very well (...) and I probably underestimated her, you know, her capabilities and abilities for coping (...). I suppose their childhood was definitely over there and you know, they had to realize that we are now kind of adults and you know...’’

(Miriam, 53).

Supporting this idea of adolescent independence and maturity, mothers described how adolescents became actively involved in their care or had a caring attitude towards her that was appreciated and noticed by the mothers, which was similar to that of a parent or a very concerned adult.

Mothers mentioned that their adolescents had caring like behaviours towards them like offering a cup of tea, bringing medicines and making their mum feel comfortable. Adolescents were providers of support and not only seen as in need of it, as their mothers initially seem to have expected to see (Molly 51, Ivy 52, Jasmine 38, Miriam 53).

Well he was very careful with me. He insisted to come when I was coming down for my first surgery, he insisted coming in with me to the door of the theatre, you know with my husband but he had to be there because he knew how difficult it was, that he was giving me the benefit of his experience, which was very interesting, you know, and he was very careful for me and of me while I was going through this, he was afraid that I would be upset or nervous or whatever you know, and he would do the very best to take care of me (Katie, 60).

Mothers described that their adolescents were also more involved in household chores. (Katie 60, Ivy 52, Molly 51, Jasmine 38, Miriam 53, Melissa 45). These chores ranged from tidying their own rooms and dealing with their own clothes to cooking for the whole family or taking care of younger brothers and sisters, which again suggests adolescent independence and ability to provide care instead of only needing it which could have reduced the burden on their mothers and the level of disruption they experienced.

She did yeah, (...) specially during my surgery and during my radiotherapy, I was getting very tired you know, she would take over you know, sometimes she'd be cooking the dinner you know or the tying up around the house you know, she is my son's second mother, they have a very good connection and she looked after him while I couldn't and she still does. Yeah she is very good like that (Jasmine, 38).

One mother described a different situation from the other mums and this may have been an indicator of additional disruption and role conflict in their lives. Molly described that her adolescent daughters instead stopped

doing the chores that they usually did before and had to be asked to help around the house. This behaviour change was understood by the mothers as a lack of motivation and constant thinking about the illness situation. Mothers blamed the illness for this change in their adolescents and although not mentioned explicitly as such it may have caused additional disruption and demands on the mother.

Well as I said they stopped doing a lot of the normal things. Normal for me would be take your clothes down to the washing, you know, tidy your bedroom, clean the living room, they stopped doing them but it would take many times to ask them. I think they just got lost in their own little world... (Molly, 51).

Mothers also described that adolescent children were stronger and more able to understand the illness situation than their mothers initially thought they could (Molly 51, Melissa 45).

I would say to them [other mothers in similar circumstances] ...be totally honest...we think sometimes with our kids that they aren't that strong or they are not old enough you know to maybe understand everything, but they really are you know, kids today are very intelligent and very very strong...they understand more than we give them credit for so I would say be honest in the very beginning because you don't always know how our cancer is going to go (Molly, 51).

In line with the biographical disruption framework, even though adolescents showed independence and maturity, mothers still had fears and concerns during their illness but also worried about the long term impact that this experience would have on their adolescents, their developmental processes and their lives: *“I don't know, maybe I don't know, maybe its affected them already and I am not aware of it”* (Ivy, 52).

The fear of recurrence remained over time and it was difficult for mothers to deal with themselves and to know how to deal with it with their children (Ivy 52, Katie 60).

Well I suppose a friend of the family that had breast cancer nine years ago had a relapse in December. And he was absolutely shocked that somebody could be after being so long cured (...) shortly after somebody that we knew had a recurrence as well which, you know (...) I felt that I was translating this experience for him (...) in a less threatening way...(Katie, 60).

Mothers expressed difficulties on how to return to 'normality' after the illness and struggled to make sense of the cancer experience themselves, this may also be considered consistent with the biographical disruption framework, referring specifically to the maternal identity as 'sick person' and 'cancer survivor', while still dealing with demands of the maternal role.

The whole thing just seems like sort of a haze because it happened so quickly. There was no time to think. I think I started to process it maybe in the last month because up to now I was nearly in denial I think I was I am okay, I will be fine, once this is out it will be the end (...) so it's probably only in the last month or six weeks that I've started to think about the whole thing and how my life has changed since...I mean I know it is a temporary change but ...I am getting used to that....(Emma, 46).

The knowledge referring to maternal identity as a cancer survivor, 'after treatment' in this thematic analysis is limited as it was not a topic broached often by mothers because some were still undergoing active treatments at the time of the interview (Linda 49, Vivien 41, Molly 51, Emma 46).

Mothers suggested, however, that health personnel could have an active role in providing support to improve adolescent experiences, however, this could have also helped by reducing the level of disruption in mothers, and may have reassured them of their adolescent wellbeing. Mothers suggested that health care professionals, specifically GPs, should be better trained on how to treat and help young people.

Like when you think that many young people, so much cancer in families, so many young people, that age group

that you are dealing with (...) the whole thing is totally inadequate and the mental health side of it is probably going down to the training and all that, not just the physical body (Miriam, 53).

This same mother also suggested that children and young people should at least have one compulsory session with a health professional to determine whether they are struggling (Melissa, 45).

“I don’t know if that should be compulsory (...) I think some kids do need it and probably school is the only environment outside home that they can...like they are in school every day and there should be something available to kids like that (...) and maybe all kids find it difficult to actually make an appointment and talk to someone (...) maybe it could be compulsory to have at least one discussion or one conversation or one meeting with somebody and see how it goes from there...”(Melissa, 45).

Discussion

The analysis of maternal interviews identified maternal perspectives of adolescent experiences of adjustment to the illness. It revealed that mothers seem to struggle with their own adjustment to the illness and experience a biographical disruption that affects their lives in such a way that they are dealing with conflicting roles that also lead to conflicting demands. Mothers are ill and in need of care (sick role) but are also concerned about the impact their illness will have on their families and particularly children and adolescents (mother role).

This finding is very important, as previous research has suggested that adolescents who experience adjustment difficulties have parents who also struggle to adjust to their illness (Nelson & While, 2002). The analysis, however, suggested that even if mothers are struggling themselves they will do anything to protect their children and families which may be a buffering factor that protects adolescents from the negative effect that their own adjustment struggles may have on their adjustment. The analysis also suggested that adolescents can be more independent and self sufficient and

this allows mothers to be less focused on their care and focus instead on recovering from their illness. Previous research has suggested that mothering an adolescent child during maternal illness can be particularly challenging and emotionally demanding (Ares et al., 2014), but the AMC study has also showed that adolescents can instead help their mothers and reduce their physical and emotional burden.

Cancer: The biographical disruption.

The AMC study provides a description of maternal cancer as a ‘biographical disruption’ (Bury 1982; 2001) to maternal identity and to adolescents normal developmental processes and outcomes. While this framework has been applied to cancer research previously, this is the first study to focus on the impact of maternal cancer in an adolescent group from a biographical disruption framework. Ares et al. (2014) evaluated the impact of motherhood in young breast cancer survivors and identified that parenting children while coping with cancer can hinder parental well being and increase parenting demands.

Maternal accounts in the AMC study suggested that cancer diagnosis is an unexpected experience that is a threat to motherhood and this leads to fear in mothers of the short term and long term impact that the experience can have on their adolescent children, while simultaneously, mothers go through a process of accommodating their new identity as an ‘ill person’. Previous research has described that these maternal changes can be challenging for adolescents and this is a concern for mothers in this study, as they described changes in their adolescents such as becoming more quiet or showing increased irritability. Davey (2011) identified that parent-child conflict was associated with changes in parental behaviour such as increased irritability, impatience, moodiness and paranoia.

Similar to the AMC study, previous research by Fitch et al. (1999) found that women in their study were tense because of their need for self care and because they knew their children were still in need of care themselves. Some women in the AMC study felt insecure about their parenting skills, as they struggled to keep routines and activities as normal while also experiencing illness demands and changes. Semple and McCance

(2010) identified that parents experienced significant feelings of guilt and sadness associated with not being able to be a good parent.

Mothers experienced further disruptions as they needed to share unusual experiences together, for example, buying a wig, which physically healthy parents would never have to experience with their adolescents. Fisher & O'Connor (2012) described that communicating with children about cancer was an integral but at the same time an unwanted aspect of the changing identity as mothers. Mothers try to prepare for this moment when they have to disclose their cancer diagnosis to their children but this cannot protect them from strong emotional reactions to the news such as pain, shock and fear that can lead to mood and personality changes in adolescents (Curtis, Groarke, McSharry & Kerin, 2013). 'Regular' mothers would never expect to trigger that kind of emotions in their adolescents, again supporting the idea that mothers experience a significant biographical disruption.

The level of biographical disruption varied across mothers as one of them (Melissa) described maternal cancer as a 'bit of a blip' and also reported no changes in the relationship between her and her adolescent children during the illness. This could have been an attempt by mothers to control the disruption by minimising it.

Fisher and O'Connor (2012) described that part of maternal identity changes was contemplating the future of her children if their illness became terminal. One of the biggest concerns for mothers was the fear of recurrence in themselves but also the impact this would have on their adolescents. Ares et al. (2014) found that mothers experience higher levels of fear of cancer recurrence, both in the short term survivorship period and also into long term survivorship compared to women without children. In line with the biographical disruption framework, mothers struggle to make sense of their identity as 'sick' and 'cancer survivors' long after the completion of their treatments. This could be a consequence of mothers focusing on their roles and their goal to protect their families at the time of illness, delaying or denying their own assimilation of the illness experience.

The 'good mother'.

In line with previous research and the biographical disruption framework, mothers, despite illness, try to remain as responsible wives and mothers to reduce the cancer burden on other family members (Asbury, Lalayianni & Walshe, 2014; Shands, Lewis & Zahlis, 2000; Wolf, 2015). In the AMC Study mothers wanted to protect their children and families and did so by keeping routines normal, selecting the type of information they disclosed to them and also avoiding upset and fear, however, this was a strong burden for them as secondary effects of illness could cause fatigue or impede them from carrying out normal activities. Despite maternal fatigue, mood changes and physical changes, mothers feel guilty and concerned about the impact that all of these changes will have on their adolescents, sacrificing their own needs to provide for their adolescents. According to Helseth and Ulfsaet (2005) “parents tend to strive to keep life normal so that their children stay safe and happy” (p.44).

Previous research has suggested that mothers have a tendency to protect their children by selectively sharing information with them. Asbury et al. (2014) described that women minimised the expression of their own feelings as a way to put their children first and maintain normality. In attempting to protect the child from disruption, the strategy of selective sharing could be counterproductive instead. Huizinga et al. (2005) investigated parent-adolescent communication in families with parental cancer. They described ‘the phenomenon of double protection’ where adolescents could experience less open communication with their mothers as a way of protecting themselves and their mothers. Previous research by Sigal et al. (2003) suggested that encouraging mutual disclosures of fear, anxiety and hope had mutual benefits for the mother child relationship. Maynard et al. (2013) found that families who encouraged open communication of feelings about the cancer diagnosis had better outcomes. When information was withheld from them, Rosenfeld et al. (1983) described that adolescents felt ignored, Hilton and Elfert, (1996) identified that adolescents felt hurt and Fitch and Abramson (2007) suggested that adolescents felt a sense of separation and uncertainty. In line with the biographical disruption framework, selective sharing is a way in which

mothers attempt to neutralize the potential disruption that the illness may have on adolescent and family functioning.

A developmental understanding of adolescence.

Previous research, however, has suggested that parental cancer can have a negative impact on normative development of adolescent children, Sears and Sheppard (2004) suggested that the experience of parental cancer may sidetrack some young people from pursuing normative developmental tasks but this tends to be only temporarily. Ohannessian (2007) described that fundamental changes need to take place during adolescence and cancer may cause natural developmental processes of families to be left on hold. Lewis et al. (1985) described the experience of maternal cancer as the ‘ultimate test’ for an adolescent as they are going through the developmental need to withdraw from their mothers, and instead they are needed at home. Sears and Sheppard (2004) also suggested that it was very important that parents encouraged the individuation of adolescents, mostly when family demands were interfering with their normative developmental tasks of living away from the house or working over the summer. Mothers in the AMC Study were sensitive and aware of the developmental stage of their adolescent. The AMC Study identified context specific issues and characteristics specific to the experience of managing the threat and disruption of mothering adolescent children.

Mothers were able to identify and describe the potential duality generated between developmental and illness demands for adolescents. They were concerned about the short and long term impact that this could have, for example, mothers noticed that adolescents were spending more time with the family instead of being involved in more social activities with their peers at an age where independence is relevant (Arnone, 2014).

The possible detrimental effects of maternal cancer on adolescents could instead be buffered by positive gains such as closer relationships between mother-adolescent and family relationships that would encourage mutual communication, awareness and expression of mutual affection. This

would also allow mothers to notice any difficulties or struggles in their adolescents.

It can be suggested that adolescents themselves could have contributed to reduce the burden of the disruption caused by maternal cancer by being more independent, self sufficient and providing support and help in the family home instead of just requiring it. Mothers were surprised at adolescent responses to maternal cancer, even if they mentioned being aware of their age, they were not expecting adolescent ability to respond to their illness with maturity, sensitivity, care and active involvement. Adolescents were not dependant on their mothers for care; instead they provided care and support for them, reducing the level of disruption particularly in the maternal role. In one case (Molly), adolescents stopped being helpful and instead had to be asked to help, which may have been an additional disruption for the mother to deal with the situation and also interpreting this change as a result of the negative impact of her illness on the adolescent.

Summary

The thematic analysis (Braun & Clarke, 2006) provided an understanding of adolescent experiences of maternal cancer from the perspective of mothers. Maternal illness is experienced as a 'biographical disruption' that impacts all aspects of maternal lives, particularly their maternal role which is demanding and in contradiction with the 'illness' or sick person identity which also demands time and physical effort from mothers and reduces their availability to fulfil the maternal role. Mothers went through a drastic change in their identity to a 'sick person' while trying to continue to be good mothers. They wanted to be good mothers and developed different coping strategies to achieve that, for example using their sense of humour, selective disclosure and seeking to maintaining normality. Despite their efforts, there were circumstances that they could not control and from which they could not protect their adolescents. Mothers tried to keep family routines normal while dealing with side effects and illness demands until they realized they could not do this on their own and accepted help from external supports, giving up some of their usual roles and duties.

Mothers were sensitive to adolescent developmental demands and how these were in conflict with illness demands and they were worried about the short term and long term impact that their illness would have on adolescent normal development. Adolescent attitudes towards the illness could minimise the disruption or make the disruption more difficult for mothers attempting to deal with issues and problems such as increased anger and irritability in their adolescents. Adolescents that were more cooperative and caring towards their mothers contribute positively to maternal experience.

QUALITATIVE SELF REFLECTION

This self-reflection process is based on the recommendations included by Ortlipp (2008) on using reflective journals in qualitative research. The purpose of this exercise is to examine personal assumptions, goals, beliefs and subjectivities that may have an impact on the research design and the research process.

The Context of the Study from a Personal Perspective

This research study has been very challenging for me not only as a researcher but as a person. I had the experience of breast cancer in my family, one of my aunts died when I was four years of age and I never really got to meet her and I always felt a bit angry about that, as I was missing out on what seemed to be the best person ever. Another of my aunts had a tumour removed from her breast when I was older, so by then my level of understanding had drastically improved. Breast cancer has been in my family for several years and the possibility of getting it has also been in my mind all my life. My best friend's mum was diagnosed with breast cancer the year before I started this research and in a way I believed she motivated me to choose this topic. I believed cancer was a 'monster to be terrified of' from a distance until I did this research so I could relate to adolescents telling me that they lacked factual information about cancer and the first thought that came to their mind was death. Our starting point was practically the same to be very honest.

When I was in my second year of the PhD a very close friend lost her husband to stomach cancer. We had all been to college together; I knew both of them quite well....they were married for only two years. On year three my best friend lost her auntie to a breast cancer recurrence. On my last year of this PhD my best friend's mum (the sister of the lady that passed away just a year before!) was diagnosed with cancer again and is in palliative care. The doctors consider that chemotherapy is not recommended, she has a treatment that reduces the pain and improves her well being, she is alive and enjoying her life, she is a good loving and kind woman. Once again I realized what I was dealing with: Cancer. And it hurt a bit more this time.

Adolescent and maternal interviews allowed me to understand even further what I was dealing with. I had read many articles by the time the interviews started but no article suggested that one of my adolescents was going to start crying in the middle of an interview and the worst part was that I was not there to give her a tissue or a hug as I would have done otherwise because we were separated by a piece of technology that allows long distance communication, but that is all they facilitate. Once again I reminded myself that I was a researcher and tried to move on after asking her if it was okay if we did. Articles did not say either that mothers were going to start crying either because they felt guilty for having cancer, even if they were not to blame and some part of them knew that, cancer kept them away from their families and cancer made them bad mothers. I think my eyes filled with tears in that interview and once again I tried to remind myself that I was the researcher. Sooner rather than later I also realized that this ‘researcher’ was only a defence mechanism of the person that was trying to do a research study but above and beyond was just a person.

Trying to do community recruitment I met many people diagnosed with cancer that did not take part in my research physically but probably had an impact on the research through me. There was a Dad in one of the workshops on how to talk to children about cancer who shared that he had terminal cancer of the throat and he had an 18 month old little girl and another 3 month old and he wanted to know how to explain to his daughter that he was going to die. I was shocked and I am sure I said something I just can’t remember any of what I said, but I will never forget him. I remember another man, a lovely man, who started to cry in one of the workshops because he could not bear the idea that he didn’t have enough time to make sure his son was a good man, he had terminal cancer too and his son had brought his first girlfriend ever to the house the day before, this Dad wanted to make sure his son loved this girl. I met children with cancer in Conferences, particularly a young teenage girl that had recently been told that she could no longer have kids and she was very angry because she wanted them and cancer had ripped her dream away at a very young age.

All of these people made me keep going, even if I was struggling to convince myself that despite the enormous recruitment difficulties this

research was worth doing and it is because of them that I strived on, despite everything I could do something for someone and I could fight cancer the way I knew, the only way I could. I had moments when I was angry at cancer too.

I had lunch last Tuesday with one of my closest Irish friends, one of those that helped me and cared about me when I didn't know anybody in a foreign country, one that I truly care about. She was diagnosed with cancer four months ago and that day she told me she was 'scared'. I shared with her some of the things I have learnt in my research, she wanted to know when her hair would grow back. I remembered the research participants talking about what it was like for them to deal with losing their hair and the impact it had on them and their families.

I feel a deep admiration and respect for all the adolescents and Mums that took part in this research, the way they opened up to me and shared one of the probably hardest, saddest and most challenging experiences of their life. I don't think I would be as brave and as positive as they were. Thanks to them I am not scared of cancer anymore. I will never be able to thank them for the way they changed my life. I tried to be 'true' to their experiences, their words, their voices and their descriptions as I felt I had the tough challenge of letting other people through my analysis know who they really are and respect their voices and perspectives to be as 'truthful' as possible of their views and experiences.

Engaging in the Idea of Transparency in the Research Process

One of the aspects that I struggle with in qualitative research is the way in which visibility and transparency are achieved as an essential part of the research process. One of my main concerns particularly during data collection was to be 'non-reactive' as this was a way of increasing reliability in participant responses, as this would guarantee the same answers would emerge if these same questions were asked in a different time, place and context (Ortlipp, 2008). It was definitely hard for me to remain neutral and 'non-reactive' in a topic that I feel passionate about but also a delicate topic where people's sensitivities are evident. I am an empathic person that can understand other people's suffering and pain. Remaining 'non reactive' in front of a person that cries in front of me was

not possible. I believe this could have had an impact on my neutrality and my recruitment method. I do feel that other people can detect when a person is honestly accepting and engaging in their own suffering but I do believe this instead increased their level of trust in me and also motivated them to engage and feel safe to express themselves, particularly in face to face interviews. I played an active role during the interviews and I thought it was appropriate from my own previous experiences working with adolescent populations.

‘The Interpretative Crisis’

This is a term coined by Denzin (1994 as cited by Orlick, 2008) which refers to the lack of consensus regarding the amount and type of researcher influence that is acceptable, the way it should be controlled and accounted for. Orlick, (2008) suggested that possible sources of bias such as history values and assumptions should be acknowledged. Perhaps one of the main difficulties I had was trying to adopt my ‘researcher’ role and not my ‘clinical psychologist’ role as I was concerned with being as objective and distant as possible from the data as I could but I must admit that it was not always possible to do that. I had an excel spreadsheet with names and contact details of people I did not meet face to face. I sent people a letter and followed up with a call. I followed the same procedure every single time, some calls were successful but the majority were not. One day I spoke with a lovely lady on the phone. She explained to me that she had not seen my letter yet because she was in the hospital but was interested in my research for her son and she wanted me to send her more information to her house. I hang up the phone thinking that she was one of the loveliest people I had spoken to and happily sent her the information package by post. I called her a few days after to find out if the information had reached her, her mobile phone was off so I left a message. The next Friday I had to go to the cancer centre that she was attached to. I asked her designated nurse about her ...she went quiet for a moment and looked at me and told me that the ‘lovely lady’ had passed away. My heart felt this, my heart felt the loss of a stranger that I had spoken to on the phone...I thought my heart felt nothing for these ‘strangers’ on a list... from that moment onwards I realized what I was dealing with: Cancer.

Critical self-reflection on the research design

This research was initially based only on breast cancer and had a more quantitative methodology, however, as time went by I realized that I had to give up on this initial idea and adapt the research to something that was actually achievable. This research study went through several methodological changes, it was initially proposed as a quantitatively focused study which then became more qualitatively centred. I had previous experience with qualitative research but I doubted my own expertise in the topic. My own limitations motivated me to carry out further research and further reading of new qualitative methods that I had not used before. I knew I wanted to understand adolescent experiences of maternal cancer and then provide possible recommendations to facilitate these experiences for them and their families.

Study 2 (a): Predictors of Adolescent Adjustment to Maternal Cancer

Adolescent adjustment to maternal cancer has been examined in previous research; however, the findings of such studies are conflicting, some suggesting difficulties for adolescents and others not identifying any such problems. This chapter outlines a study aimed at understanding the predictors of adjustment in adolescents.

Rationale

Parental cancer is a stressful situation (Su & Ryan-Wenger, 2007) and adolescents dealing with parental cancer have shown more psychosocial problems than those who have healthy parents (Giesbers et al. 2010). Previous research has suggested that youth who are facing parental cancer have difficulties adjusting, resulting in anxiety or depressed mood and lower social competence (Brown et al., 2007; Compass et al., 1994, Finch & Gibson 2009; Plumb et al., 2006; Hymovich, 1995). Pedersen and Revenson (2005) reported that adolescents can turn a negative event into a way of enhancing their skills and psychological resources. Individual and contextual characteristics can determine if a stressful experience such as parental disease becomes an opportunity for growth or not. Given the variability in adjustment to parental cancer, identifying factors that enhance adaptation to this event is an important research endeavour.

The transactional model of stress, (Lazarus & Folkman, 1984; 1987) provides a useful framework within which to examine adolescent adjustment to a stressful event such as parental cancer. It suggests that coping depends on the appraisal of the stressor and this, combined with cognitive appraisal, accounts for individual differences in people's ability to cope with perceived stressful events. There has been little research on the specific impact of general perceived stress on adjustment in adolescents who have a parent diagnosed with cancer. This study, therefore, examines the role of perceived stress and coping in this group. The transactional model also posits that personal resources, for example, social support and self-efficacy, impact on the stress transaction.

A relationship between stress and adjustment has been identified in previous research with adult and younger populations (Hampel & Petermann, 2006; Moskowitz, 2011). Previous research has proposed that social support has a buffering effect when facing stress; this is known as the Stress Buffering Hypothesis (Dolan et al., 2006; Aldwin, 2011; Van Oost & Debourdeaudhuij, 2003). Social support has been found as a coping strategy used by adolescents who experience parental cancer (Davey et al., 2011). Haffen and Laursen (2009) and Laursen and Mooney (2008) conceptualized adolescent adjustment as being directly linked with social support, as close relationships are crucial indicators of adjustment across the life span. Previous studies have also explained that support from significant others is associated with positive affect and well being (Matsuda et al., 2014; Ammar et al., 2013; Chao, 2011; Lakey & Cohen, 2000). Parental attachment and parent-adolescent relationships are also relevant for adolescent adjustment, Cutrona, et al. (1994) described that adolescents who achieve competent adult status have close relationships with their parents, which also allows them to acquire other life skills such as self confidence and independence. Self- efficacy has also been linked to better adjustment outcomes, specifically with people's mood (Bandura, 1997), coping (Cicognani, 2011), social support (Trouillet et al., 2009) and well being in adolescent populations (Vaezi & Fallah, 2011; Vecchio et al., 2007).

Previous research by Greenglass and Fiksenbaum, (2009) found a reciprocal relationship between coping and social support. Social support appears to buffer the relationship between perceived stress and psychological adjustment and this moderating effect is mediated by problem focused coping (Chao, 2011; Lakey & Cohen, 2000). Matsuda et al. (2014) suggested that perceived social support was associated with life satisfaction through positive affect and negative affect, suggesting a mediating role for social support.

The purpose of the current study is to compare the predictive role of a number of psychological correlates of adjustment, namely, stress, coping, social support, maternal attachment and self-efficacy. This is the first study to report on this combination of predictors in adolescent adjustment to

maternal cancer. The mediating and moderating role of social support is also explored.

Study aims:

(iib) Examine the role and relative impact of perceived stress, coping, perceived social support, maternal attachment and self-efficacy on adjustment (mood and life satisfaction).

(iic) Examine the mediating and moderating effects of social support in the relationship between perceived stress, coping and adjustment (mood and life satisfaction).

Study hypothesis:

1. Adolescents with lower perceived stress will have
 - (a) higher positive affect and life satisfaction.
 - (b) lower negative affect, anxiety and depression.
2. Adolescents with higher coping scores will have
 - (a) higher positive affect and life satisfaction.
 - (b) lower negative affect, anxiety and depression.
3. Adolescents with higher perceived social support will have
 - (a) higher positive affect and life satisfaction.
 - (b) lower negative affect, anxiety and depression.
4. Adolescents with higher parental attachment will have
 - (a) higher positive affect and life satisfaction.
 - (b) lower negative affect, anxiety and depression.
5. Adolescents with higher self-efficacy will have
 - (a) higher positive affect and life satisfaction.
 - (b) lower negative affect, anxiety and depression.

Method

This study collected baseline data on perceived stress, coping, perceived social support, maternal attachment, self-efficacy, mood and life satisfaction in adolescents prior to the AMC intervention.

Recruitment.

Women who had a cancer diagnosis in the previous 24 months and who had a teenage child were recruited with the approval and assistance of the medical nursing team at The Symptomatic Breast Centre (University Hospital Galway) and The Irish Cancer Society affiliated Cancer Support Centres (9). In addition, cancer support centres in United Kingdom (15), United States (38), Spain (2) and Costa Rica (14) were contacted. First year students from National University of Ireland, Galway were contacted directly.

Mothers attending these centres were contacted personally or via post. They were informed that their adolescents could be part of an online programme to improve their life skills and facilitate their adjustment to maternal cancer and other challenging situations in life. Those mothers contacted by letter, were phoned a week later to further explain the research and determine their interest in taking part in the study. University students were contacted through media and official University emails for all registered students. All potential participants received online information or an information package (with SAE) which included information sheets and informed consent forms.

Participants.

Participants in this study were 40 male and female adolescents between 13 and 23 years of age. ($M = 16.78$, $SD = 2.19$) whose mothers had a diagnosis of cancer within the previous two years.

Table 9 *Participant demographic characteristics.*

Variable	<i>N</i>	%
Gender		
Male	9	22.5
Female	31	77.5
Cancer type		
Breast	33	82.5
Colon	3	7.5
Gastrointestinal	2	5
Bowel	2	5
Country		
Ireland	31	77.5
International	9	22.5
Time since diagnosis		
0-12 months	25	62.5
13 – 25 months	12	30
26-38 months	3	7.5

Procedure.

When adolescents had completed consent forms they were given a personal research number and were sent a link by email to the first phase of the study which consisted of completing baseline measures to evaluate levels of perceived stress, coping, perceived social support, maternal attachment, self-efficacy, depression, anxiety, positive affect, negative affect and life satisfaction (AMC Survey). In the second phase, adolescents were then sent a link to each of the eight sessions of the AMC Programme. Once adolescents completed one session, the next link was sent. Phase three consisted of completing the same measures as in phase one (AMC Survey), this was the post test measure. Finally adolescents were sent the same measures (AMC Survey) two months after they completed the programme, however, not enough power was achieved to evaluate changes over time because of the small number of adolescents ($n = 14$) that completed all phases of the study.

Measures.*1. Social Network Questionnaire and the Perceived Social Support Questionnaire (Cutrona & Dolan, 2002).*

The Social Network Questionnaire (SNQ) was developed by Cutrona and Russell in 1987 (further amended by Dolan, 2003). The questionnaire assesses an individual's perception of sources of support and the overall quality of a person's individual relationships in their social network. The SNQ is completed in three phases. Respondents list members in their social network (14 nominations). Then they complete three columns in respect to each nominee, whether they live in the same household as the respondent, the relationship with the respondent and thirdly they rate the overall quality of the relationship (bad, half good, half bad, good). The SNQ is scored separately for each person according to their number of nominees and subgroups (siblings, friends, extended family). Quality of relationships are assigned a numerical value bad (0), half good and half bad (1) and good (2). Respondents obtain a score on perceived quality of their relationships.

The SNQ, however, is sensitive to recent events. People may be excluded due to recent discussions or altercations with a person that may have been key in the network otherwise. Also a person may be introduced in the network on the basis of one recent supportive intervention which occurred prior to the interview. The repeated use of the SNQ over time can reduce this limitation.

The Social Provisions Scale (SPS) provides information on the level (quantity) and types of support available from network members across key areas of social support. According to Dolan and Brady (2012) a balance of support is needed across the four types of perceived support to achieve optimal functioning. Identifying gaps in types of social support is important when planning interventions. SPS quantifies social support based on the classification made by Weiss (1974) which includes: tangible, emotional, esteem and advice. SPS also measures forms of support from four sources: friends, parents/carers, siblings and other adults. A series of repeated 'four picture prompt' symbols are used to increase comprehension mostly in respondents with limited literacy and comprehension skills. Each SPS is

scored separately with an overall total score. The SPS has four sources containing four questions each. The range of scores is a minimum of 16 (all responses are awarded no) to a maximum score of 48 (all responses are awarded yes), however if a respondent had no siblings their maximum score would be reduced.

2. *Adolescent Coping Orientation for Problem Experiences (A-COPE)*
(Patterson & Mc Cubbin, 1983).

The A-COPE is a 54 item self report questionnaire to identify coping strategies employed by adolescents (11-18 years) when managing problems and difficult situations. The scale is divided into 12 factors: ventilating feelings, seeking diversions, developing self reliance and optimism, developing social support, solving family problems, avoid problems, seeking spiritual support, investing in close friends, seeking professional support, engaging in a demanding activity, being humorous and relaxing. A total adolescent coping score may be obtained by adding the number circled by the respondents (Never 1, Hardly ever 2, Sometimes 3, Often 4, Most of the time 5). Some items need to be reversed (7, 8, 19, 24, 26, 28, 42, 46 and 49) to ensure all items have the same weight and positive direction, such that higher scores indicate more positive coping resources. Subscale scores are calculated by adding the number circled by the respondents for all items in each of the 12 subscales. The reported scale reliability (Cronbach Alpha) for this scale is between 0.50 to 0.76 (Patterson & Mc Cubbin, 1983).

3. *Inventory of Parent and Peer Attachment IPPA* (Armsden & Greenberg, 1987).

The IPPA was developed to assess adolescent perceptions of positive and negative affective and cognitive dimensions of the relationships with their parents and closest friends. It is a self- report questionnaire with a five point Likert scale format. Attachment Theory (Bowlby, 1969) is the theoretical framework supporting this instrument. Attachment is defined as ‘close emotional relationship between two persons, characterised by mutual affection and a desire to maintain proximity’ (Schaffer & Kipp, 2007).

Three dimensions are assessed by the scale which are: Degree of mutual trust, quality of communication and the amount of anger and alienation.

In this study, the revised version was used, it consists of 25 items for the mother, father and peers which provide separate attachment scores for each one. Only the mother scale was completed by participants to determine the relationship between adolescents and their mothers. Armsden and Greenberg (1987) reported a Cronbach Alpha value of 0.87 for the maternal attachment subscale. The IPPA is scored by reverse-scoring negatively worded items and then adding the response values in each section. Parent scores are calculated by adding the total trust and Communication scores, and subtracting from that sum the Alienation raw scores (Armsden & Greenberg, 1987) The items provide a global score of security attachment, higher scores are an indication of more secure attachment.

4. *General Self-efficacy Scale (Schwarzer & Jerusalem, 1995).*

The General Self-efficacy Scale is a one-dimensional scale which assesses a general sense of perceived self-efficacy to predict coping with daily hassles and adaptation to stressful events. It is designed for the general adult population, including adolescents (12 years and more). The ten items in the scale assess the strength of an individual's belief in their own ability to respond to new or difficult situations and the setbacks faced. Responses are made on a 4 point scale. To obtain a score, all responses to the 10 items are added. Possible scores range from 10 to 40, subjects with higher scores are those with higher levels of generalized self-efficacy. Schwarzer and Jerusalem (1995) reported Cronbach Alpha values of 0.76 - 0.90 for this scale.

5. *Depression Anxiety and Stress Scales (DASS-21) (Lovibond & Lovibond, 1995).*

DASS-21 is a self report scale to achieve maximal differentiation between affective syndromes of depression, anxiety and tension/stress. Respondents determine the extent to which they experienced each symptom in the previous week. DASS 21 includes a dimensional and not a categorical conception of psychological disorders. Differences in anxiety, depression

and stress experienced by clinical and norm populations are essentially differences of degree. It categorises severity levels into normal, mild, moderate, severe and extremely severe. (All scores have to be multiplied by 2 to obtain the final score).

Each scale contains 7 items, split into subscales with similar content. Depression includes: dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia, and inertia. The anxiety scale includes: autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The stress scale is sensitive to levels of chronic and non specific arousal including difficulties relaxing, nervous arousal, and being easily upset/agitated, irritable/over-reactive and impatient. Separate scores are calculated by adding the scores corresponding to each item. The depression and anxiety scale were utilised in the current study. Regarding reliability, Lovibond and Lovibon (1995) reported a Cronbach Alpha value of 0.88 for this scale.

6. *Perceived Stress Scale (Cohen, Kamarck & Merlstein, 1983).*

The Perceived Stress Scale consists of 10 items on a 5 point scale, ranging from 0 (never) to 4 (very often). An overall score is obtained by adding all responses. PSS scores have to be reversed on items 4, 5, 7 and 8. The original version of the PSS was designed for samples with at least a level of junior high school education. The PSS, however, has been used with adolescent populations (Nguyen- Rodriguez, Chou, Unger & Spruijt-Metz, 2008). Higher scores indicate high stress. Cohen et al. (1983) reported Cronbach Alpha values of between 0.67-0.86 for this scale.

7. *Feelings and Emotions (PANAS-C) (Laurent, Catanzaro, Joiner, Rudolph, Potter, Lambert, Osborne & Gathright, 1999).*

The Positive and Negative Affect Schedule measures the broadest dimensions of emotional states (positive and negative affect) and includes subscales to measure more specific emotions within these groups. The PANAS-C (Child form) is a 30 item self report to measure respondent's emotions in the past weeks. Each respondent is asked to read several words which describe feelings and emotions and choose the most appropriate value

on a 5 item scale ranging from 1 (not at all) to 5 (a lot). The feelings and emotions included as positive affect are: interested, alert, excited, happy, strong, energetic, calm, cheerful, active, proud, joyful, fearless, delighted, daring and lively. Negative affect include: sad, frightened, ashamed, upset, nervous, guilty, scared, miserable, jittery, afraid, lonely, mad, disgusted, blue and gloomy. Regarding reliability of this scale, Cronbach Alpha values reported for negative affect range between 0.92-0.94 and the values for positive affect range from 0.89-0.90 (Laurent et al., 1999).

8. *Satisfaction with Life Scale (Diener, 1985).*

The Satisfaction with Life Scale (SWLS) was designed to measure global cognitive judgments of subjective well being and satisfaction with life. The scale does not assess satisfaction with life components such as health and finances, but it allows respondents to include these domains as they wish. The scale has shown sensitivity to detect change in life satisfaction due to clinical intervention. Diener, Emmons, Larsen and Griffin (1985) reported an Alpha Cronbach coefficient of 0.93 for this scale.

The SWLS is a short 5-item instrument designed to measure global cognitive judgments of satisfaction with one's life. Each question is rated on a seven point scale ranging from strongly disagree to strongly agree. According to the overall scores obtained by a participant, these are put into different categories: very high score, high score, average score, slightly below average in life satisfaction, dissatisfied, extremely dissatisfied.

Statistical analyses

Data was input into SPSS Version 20. Data was prepared and screened for normality and reliability. Bivariate analyses were carried out on the data set (independent sample T-test, analysis of variance ANOVA, Pearson correlation coefficient). Predictors of adolescent adjustment to maternal cancer were analyzed using hierarchical regression, moderation and mediation analyses. An a priori power analysis was carried out for linear multiple regressions using the subject to variable ratio of Cohen (1992), with a medium effect size (0.15) and a power of 0.8 with five predictors the

analysis determined that the total sample size needed was 92 participants. Due to recruitment difficulties only 40 participants were included in the AMC Study. Caution is thus warranted in interpreting the results of the regression analyses.

Results

Data Preparation.

Data was screened to detect possible erroneous entries or missing data. Descriptive statistics (mean, range) were used to ensure the maximum and minimum variables were within the ranges for that specific instrument.

Positive and negative affect raw scores on the PANAS Scale were standardized (Z score) and then converted to T scores, to allow comparison of scores from different tests measuring the same construct (Streiner & Norman, 2005) as the version of the PANAS in Spanish and English were different. The English version (PANAS C) was made up of 30 items and the Spanish version (PANAS X) had a total of 46 items.

The stress scale of the Depression, Anxiety and Stress Scale (DASS 21; Szabo M., 2010) was excluded from the analysis as stress was measured by the Perceived Stress Scale (Cohen, Kamarck & Merlstein, 1983). All variables were assessed for normal distribution. Skewness was used as an indicator of symmetry of the distribution. The values for skewness between -2 and +2 are suggested as acceptable to prove a normal distribution (George & Mallery, 2010). According to Tabachnick and Fidell (2013) the acceptable range for skewness or kurtosis is below +1.5 and above -1.5. All scales fell within these normal ranges.

Scale reliability.

Reliability analysis was carried out for each of the measures. Adolescent Coping Orientation for Problem Experiences had the lowest reliability with alpha values ranging from 0.4 to 0.74. All other scales had an alpha value of 0.6 or more.

Table 10 *Summary of Reliability Analysis of Scales compared with the AMC Study*

Scale	Scale alpha	AMC Study Alpha
Perceived Stress Scale (Cohen et al., 1983)	0.67- 0.86	0.68
Adolescent Coping Orientation for Problem Experiences ACOPE (Patterson & Mc Cubbin, 1987)		
Ventilating feelings	0.75	0.4
Seeking diversions	0.75	0.44
Developing self reliance and optimism	0.69	0.53
Developing social support	0.75	0.74
Solving family problems	0.71	0.73
Avoiding problems	0.71	0.60
Seeking social support	0.72	0.56
Investing in close friends	0.76	0.47
Seeking professional support	0.50	0.64
Engaging in demanding activity	0.67	0.63
Being humorous	0.72	0.74
Relaxing	0.60	0.44
Perceived social support (Cutrona & Dolan, 2002)		
Friends	NA	0.6
Parents/ carers	NA	0.6
Siblings	NA	0.9
Other adults	NA	0.9
Inventory of parent and peer attachment (Armsden & Greenberg, 1987)		
Trust	0.91	0.86
Communication	0.91	0.72
Alienation	0.86	0.72
General Self-Efficacy Scale (Schwarzer and Jerusalem, 1995)	0.76- 0.90	0.83
Satisfaction with Life Scale (Diener, 1985)	0.84	0.87
Feelings and emotions (PANAS C) English (Laurent et al., 1999)		

Positive affect	0.89	0.92
Negative affect	0.92	0.87
PANAS Spanish (Grimaldo, 2007)		
Positive affect	0.71- 0.77	0.59
Negative affect	0.74- 0.73	0.91
Depression, Anxiety and Stress Scale (DASS 21) Szabo M. (2010)		
Depression	0.87	0.83
Anxiety	0.79	0.63

Table 11 *Descriptive Analysis of Study Variables*

Variable	Mean	Standard deviation	Test Norms ¹⁰
Perceived stress	18.8	5.4	Mean 18- 29 years (14.2)
Coping	160.4	21.1	Mean 168.6/ 168.7
Perceived social support	40.2	5.3	NA ¹¹
Social network	7.1	3.5	NA
Attachment	56	16.4	Mean score 60.7 (Armsden and Greenberg, 1987)
General self- efficacy	30.3	4.4	Mean level (29)
Satisfaction with life	24.1	6.7	Mean score (20-24)
Positive affect	38.8	9.0	Mean 31 (Crawford, 2004)
Negative affect	39.8	11.3	Mean 16 (Crawford, 2004)
Positive Spanish	73.67	6.15	Mean 31 (Crawford, 2004)

¹⁰ This column represents the average scores reported by the original instruments to determine if the scores fall into normal ranges or clinical samples.

¹¹ Reliability analyses have not been carried out by previous research with the Perceived Social Support and Social Network Questionnaire.

Negative Spanish	51.7	15.7	Mean 16 (Crawford, 2004)
Depression	10.5	7.9	Bordering normal/mild
Anxiety	7.5	6.1	Bordering normal/mild

Adolescents reported average levels of life satisfaction, general self-efficacy, perceived stress, depression and anxiety. Attachment levels were high. The coping score was below average. Positive affect and negative affect are above average, particularly negative affect, both Spanish and English versions.

Sample characteristics.

Analyses were conducted to evaluate differences across groups on perceived stress, coping, perceived social support, attachment, self-efficacy, life satisfaction, positive affect, negative affect, depression and anxiety.

An independent sample t-test was conducted to compare perceived stress, coping, perceived social support, attachment, self-efficacy, life satisfaction, positive affect, negative affect, depression and anxiety between males and females.

Table 12 Summary of *t* tests Examining Gender Differences Across Study Variables

Variable	Males		Females		<i>Df</i>	<i>T</i>	<i>p</i>	η^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
Perceived stress	4.045	.4635	4.36	.6669	38	-1.326	.193	.04
Coping	159.4	20.671	160.65	21.545	38	-.148	.883	.00
Perceived social support	89.67	10.642	85.39	8.048	38	1.303	.200	.04
Social network	8	3.2	6.8	3.6	38	.915	.366	0.02
Maternal attachment	69.33	7.599	52.10	16.241	29.466	4.462	.000	.34
Self- efficacy	31.44	4.85	29.90	4.29	38	.923	.362	.02
Positive affect	54.8	13.4	48.6	8.4	9.869	1.3	.219	.04
Negative affect	45.1	9.9	51.4	9.6	38	-1.744	.089	.07
Depression	7.33	8.25	11.39	7.645	38	-1.377	.177	.05
Anxiety	6.67	7.211	7.68	5.850	38	-.433	.667	.005

There was a significant difference in maternal attachment scores with males scoring higher ($M= 69.3$, $SD= 7.6$) than females ($M= 52.1$, $SD= 16.2$); $t(40)=4.46$, $p=.000$, two tailed). The magnitude of the differences in the means was very large (eta squared=.34) and 34% of the variance in maternal attachment is explained by gender.

Table 13 Summary of *t* tests Examining Country of Residence Differences Across Study Variables

Variable	Irish sample		International sample		<i>Df</i>	<i>T</i>	<i>p</i>	η^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
Perceived stress	18.84	5.76	18.67	4.24	38	.083	0.93	0.00
Coping	156.7	21.49	173.2	14.08	38	-2.17	0.04	0.11
Perceived social support	86.47	9.25	85.97	7.15	38	.15	0.88	0.00
Social network	7.06	3.67	7.0	3.20	38	.048	.96	0.0
Maternal attachment	59.16	13.99	45	19.9	38	2.42	0.02	0.13
Self- efficacy	29.5	4.5	32.9	2.8	38	-2.13	0.04	0.11
Satisfaction with life	24	6.8	24.4	6.78	38	-.172	.864	0.07
Positive affect	49.6	10.4	51.3	8.2	38	-.449	.656	0.01
Negative affect	49.2	9.69	52.8	10.6	38	-.973	.336	0.02
Depression	10.29	8.259	11.11	6.72	38	-.272	.787	0.16
Anxiety	7.03	5.419	8.89	8.253	10.086	-.636	.539	0.01

There was a significant difference in self- efficacy scores with lower scores for the Irish sample ($M=29.5$, $SD = 4.5$) compared to the international sample ($M=32.9$, $SD=2.8$); $t(40) = -2.13$, $p.0.04$, two tailed). The differences in the means was small ($\eta^2=.011$) and 1.1% of the variance in self-efficacy is explained by country of residence.

There was a significant difference in coping scores with lower scores for the Irish sample ($M=156.7$, $SD = 21.49$) compared to the international sample ($M=173.2$, $SD=14.08$); $t(40) = -2.17$, $p=0.04$, two tailed). The differences in the means was small ($\eta^2=.011$) and 1.1% of the variance in self-efficacy is explained by country of residence.

There was a significant difference in maternal attachment scores with higher scores for the Irish sample ($M=59.16$, $SD = 13.99$) compared with the international sample ($M=45$, $SD=19.9$); $t(40) = 2.42$, $p=0.02$, two tailed). The differences in the means was large ($\eta^2=0.13$) and 13% of the variance in self-efficacy is explained by country of residence.

A one way between groups analysis of variance was conducted to explore the impact of age (early, middle and late adolescence) on perceived stress, coping, perceived social support, attachment, self-efficacy, life satisfaction, positive affect, negative affect, depression and anxiety. There were no statistically significant differences between study variables by age group.

A one way between groups analysis of variance was conducted to explore the impact of length of time since diagnosis on perceived stress, coping, perceived social support, attachment, self-efficacy, life satisfaction, positive affect, negative affect, depression and anxiety. There was a statistically significant difference in adolescent social network by length of time since diagnosis. The effect size calculated using eta squared, was 0.17 (17%). Post hoc comparisons using the Tukey test indicated that the mean score between the 0 to 12 months group was significantly different to the mean of the 26 to 38 months group, suggesting that adolescents whose mothers were diagnosed for the longer time have significantly larger social networks than those whose mothers were diagnosed within the past year (0 to 12 months).

Table 14 *Summary of Anovas Examining Age Groups Across Study Variables*

Variable	Early		Middle		Late		<i>Df</i>	<i>F</i>	<i>p</i>	η^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
Perceived stress	4.30	.53	4.16	.67	4.47	.64	39	.99	.38	.05
Coping	156	25.9	160.5	22.1	162.4	18.36	39	.204	.82	.01
Perceived social support	88.67	7.72	85.89	9.07	85.82	9.17	39	.29	.75	.02
Social network	6.86	3.436	7.05	3.551	7.14	3.80	39	.015	.986	.00
Attachment	63.86	11.55	51.42	17.42	58.21	15.89	39	1.74	.19	.09
Self- efficacy	33	3.56	19	29.79	40	30.25	39	1.74	.190	.09
Satisfaction with life	26	5.83	25.05	7.19	21.86	6.34	39	1.26	.295	.06
Positive affect	54.4	12.4	51.4	8.17	45.9	9.9	39	2.19	.13	.11
Negative affect	48.4	9.2	48.6	10.7	52.7	9.0	39	.779	.466	.04
Depression	6.43	6.48	10.21	8.38	12.86	7.35	39	1.63	.210	.08
Anxiety	7.29	6.65	7.2	7.15	7.86	4.47	39	.046	9.55	.002

Table 15 *Summary of Anovas Examining Maternal Cancer Type Across Study Variables*

Variable	Breast		Colon		Gastrointestinal		Bowel		<i>Df</i>	<i>F</i>	<i>p</i>	η^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
Perceived stress scale	4.26	.63	3.83	.20	5.2	.41	4.55	.78	39	2.18	.11	.15
Coping	160.36	22.34	151	17.58	166	2.83	169	16.97	39	.34	.80	.03
Perceived social support	86.67	8.69	84.33	15.31	82	1.41	88.50	4.95	39	.26	.86	.02
Social network	6.73	3.46	9.67	2.31	6	7.07	9.5	2.12	39	1.02	.39	.08
Attachment	54.61	16.53	73.33	10.69	44	8.49	64.50	.71	39	1.85	.16	.13
Self-efficacy	30.70	4.65	28.67	2.89	27.50	2.12	28	1.41	39	.66	.58	.05
Satisfaction with life	23.39	6.88	31	3.0	23	1.41	26.50	7.78	39	1.30	.29	.10
Positive affect	49.7	9.9	56.5	11.1	47.5	13.3	48.1	7.8	39	.499	.685	.04
Negative affect	51.3	9.6	35.9	3.9	50.2	2.5	50.2	13.8	39	2.454	.079	0.17
Depression	11.18	7.92	2.00	2.00	12.00	5.66	10	11.31	39	1.31	.29	.098
Anxiety	7.94	6.42	2.0	2.0	8.0	2.83	7.9	4.24	39	.87	.47	.07

Table 16 *Summary of Anovas Examining Time since Diagnosis across Study Variables*

Variable	0-12 months		13-25 months		26-38 months		<i>Df</i>	<i>F</i>	<i>p</i>	η^2
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>				
Perceived stress scale	17.72	5.18	20.50	5.87	21	4.36	39	1.37	.27	0.07
Coping	159.1	23.49	164.5	17.83	154.7	11.72	39	.374	.69	0.02
Perceived social support	85.9	9.57	87.81	7.8	84	5.57	39	.292	.75	0.02
Social network	8.04	3.3	5.92	3.18	3.33	4.04	39	3.72	.034	0.17
Attachment	55.68	18.03	56.58	13.66	56	17.09	39	.012	.99	0.00
Self- efficacy	30.8	4.7	29.8	3.49	27	4.58	39	1.10	.34	0.06
Satisfaction with life	25.12	6.4	23.25	7.69	19	3.61	39	1.26	.30	0.06
Positive affect	50.5	10.1	50.7	9.3	43.3	11.8	39	.747	.48	0.04
Negative affect	48.7	9.4	50.8	11.1	57.8	7.4	39	1.23	.305	0.06
Depression	10.76	8.0	8.50	7.63	16.0	6.93	39	1.14	.330	0.06
Anxiety	6.96	6.39	7.5	5.92	11.33	4.16	39	.68	.514	0.04

Table 17 *Summary of Intercorrelations between Study Variables*

Scale	1	2	3	4	5	6	7	8	9	10	11	12
<i>Outcomes</i>												
1. Life satisfaction												
2. Positive affect	.600**											
3. Negative affect	-.500**	-.389*										
4. Depression	-.453**	-.548**	.644**									
5. Anxiety	-.354*	-.109	.554**	.527**								
<i>Predictors</i>												
6. Self-efficacy	.368*	.408**	-.321*	-.222	-.320*							
7. Perceived stress	-.373*	-.382*	.522**	.329*	.342*	-.374*						
8. Coping	.173	.236	.114	-.045	.167	-.010	.094					
9. Maternal attachment	.314*	.161	-.060	-.055	.058	-.212	-.059	.061				
10. Perceived social support	.445**	.355*	-.301	-.247	-.348*	.143	-.203	-.005	.326*			
11. Social network	.398*	.263	-.192	.024	-.028	.149	.057	.328*	.210	.330*		
12. Age	-.285	-.380*	.157	.182	-.021	-.188	.215	.120	-.203	-.083	-.108	
13. Country of residence	.028	.073	.156	.044	.129	.327*	-.013	.332*	-.366*	-.255	-.008	-.110

** Correlations significant at the 0.01 level (2-tailed) *Correlations significant at the 0.05 level (2-tailed).

Multivariate analysis.

Hierarchical multiple regressions (Table 18) were used to identify sets of variables which significantly predicted adjustment (mood and satisfaction with life).

Stress and coping were introduced at Step 1.

Previous research suggests that parental cancer can be described as a stressor in young people's lives (Hymovich, 1995; Dehlin & Reg, 2009; Issel, et al., 1990; Welch et al., 1996, Leedham & Meyerowitz, 1999; Faulkner & Davey, 2002; Huzinga et al., 2005; Edwards et al., 2008). One of the main objectives of this research study was to explore the subjective experiences of adolescent adjustment to maternal cancer and so it was decided to explore adolescent levels of perceived stress as this subjective approach describes the person as an active being in interaction with their environment, appraising threatening and challenging events according to their own coping resources (Cohen et al., 1983), cognition, motivation and meanings (Lazarus, 1990).

The theory of perceived stress selected was the transactional model of stress (Lazarus & Folkman, 1984; 1987). This theory suggest that people's ability to cope with stressful events depends on the appraisal of the stressor and individual differences in coping skills and cognitive abilities. According to Cohen et al. (1983) perceived stress is an outcome variable- which means that it is a measure of experienced levels of stress as a function of objective stressful events, coping processes, personality factors, etc.

Personal resources which impact on adjustment were entered in the next step: Perceived social support¹² and attachment.

Based on the Transactional Model of Stress, once a person appraises a situation as stressful, they will call on coping processes, as a consequence of this appraisal, to manage the troubled person-environment relationship. Perceived social support has been identified as having a significant role in

¹² Perceived social support was selected over the social network as preliminary analyses suggested that perceived social support was a stronger predictor of research outcomes. The social network did not yield any significant results, whereas perceived social support was a significant predictor of life satisfaction and anxiety. Additional information on such analyses can be obtained by contacting the researcher.

coping with stress, which is known as the ‘Stress Buffering Hypothesis’ which explains that social support has an indirect stress reducing effect acting as a buffer for the negative consequences of stressful events (Bal et al., 2003; Dolan et al., 2006; Aldwin, 2011; Van Oost & Debourdeaudhuij, 2003). In the context of cancer research, social support is a coping strategy used by adolescents who experience parental cancer (Davey et al., 2011).

Perceived social support was entered alongside maternal attachment as quality of family relationships can be linked to availability of family as a source of support and has an impact on adolescent levels of social support. Previous research has suggested that adolescent attachment to their parents impacts on the quality of relationships that they establish (Sarason, Pierce & Sarason, 1990). Gorrese and Ruggieri (2012) identified that adolescents who have more secure relationships with their parents tend to also establish secure relationships with their friends. The introduction of both variables was also supported by the bivariate analyses in the AMC study which showed that perceived social support was correlated with maternal attachment.

Self-efficacy was entered at Step 3.

Self-efficacy is an individual belief on the capability to perform a specific action to achieve a specific outcome. Self-efficacy was introduced as the last step as previous research has identified that self-efficacy is strongly influenced by a person’s level of social support (Hirsch, 1980). Dolan and Brady (2012) suggested that social support in young people can enhance their self-efficacy and self-esteem. Cicognani (2011) found that adolescents with higher self-efficacy and family support tended to use less withdrawal (as a coping strategy) and reported higher levels of well-being. Trouillet et al. (2009) found that higher levels of social support satisfaction predicted higher levels of self-efficacy.

Positive affect.

The Perceived stress and coping set accounted for a significant proportion of the variance in positive affect (23%). The β or standardized correlation coefficients show that more positive coping ($\beta=0.44$, $p<0.05$)

was associated with higher levels of positive affect and higher perceived stress ($\beta=-0.31$, $p<0.05$), was linked to lower positive affect

Perceived social support and maternal attachment entered in step 2 did not account significantly for any additional variance in positive affect.

Self-efficacy in step 3 accounted for an additional 12% of variance in positive affect (adjusted R^2 change = 0.12, $p < 0.05$). Higher self-efficacy was linked with higher levels of positive affect ($\beta=0.41$, $p<0.05$).

Negative affect.

The perceived stress and coping set accounted for a significant proportion of the variance in negative affect (21%). The β or standardized correlation coefficients showed that it was higher perceived stress rather than coping that was associated with higher negative affect ($\beta=0.44$, $p<0.05$). Further sets did not contribute significantly to explanation of variance on negative affect.

Satisfaction with life.

The perceived stress ($\beta=-0.4$, $p>0.05$) and coping ($\beta=0.2$, $p>0.05$) set of variables accounted for a significant proportion of the variance in satisfaction with life (14%). Perceived social support and maternal attachment at Step 2 accounted for an additional 14% of the variance in satisfaction with life (Adjusted R^2 change = 0.14, $p < 0.05$). The β or standardized correlation coefficients showed that higher perceived social support ($\beta=0.33$, $p<0.05$), was associated with higher satisfaction with life. The addition of self-efficacy on the third step accounted for an additional 6% of the variance in satisfaction with life (Adjusted R^2 change = 0.06, $p < 0.05$). The β or standardized correlation coefficients showed that higher self-efficacy was linked with higher satisfaction with life ($\beta=0.31$, $p<0.05$).

Depression.

The study variables entered in the regression model failed to account for any significant proportion of the variance in depression.

Anxiety.

The study variables entered in the regression model failed to account for any significant proportion of the variance in anxiety.

Table 18 *Hierarchical Multiple Regression of the Role of Perceived Stress, Coping, Perceived Social Support (PSS), Attachment, Self-efficacy on Positive Affect, Negative Affect and Life Satisfaction.*

Predictors	Positive Affect				Negative affect				Satisfaction with life			
	<i>B</i>	<i>F change</i>	<i>Adj R²</i>	<i>Adj R² ch</i>	β	<i>F change</i>	<i>AdjR²</i>	<i>Adj R² ch</i>	β	<i>F change</i>	<i>AdjR²</i>	<i>Adj R² ch</i>
(1) Perceived stress	-.313*	6.73*	0.23		.443*	6.05*	0.21		-.393	4.14*	0.14	
Coping	.441*				.187				.210			
(2) Perceived SS	.157	1.69	0.26	0.03	-.200	1.11	0.21	0.0	.325*	4.45*	0.28	0.14
Maternal attachment	-.259				-.041				.177			
(3)Self- efficacy	.407*	8.14*	0.38	0.12	-.030	.035	0.19	-0.02	.312*	4.5*	0.34	0.06

*P < 0.05

Table 19: *Hierarchical Multiple Regression of the Role of Perceived Stress, Coping, Perceived Social Support(PSS), Attachment, Self-efficacy on Depression and Anxiety.*

Predictors	Depression				Anxiety			
	β	<i>F change</i>	<i>Adj R²</i>	<i>Adj R² ch</i>	β	<i>F change</i>	<i>Adj R²</i>	<i>Adj R² ch</i>
(1) Perceived stress	.336*	2.377	0.07		.329*	2.89	0.09	
Coping	-.076				.136			
(2) Perceived SS	-.197	.705	0.05	-0.02	-.35*	2.58	0.16	0.07
Maternal attachment	.031				.181			
(3) Self- efficacy	-.098	.304	0.03	-0.02	-.17	.988	0.16	0.00

* $P < 0.05$

Mediation and Moderation analysis

The AMC Study explores the subjective experience of adolescents' psychological adjustment to maternal cancer with particular focus on perceived social support. Based on this objective and on the results obtained in the hierarchical multiple regression showing that perceived stress, coping and social support were significant predictors of adjustment, moderation and mediation analyses with bootstrapping were carried out to determine the potential role of social support in the relationship between perceived stress, coping and life satisfaction, positive affect and negative affect.

Depression and anxiety were excluded from the mediation and moderation analyses as regression models failed to significantly predict variability in these two components, it is hypothesized that the reason for this is that the sample of adolescents fell within normal ranges of depression and anxiety and were not clinical samples.

The method of moderation and mediation with bootstrapping was chosen as it is more suitable for small samples (N=40) because it makes no distributional assumptions (Hayes, 2013). In the present study, the 95% confidence interval of the indirect effects was obtained with 1000 bootstrap samples (Field, 2013). The software used was PROCESS for SPSS (Hayes, 2013)

Mediation.

Mediation did not emerge in any of the sets of analyses

Moderation.

The PROCESS add-on for PASQ was used to test moderation. Moderation analyses were carried out to determine if social support moderated the relationship between perceived stress and adjustment (positive affect, negative affect and life satisfaction). As a result of the multivariate analysis and based on previous research findings the possible moderation effect of social support in the coping and mood (positive affect) relationship was also tested.

The moderation analysis produces three core results. First it identifies if the relationship between the core predictor (e.g. perceived stress) and the outcome (e.g. positive affect) is significant. Second, it identifies if the relationship between the hypothesised moderator (e.g. social

support) and outcome is significant. Finally, it tests if the moderator actually moderates the relationship between the predictor and the outcome.

PROCESS creates a new variable (e.g. perceived stress X social support) and enters this into the regression equation. If moderation is occurring, then this interaction will be significant and post-hoc analyses will suggest that the relationship between the core predictor and outcome will change as a function of the moderator.

Table 20 and 21 present the summary data on the moderation analysis. Moderation emerged in one of the sets analyzed.

Social support emerged as moderator of the relationship between perceived stress and positive affect. In this analysis, there were no main effects for both the predictor (perceived stress, $b=0.46$, $t=-1.64$, $p>.05$) and the moderator (perceived social support, $b=-0.45$, $t=1.54$, $p>.05$). These two effects, however, were qualified by an interaction effect between perceived social support and perceived stress ($b=-0.14$, $t=-2.67$, $p <.05$).

Analyses at three levels of the moderator (low, medium and high perceived social support) suggests that this interaction occurs at high levels of social support ($b=-0.14$, $t=-2.67$, $p <.05$), but not at medium or low levels. This is illustrated in the interaction chart (Figure 12). There is a non-significant relationship between perceived stress and positive affect at low and medium levels of perceived social support, but this relationship becomes significant at high levels of perceived social support (i.e. perceived social support moderates the relationship between perceived stress and positive affect).

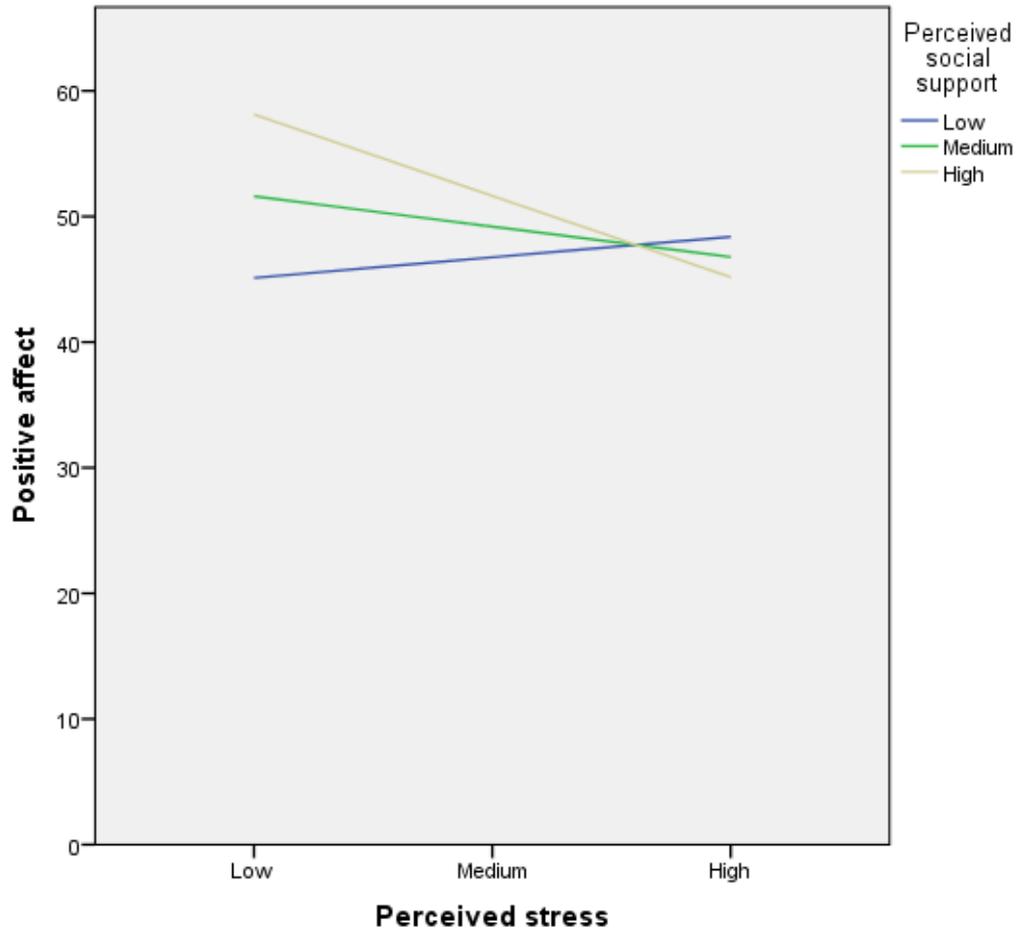


Figure 13. Moderating effect of perceived social support in the relationship between perceived stress and positive affect.

Table 20 *Mediation Analysis*

Predictor (X)	Outcome (Y)	Mediator (M)	Total Effect (β) of X on Y	Indirect of Effect (β) of X on Y	95% Confidence Interval (Indirect Effect)	
Perceived stress	Life satisfaction	Social support	-0.46*	-0.10	-0.34	0.03
Perceived stress	Positive affect	Social support	-0.70*	-0.11	-0.44	0.02
Perceived stress	Negative affect	Social support	0.95**	0.08	-0.03	0.31
Coping	Positive affect	Social support	0.11	-0.00	-0.05	0.07

* $p < 0.05$. ** $p < 0.01$ Table 21 *Moderation Analysis*

Predictor (X)	Outcome (Y)	Moderator (M)	B (Predictor)	B (Moderator)	B (Interaction)
Perceived stress	Life satisfaction	Social support	0.48*	-0.35	-0.01
Perceived stress	Positive affect	Social support	0.46	-0.45	-0.14*
Perceived stress	Negative affect	Social support	-0.41	0.93*	-0.05
Coping	Positive affect	Social support	0.66*	0.11	0.00

* $p < 0.05$

Table 22 *Support for Research Hypotheses*

1. Adolescents with higher perceived social support will have (a) higher positive affect and life satisfaction. (b) lower negative affect, anxiety and depression.	Supported Hypothesis supported for negative affect only
2. Adolescents with higher parental attachment will have (a) higher positive affect and life satisfaction. (b) lower negative affect, anxiety and depression.	Supported Not supported
3. Adolescents with lower perceived stress will have (a) higher positive affect and life satisfaction. (b) lower negative affect, anxiety and depression.	Supported Hypothesis supported for negative affect only
4. Adolescents with higher coping scores will have (a) higher positive affect and life satisfaction. (b) lower negative affect, anxiety and depression.	Supported Not supported
5. Adolescents with higher self -efficacy will have (a) higher positive affect and life satisfaction. (b) lower negative affect, anxiety and depression.	Supported Not supported

Discussion

Stress, coping and adjustment.

Previous research has identified that parental cancer can be a stressful experience for young people (Hilton & Elfert, 1996; Hilton & Gustavson, 2002; Rosenfeld et al., 1983; Visser et al., 2004; Huizinga et al., 2005; Leedham & Meyerowitz, 1999; Issel et al., 1990; Huzinga et al., 2005). Adolescence has been described as a stressful developmental stage in itself. Cicognani (2011) described adolescence as a transitional stage where young people experience physical, cognitive, psychosocial and normative changes that can be significant sources of stress, therefore maternal cancer can be a stressor but probably not the only stressor in adolescent's lives. This study used the transactional model of stress and coping as a framework (Lazarus & Folkman 1984; 1987) to identify predictors of adolescent adjustment to maternal cancer.

In the present investigation perceived stress and coping together explained variance in both positive affect (23%) and in negative affect (21%) highlighting the importance of including an assessment of stress appraisal and coping strategies when examining adjustment to maternal cancer. These findings are in line with previous research showing that perceived stress and maladaptive coping were positively associated with adjustment problems (e.g. emotional distress) in a general adolescent population (Hampel & Petermann, 2006; Compass et al., 2001).

Groarke et al. (2011) identified that high global stress predicted both lower positive affect and higher negative affect at diagnosis and post surgery in women with breast cancer. Similar findings in the current study indicate its relevance as a predictor of affective states in an adolescent population faced with maternal cancer and suggest it may help to identify those at greater risk for adjustment difficulties. Previous research (Moskowitz, 2011) has also described a relationship between stress and negative emotions which has been associated with ill health, higher mortality rates in people with chronic illness, depression and other forms of psychopathology. It is important to acknowledge that there may be a conceptual overlap between perceptions of stress and perceptions of negative affect.

Previous research has suggested that people's mood and emotional responses can impact on people's mood perceptions. Groarke, Curtis, Coughlan and Gsel (2004) found that the perception of an illness (perceived stress) rather than the actual medical disease (objective stressor) that explained variability in mood status of adult patients with rheumatoid arthritis. Cohen et al. (1983) carried out research with college students and found that perceived stress was, in effect, highly correlated with depressive symptomatology but these were different and independent predictive constructs.

Due to the exploratory nature of the current research and the objective of exploring subjective experiences of adolescent psychological adjustment to maternal cancer, it was considered more suitable to use measures of , perceived rather than objective stress. According to Cohen et al. (1983) objective measures can provide an estimate of the increased risk for disease associated with the occurrence of identifiable stressful events. Cohen et al. (1983) also described the limitations of these objective measures. From this perspective, events would be the precipitating cause of pathology and illness behaviour. This ignores the view that people actively interact with their environments and appraise potential threatening and challenging events according to their available coping resources. The cognitive mediated emotional responses, personal and contextual factors would be associated with stress and not the objective event by itself (Cohen et al., 1983). Lazarus (1990) added that objective measurements of stress only focus on changes in conditions of life and disregard sources of stress associated with recurrent conditions, such as daily hassles. The person contribution to life events is not included nor is the meaning or significance that life events can have on people with different cognitive and motivational styles and skills. This issue; however, is highly complex and may have to be disentangled in future research studies with a prospective design. Such a design can indicate if perceived stress contributes to or merely reflects the effects of negative affect.

In this study, stress and coping accounted for 14% of the variance in life satisfaction, with lower stress and more positive coping linked to higher life satisfaction. Similarly, previous research by Gilmand and Huebner (2003) found that stress in adolescents, particularly social stress, correlated negatively with life satisfaction.

Overall, stress and coping, explained the highest amount of variance on adjustment indices in the model, however, they failed to significantly predict variance in depression and anxiety levels. This could reflect limitations in the assessment of depression and anxiety, but a point to note is that adolescents in this study reported low levels of depression and anxiety.

In contrast to current findings, previous research has identified a relationship between stress and depression and anxiety. Compass et al. (1994) identified that cancer patients, their spouses and their children experience considerable stress at the time of cancer diagnosis. This stress manifested itself as different symptoms including depression. Other research which identified feelings reported by children experiencing parental cancer reported depression, anxiety and lower social competence (Compass et al., 1994; Finch & Gibson, 2009; Plumb, Ziebland & Stein, 2006; Hymovich, 1995). Perceived stress, however, was not specifically measured in these studies. Given their role in the current study, further research is warranted to examine the impact of stress appraisal and coping strategies on distress in this adolescent group.

Perceived social support, maternal attachment and adjustment.

In the current study, the impact of perceived social support and maternal attachment on adjustment was examined. Perceived social support has been identified in previous research as having a crucial role in coping with stress. This is known as the 'Stress Buffering Hypothesis' This hypothesis explains that social support has an indirect stress reducing effect acting as a buffer for the negative consequences of stressful events (Bal et al., 2003).

Bivariate analyses in the AMC study showed that perceived social support was correlated with maternal attachment. Previous research has suggested that adolescent attachment to their parents may have an impact on the quality of relationships they establish (Sarason, Pierce & Sarason, 1990). Gorrese and Ruggieri (2012) identified that adolescents who have more

secure relationships with their parents tend to also establish secure relationships with their friends. Mikulincer, Shaver and Pereg (2003) argued that people with more secure attachments know that their actions, self worth and self -efficacy will reduce their distress and allow them to overcome obstacles.

In multivariate analysis perceived social support and maternal attachment significantly accounted for 14% of the variance in life satisfaction. Higher social support and higher attachment was associated with higher life satisfaction. This finding is similar to previous research which reported a positive relationship between social support and well being (Cicognani, 2011; Chu, Saucier and Hafner, 2010; Ammar, Nauffal & Sbeity, 2013; Greenglass & Fiksenbaum, 2009; Gilman and Huebner, 2006). The relationship between attachment and life satisfaction has been less explored in the literature but for example Ma and Huebner (2008) concluded that the quality of attachment relationships significantly contributed to adolescent global satisfaction with life and they reported that parental attachment predicted more variance than did peer attachment.

In the current study perceived social support and maternal attachment did not account for variance in mood (positive affect, negative affect, depression or anxiety). This contrasts with previous research, for example, Matsuda, Tsuda, Kim and Deng (2014) in a study with University students found that perceived social support was associated with life satisfaction directly and indirectly, through positive affect and negative affect. Findings here also contradict those of Lewis and Darby (2003) who investigated the effects of parental functioning on adolescent adjustment during the acute phase of maternal breast cancer treatment and showed that adolescents who reported a poor relationship with both parents, had higher anxiety. Clemmens (2009) described that the quality of the mother-adolescent relationship can suffer when mothers are dealing with breast cancer and this can cause further adjustment problems for adolescents. Findings in the AMC study highlight the importance of including a variety of adjustment indices to fully assess relationships with social support.

Self-efficacy and adjustment

In this study, self-efficacy explained 6% of the variance in life satisfaction. In previous research, Vaezi and Fallah (2011) identified that a significant negative correlation between stress and self-efficacy, which lead to an improvement in people's well-being because people with higher self-efficacy reported lower levels of stress. In line with findings in the current study, Vecchio et al. (2007) found that self-efficacy was a significant predictor of life satisfaction in adolescents.

In the AMC Study, while self-efficacy explained 12% of the variance in positive affect and 6% in life satisfaction, it did not account for variance in negative affect, depression or anxiety. This underscores the importance of inclusion of both positive and negative indices when examining predictors of adolescent adjustment. Bandura (1997) described that mood can provide affective information to judge personal efficacy. Mood can also influence a person's judgement of their personal efficacy, as people use perceived affective reactions to recall information that forms their evaluations, they would make positive evaluations when they are feeling in a good mood and negative evaluations when they are in a bad mood. Evaluation judgements can be altered if the information provided by the affective state is also changed but this may only be applicable with positive mood and not negative, according to the findings of this study.

Previous research, however, has found a relationship between self-efficacy and negative moods. Muris (2002) examined the relationship between self-efficacy with symptoms of anxiety and depression in a general sample of adolescents. Their study identified that adolescents with low levels of self-efficacy had more anxiety and depression symptoms. Karademas (2006) reported that previous research has identified that low self-efficacy is related to more symptoms of anxiety and lower levels of subjective well being. Further research on adjustment to maternal cancer could usefully explore the role of self-efficacy on both positive and negative mood.

The moderating effects of research variables on adolescent adjustment.

The current study based on previous research findings and the multivariate analysis, examined if social support acts as a mediator of the relationship between perceived stress and adjustment (Hampel & Petermann, 2006; Moskowitz, 2011; Van Oost & Debourdeaudhuij, 2003) and of the relationship between coping and mood (Matsuda, et al, 2014). Evidence for mediation was not found.

The role of social support as a potential moderator of the relationship between perceived stress and adjustment (mood and life satisfaction) and of the relationship between coping and mood was examined. It was found that perceived social support moderates the relationship between perceived stress and positive affect in adolescents who have high levels of social support; not for those with medium or low levels of support. This moderating effect is also occurring at low levels of stress only but not at high or medium levels of stress. This finding suggests that perceived social support can have a boosting effect on adolescent positive affect at low levels of stress. This boosting effect could have a positive contribution to adolescent adjustment to a perceived stressor.

Previous research has also suggested the potential role of social support in adjustment to stressful and challenging situations. Khan and Hussain (2010) found significant positive relationships for positive psychological strengths with subjective well-being and with social support network (family, friends, and others). Specifically social support significantly moderated the relations of positive psychological strengths with subjective well-being in male and female adults.

This finding emphasizes the importance of ensuring that adolescents have supportive relationships in their lives at the time of maternal cancer because this can have a positive impact on their mood (positive affect). Previous research has suggested that adolescents experiencing parental cancer may be at a risk of isolation and lack support (Finch & Gibson, 2009) and this can increase their vulnerability to the negative effects of stress. The relevance of social support for adolescents dealing with a stressful situation such as maternal cancer cannot be underestimated. Further research however

is necessary to understand how adolescents with low levels of perceived social support and high levels of stress can be supported further as the moderation analysis suggests that the boosting effect of perceived social support is not working for them and they may be at a higher risk of adjustment difficulties than other adolescents. Manstead and Hewstone (1996), for example, have described that people with little social support have negative reactions, such as psychological distress and higher risk of illness, when they experience high levels of difficult life events versus the absence of these types of events. People with high levels of social support instead will not have such drastic changes in their reactions independent of the absence or presence of difficult life events.

Limitations

A limitation of this study is that it is cross-sectional in nature and this kind of data cannot determine causal relationships or changes over time in adolescent adjustment. Furthermore, the modest sample size and low response rate to what were significantly wide recruitment endeavours may influence generalization of the findings and statistical analyses may have lacked sufficient power to detect more significant relationships in the regression and mediation and moderation models. However, it provides useful preliminary data in this area as there has been limited examination of these relationships in previous research.

The majority of participants (82.5%) had maternal breast cancer diagnosis, while there were no significant differences in adjustment due to cancer type, the experience of cancer can be affected by illness specific variables and these may vary due to cancer type so the study may have not captured those differences.

This majority (77.5 %) of participants were female. Thus the experiences of male adolescents is not fully captured in this study, however it is important to note that there were no significant gender differences except in adolescent- mother attachment.

Conclusion

The current study is an important contribution to existing knowledge of adolescent adjustment to parental cancer. It provides useful insights into possible psychological predictors of adolescent adjustment to maternal cancer. Specifically, it identifies that those low in stress, high in positive coping, social support and self-efficacy report better affective status and life satisfaction. Perceived social support was found to moderate the relationship between perceived stress and positive affect. Taken overall, stress and coping were the strongest predictors in the model. All variables, with the exception of perceived stress, explained significant variance on positive indices of adjustment only.

While future research with larger samples is needed to confirm these findings they could inform the design of psychological interventions for adolescents, suggesting, for example, that strategies to minimise stress and enhance social support may be useful.

Study 2 (b): Design and Piloting of an Online Intervention to Enhance Adolescent Adjustment to Maternal Cancer (AMC Programme).

Introduction

This chapter describes the process of design and piloting of the AMC Programme. It also includes an overview of previous programmes available for children, young people and families facing cancer, focusing on their strengths and weaknesses. Suggestions from previous research on content of interventions targeted at adolescents who are experiencing stressful situations and parental cancer were used in the design the AMC Programme.

An a priori power analysis was carried out using the power analysis criteria of Cohen (1992), with a medium effect size (0.15) and a power of 0.8 with 5 predictors the analysis determined that the total sample size needed was 92 participants. Previous studies have suggested that a pilot study can be 10% of the projected for the larger study (Connelly, 2008; Treece & Treece, 1982), or between 10 and 30 participants (Issac & Michael, 1995; Hill 1998). The pilot study for the AMC programme included 14 participants.

Programmes and interventions for children and families.

Several programmes and interventions for children and families that experience cancer were identified. It is of note that none of the interventions identified were exclusively targeted at adolescents. According to Dehlin and Reg (2009) serious parental illness is one of the most stressful experiences for an adolescent so it is very important to provide support and programs adapted to adolescent experiences and needs. Lewis (1996) suggested that children and adolescents had limited resources, programs and services to assist them. Paying attention to children's' adjustment to parental disease can certainly enhance their quality of life and developmental prospect (Sieh et al., 2010, p. 395).

Family interventions were the 'We Can Weekend' (Walsh-Burke, 1992) The Kid's Connection (Paice, 1990) Kids Can Cope (Taylor-Brown, Acheson & Farber, 1993), For Kids Only (Bedway and Smith, 1996), Quest (Heiney & Lesesne, 1996), Enhancing Connections Programme (Lewis et

al., 2006) CLIMB®, Children's Lives Include Moments of Bravery (Semple & McCaughan, 2013) and Bear Essentials (Greening, 1992). Different interventions were also evaluated (Hoke, 1997; Stanko & Taub, 2002; Bugge et al., 2008; Davey et al., 2012; Kirsch, Brandt & Lewis, 2003).

Some of these programmes had educational components (Walsh-Burke, 1992; Paice, 1990; Bugge et al., 2008) which focused on facts about cancer, cancer treatments, anatomy, exercise and relaxation skills, communication and family dynamics. Bedway and Smith (1996) also approached fear of the unknown and death, developing coping skills (Heiney & Lesesne, 1996). Heiney and Lesesne (1996) took participants on guided tours where they learnt about radiation therapy, outpatient chemotherapy, the laboratory and the patient rooms.

Other programmes were more focused on cognitive theory and were aimed at enhancing maternal and child functioning (Lewis et al., 2006; Kirsch, Brandt & Lewis, 2003). Bugge, Helseth and Darbyshire (2008) aimed to prevent psychosocial problems in children and to promote coping. One programme was targeted at African American families only and was based on African American values of faith, spirituality, resilience and group support from the African American community. Programmes also had artistic components such as art and music (Walsh-Burke, 1992), and drawing emotions (Paice, 1990).

Previous research suggested that young people should be included in ongoing family assessment and interventions, they should be provided with age appropriate information and communication (Turner & McGrath, 1998; Sich et al., 2010, Turner, 2004; Hymovich, 1995). Costas- Muñiz (2012) and Call (1990) suggested that adolescents who are coping with parental cancer would benefit from interventions that helped them acquire more problem focused strategies and coping skills acceptance and to reduce the use of maladaptive coping styles.

Different professionals were involved in delivering these interventions including nurse, school teacher, physician, social worker, dietician, chaplain, physical therapist, cancer society staff, musician, art therapist, lifeguard, child activity facilitator (Walsh-Burke, 1992), social worker, oncology nurse (Taylor-Brown et al., 1993) nurse, physician,

pharmacist, social worker, clergy, nutritionist, psychologist, physical therapist, art therapist, occupational therapist and the support of cancer survivors (Bedway & Smith, 1996).

Programmes were successful at improving family communication, providing a positive outlook towards the illness and they helped families identify sources of support (Walsh-Burke, 1992, Davey et al., 2012). Bringing children together in similar circumstances in a safe environment was highly therapeutic as participants found a sense of belonging and 'normality' in their feelings (Semple & McCaughan, 2013; Stanko & Taub, 2002; Taylor-Brown et al., 1993; Bedway & Smith, 1996). They also shared ways of coping in difficult situations. Heiney and Lesesne (1996) described that participants were more informed and open toward the diagnosis and treatment of cancer. Other achievements included emotional management, improved listening skills and improvement in the mother child relationship (Lewis et al., 2006).

More successful programmes were based on participant needs, included parent encouragement and were supported by the hospital and medical communities (Paice, 1990). Romer et al. (2007) suggested that child centred interventions should not be offered too soon after parental diagnosis, and posited that identifying an appropriate moment is crucial for the success of the intervention. Stanko and Taub (2002) reported that some parents declined participation because they wanted their children to have a 'normal life'. They also had concerns about the child's ability to keep confidentiality.

Online interventions have several advantages Hoerger (2010) suggested that online studies have advantages over other research models as in research in psychology labs can be influenced by demand characteristics, politeness, obedience to authority and conformity but in online research these are norms are not an issue and this was a way to prevent possible dropout. Other advantages are perceived privacy and proximity from the main researcher which may motivate participants to be involved voluntarily.

Giesbers et al. (2010) investigated the use and content of web-based peer support on adolescents facing parental cancer. The study identified that children were using the internet as an outlet for their feelings and emotions.

Websites could be suggested as “woman spaces” because most participants are women and the type of communication involves warm greeting and emotional support. It is not known if this is because boys are going through a different process or if they struggle to communicate their feelings or share these with girls (Giesbers et al., 2010).

Different research studies on adolescents’ experiences of parental cancer and adolescent social support have provided recommendations for the design of interventions targeted at this population. These are summarized in Table 23.

Social support interventions.

Social support programmes for adolescents were identified but these were not specifically targeted at adolescents adjusting to parental cancer, Barth and Schinke (1984) carried out a group training program designed to enhance adolescent mothers’ skills to create and sustain high levels of social support. They had an educational component including interpersonal skills to resolve conflicts, skills for assertion, requesting help, negotiating difficult situations, and providing examples using role play practice and providing feedback. Cognitive skills included self- talk, interpersonal problem solving and staying calm during stressful exchanges. This intervention improved adolescents’ social support and mitigated their stress.

Cutrona and Cole (2000) identified mechanisms and examples of techniques to increase support in a person’s natural network: (i) increase understanding by providing information on the specific disease or problem faced by the person under stress (ii) cognitive modification techniques are used to change dysfunctional attitudes which may be blocking the possibility of a person receiving and providing support (iii) modelling of behavioural skills associated with giving and receiving emotional and instrumental social support (iv) increase communication by providing opportunities to network members to meet in a group and facilitate open communication and problem solving between them (v) encourage network members to commit to specific support responsibilities and avoid diffusion of responsibilities (vi) Strengthen bonds with positive network members (vii) weaken bonds with destructive network members (viii) provide

opportunities for interaction and communication between network members which may have been kept apart by rigid boundaries or alliances (ix) members of the network who support other members of the network may benefit from emotionally supportive counselling.

Mitchell, Billings and Moos (1982) suggested that prevention programs from a social support perspective should (i) consider the different mechanisms by which social support has effects (ii) include the need for specificity in preventive interventions (iii) examine the relationships between stress, support and functioning within the broad social context to identify the environmental circumstances in which support is likely to be provided. Mitchell et al. (1982) suggested that practitioners should include strategies to promote competence in the development and maintenance of social relationships for children and adults. The ability to maintain an ongoing support network is likely to influence availability of support during subsequent stressful situations.

Hogan, Linden and Najarian (2002) carried out a narrative review of one hundred studies on social support interventions between 1970 and 2000. Participants were facing a variety of issues including cancer, loneliness, weight loss, substance abuse, lack of parenting skills, surgery and birth preparation. Different age groups; that is middle aged adults, elderly, small children, adolescents and parents were included. Seven studies were social support interventions for cancer patients. They suggested that the way in which social support is conceptualized and operationalized in an intervention may determine its success. These interventions, however, had different delivery formats and populations. Support provided by friends, family and peers was beneficial. Social support skills are useful as people may lack the skills to foster relationships that could provide them with the support they require; particularly for people with personality disorders. Hogan et al. (2002) also found that interventions failed to include measures of social support or used ones which were not validated, this lead the researchers to conclude that it is still unclear whether support interventions are effective modes of treatment for a variety of problems people face, including a cancer diagnosis.

Adolescents in the qualitative phase of the AMC Study provided some suggestions for the content of the AMC Programme that they would find helpful. These were: including factual and reliable information about cancer, survival statistics, emotional management and expected or normal emotional reactions.

Table 23 *Summary of Recommendations for Programmes for Adolescents Facing Parental Cancer (Part I)*

Source	Objective	Benefits from the interventions	Method
Moskowitz (2011)	Improve positive affect.	Improved response to stress and psychological adjustment to illness. Better school performance, attention and retention.	Acts of kindness Setting goals Self affirmation Focus on personal strengths, values and qualities. Mediation.
Le Croy (1982) Cutrona and Cole (2000) Cohen et al.	Improve social skills.	Improved friendships, communication and their sense of competence. Improve perceived support and interpersonal relationships Increased psychological adjustment in children and adolescents.	
Hymovich (1995)	Provide age appropriate	Developed the meaning	Inform parents of children's coping

	information.	of illness.	mechanisms, encourage the expression of guilt, emphasize open and honest communication and contact, facilitate contact with other young people in the same situation, provide opportunities for expression and train schools on how to provide support for children and their parents.
Turner (2004)	Allow children to express themselves and their emotions.	Decreased distress and uncertainty.	
Call (1990)	Develop coping skills in children.	Minimized emotional difficulties. Provided a sense of order and normalization of emotions. Helped to build existing strengths, recognize their own capacity to cope with crisis and feel in	Provide a safe environment to feel that they can express their feelings and not be judged. Praise children for being part of the group, expressing their feelings, being courageous and share their feelings.

			control of their lives.	
Costas- (2012)	Muñiz	Acquire problem focused strategies, acceptance and reduce maladaptive coping styles.		
Turner McGrath (1998)	and	Increase children understanding of cancer		Age appropriate resources. Inform parents of range of emotional concerns in their children.
Giesbers, Verdonck-de Leeuw, Zuuren, Kleverlaan, van der Linden (2010)	van			Web based peer support group- outlet for feelings and emotions.
Bradburry et al. (2012)			Helped to avoid potential misinformation or distress that could be transmitted to their daughters	Educational interventions for mothers.

Heiney et al. (1997)	Educate parents	Allowed parents to be more responsive to children's stress, anxiety and adjustment difficulties.	Psychosocial intervention
Northouse (1984)	Assess needs of family members, provide support for families, provide information and assistance for families. Encourage asking for help.	Improved family coping.	Approach barriers to medical care. Growth oriented work. Address long term problems in family relationships.
Sales (1991)			
Sherman and Simonton (2001)	Enhance communication and emotional expression. Promote a sense of hope, empowerment, efficacy, family successes and highlight individual and collective strengths. Enhance family cohesion.	Helped to avoid isolation and normalize disruptive effects of cancer in the family.	All family members should be encouraged to express how the illness affects them in different contexts with: circular and reflexive questions; enactments, journals, drawings (young family members), family meetings and encouragement meetings. Redistribute responsibilities and mobilize assistance and external social supports. Provide age appropriate information

Ensure family remains healthy through the cancer experience.

and include young members of the family in the patient's recovery process.

Balance children's contributions and buffer them from excessive responsibilities. Make families aware of the meaning of cancer.

AMC Programme Design

The AMC Programme was designed based on information obtained from the qualitative interviews in Phase I of the study and it was also based on recommendations from previous published intervention programmes. The programme consists of eight one hour sessions available online on the Survey Monkey Platform (Appendix H). Each session had a specific objective and corresponding activities that adolescents completed online. Adolescents were asked to provide feedback on each session at the end to determine if they liked the session and saw perceived benefits from it.

Table 24 *Summary of AMC Programme Sessions*

Session	Objective	Activities
1	Educational session. Provide information on cancer, treatment and side effects. Encourage mutual help and support.	Cancer experience of adolescents worldwide.
2	Education session: social support definition, limitations and ways to improve perceived social support.	My circle of loved ones. Relationships.
3	Encourage self knowledge, identification of strengths and talents. Promote social support: friendship.	My lovely body. Daily act of kindness. My friendship skills. Self affirmations (audio)
4	Emotion management: self control techniques, relaxation, and meditation. Encourage communication: listening skills.	Guided meditation: 'The safe place'. Stress management for teenagers. Guiding star meditation. Inner peace affirmations. Self affirmations. Rate your own listening.
5	Communication skills: assertive communication and behaviour. Anger management.	Identify personal types of behaviour. Examples of assertive and non assertive dialogues.
6	Encourage open and honest communication about cancer.	Gifts ideas for mum.

	Family support: help ill mother and other family members.	
7	Encourage reciprocal support: asking and receiving help.	Laughter log. Making others smile and feel happy.
8	Benefits and limitations of participation in the programme.	The Story of Ralph. My journey.

AMC Programme Pilot Study

This pilot study was carried out in May 2013 with sixteen participants ($M=16.6$, $SD=1.3$); of these, 75% (12) were female. They were recruited through the Sona Systems of the School of Psychology at NUI Galway and Youth Clubs and groups in *County Wicklow (East) and the Youth Cafe in Galway City Centre (West)*. All participants in this pilot study received an information session personally delivered by the researcher. Parental and adolescent consent was a requisite for participation. Each participant was randomly assigned to one of the eight sessions on the AMC Programme.

Adolescents were asked to analyze the images, format and overall content of specific sessions included in the proposed 'AMC Programme' to see if these were adequate for adolescents of their own age. Data was analyzed using SPSS version 20. The analysis carried out on the data consisted of frequency analysis: mean and range.

Results.

Table 25 includes a summary of how many times each session was completed and the mean time it took to complete it, to determine if these components could be carried out in a session of maximum one hour.

Table 25 *Length of Time Needed to Complete Programme Sessions*

Session	Times completed	Mean time (minutes)
1	1	30
2	1	20
3	2	10
4	3	162
5	2	45
6	3	70

Participants completed the majority of sessions within one hour, except session four. Participants took between 10 and 270 minutes, for this reason, the instructions for session four were modified. Adolescents were

instructed to choose the exercises that suited them from a range of options:
Progressive relaxation, passive relaxation, mediation and imagery.

Adolescents were asked to judge the vocabulary, format and images using a five point Likert Scale from 'Not at all appropriate'(1) to 'Completely appropriate'(5). Vocabulary and format were judged positively ranging from 'appropriate' to 'completely appropriate'. Images on session three and four were rated slightly appropriate but the rest were between 'appropriate' to 'completely appropriate' (Table 26).

Participants reported that vocabulary and format of the sessions were appropriate overall. They made suggestions to change images. Both sessions three and four underwent image changes.

Table 26 *Adequacy of Vocabulary, Format and Images Included in the Sessions*

Session	Vocabulary (%)						Format (%)						Images (%)					
	1	2	3	4	5	6	1	2	3	4	5	6	1	2	3	4	5	6
Slightly appropriate (2)															50	33.3		
Appropriate (3)		100	100	33.3	50			100	100	33.3	50				50		50	
Very appropriate (4)				33.3						33.3						66.6		
Completely appropriate (5)	100			33.3	50	100	100			33.3	50	100	100	100			50	100
NA																		

Participants were asked to suggest which activities they would keep and which they would change in the sessions. Table 27 shows a summary of activities that adolescents suggested modifying.

Table 27 *Activities per Session to Change*

Activities per session	Change
Safety map (2)	3
Building a friend (2)	2
While we have been together (2)	1
Seven days (2)	2
Campaign craze/ Me on TV (3)	1
Body beautiful (3)	1
Same letter, different names/Name and adjective (3)	1
The seaweed meditation (4)	1
Still quiet ship (4)	1
Sounds around (4)	1
Role play script (5)	1
I am angry (5)	1
Love line	1

Safety map, Building a friend and Seven days were the sessions that received most suggestions to change.

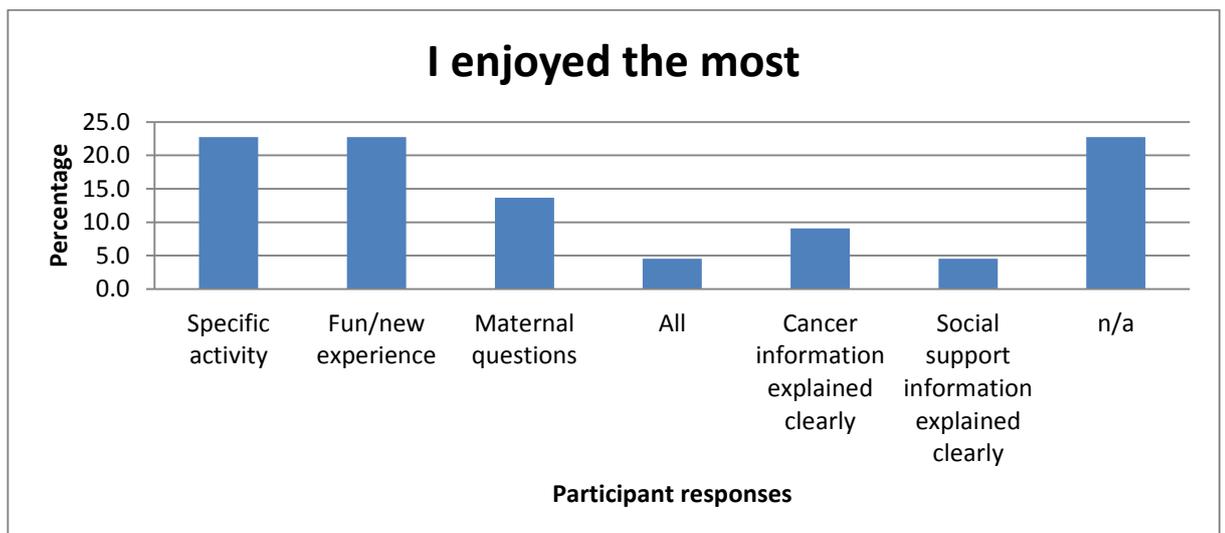


Figure 14. Participant responses to what they enjoyed the most.

The majority of participants enjoyed a specific activity in their session and described the experience as new and fun.

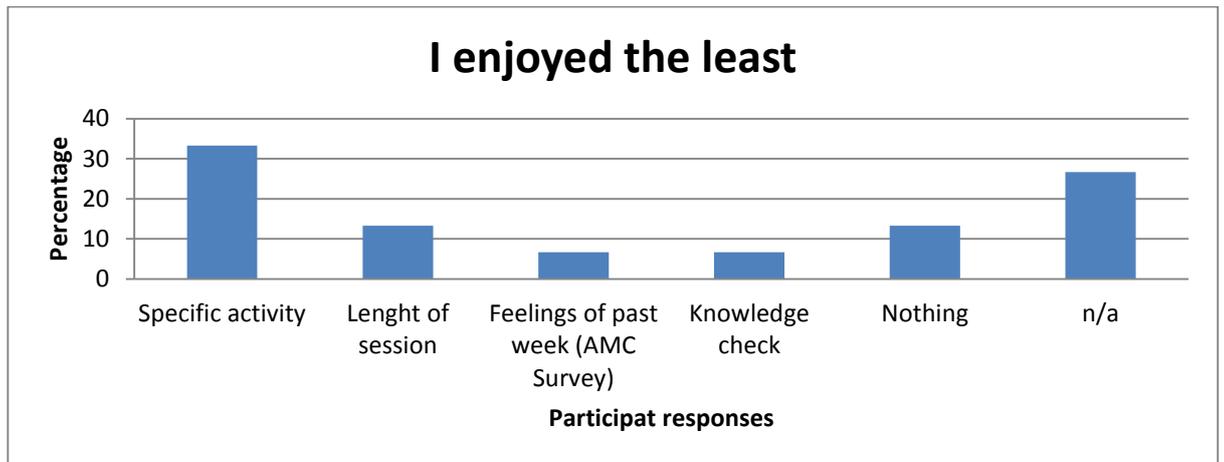


Figure 15. Participant responses to what they enjoyed the least.

Specific activities that received more votes for change in the pilot study were eliminated (Safety map, Building a friend and Seven days). Additionally 'Love line' was eliminated as participants suggested this activity could have caused further distress to the ill mother. One participant mentioned that 'Same letter, different name' activity was often done in school so this was also eliminated. One participant mentioned the 'Knowledge check' at the beginning of session one and two felt like a test. The format and wording of the knowledge check was revised.

Limitations.

Overall, most participants in the AMC Pilot Study were females yet the intervention was designed for males and females.

Some participants misunderstood the instructions and completed information which did not belong to their own session. Information could only be used when answers corresponded to the session assigned to a specific participant. Some participants skipped activities in their session and did not mark if these should be kept or changed. Some participants also did not provide any kind of feedback on what they enjoyed the most and the least.

The balance of session distribution was not adequate as some participants did not complete the session they were assigned. These were

distributed in a logical order which was only functional if all 18 time slots available for the study had been completed, Hence this is why, for example, session 1 has one participant and session three had three, however, each session and the feedback provided was carefully analyzed.

The AMC Programme

Recruitment.

Ulrich et al. (2010) stated that recruitment and retention of participants in oncology clinical trials was a problem and this leads to longer and more expensive recruitment periods, up to 80% of randomized clinical trials experience recruitment and retention difficulties. Some of the reasons identified for this were time commitment and people's difficulties understanding research terms such as randomization and placebo. Wang (1992, as cited in Cantrell, 2012) suggested that potential participants from vulnerable populations, for example, those experiencing illness, may feel the research protocol and all the research requirements are too inconvenient or burdensome due to the illness restraints they are already experiencing. Recruiting adolescents that were experiencing maternal cancer proved very challenging and thus the methodology for recruitment was modified over the course of the study.

Community recruitment.

A website was designed for the original version of the study (AMBC) for adolescents of mothers with breast cancer. The website included a welcome message from the research team, the purpose of the study, phases of the study, benefits of taking part, risks of taking part, participant protection strategies. Potential participants could download consent forms and information sheets if they wanted additional information (Appendix A). The website also included a video message from the principal researcher.

The first recruitment phase began in July 2013. This phase consisted of informing people in the community about the study. A media piece was published in several local and national newspapers: Galway Independent, Galway Advertiser, Galway City Tribune, The Irish Times, The Irish Independent, SIN Newspaper (NUI Galway) Liffey Champion (Leixlip),

Irish Health.com, Forum and Cancer Professional. A total of 37 student newspapers in Ireland and the UK were contacted and asked to publish the media piece to inform students about the study. One of these published the piece. The researcher and lead supervisor also took part in interviews on local radio stations: Galway Bay FM, Mayo Radio and Newstalk Radio Ireland. One Irish breast cancer blog sent information by email to all its members; however, the information about the study was not published on the blog.

Cancer centres and support groups.

Cancer support groups in the Republic of Ireland and in the United Kingdom were informed about the study. A total of 75 received emails or letters by post. Participation was declined because affiliates did not fit the recruitment criteria and research involvement was not part of their policies. Eight centres and groups were sent recruitment posters and brochures.

Breast cancer units.

Breast Check Southern Unit (Cork) expressed interest in the study. The principal researcher visited the unit and met with the breast cancer. No participants were recruited. Breast Check Western Unit (Galway) was approached by the researcher and lead supervisor. A meeting was conducted with the Director of the unit to provide further details about the study. Recruitment materials were submitted to the National Executive Board but only partial support was granted. Breast care Nurses in the unit provided envelopes to potential participants but no participants were recruited.

Staff at the The Symptomatic Breast Centre, University Hospital Galway were approached by the researcher and lead supervisor and were provided with information about the study. The study was given very positive support. Ethical Approval was obtained from the University Hospital Clinical Research Ethics Committee. Potential participants were sent the recruitment letter by post, followed by a personal call from the researcher. Those who expressed further interest were sent information sheets and consent forms. A total of 39 participants were contacted, 22 declined participation, seven took part and 10 did not return the consent forms.

Women provided reasons for non participation: Adolescent children were coping well and did not need to take part in the study, mothers did not want their adolescent children to remember the experience, adolescents wanted to ‘forget’ about it, life was back to normal, adolescents had exams either the Junior Certificate or Leaving Cert.

While staff approached at St Luke’s Hospital Dublin showed interest in the study and Ethical Approval was obtained in January 2015, no participants were recruited through this institution. University Hospital Limerick declined participation due to ethical considerations but the research team was not given an opportunity to clarify the issues.

Other institutions.

Several other institutions were contacted: Carers Associations (4), Secondary Teachers Associations (4), Nurses and Midwives Organisations (12), General Practitioners Associations (3), General Practitioners in Galway (111), Guidance Counsellors (1), Social Workers Associations (4), Principal and Deputy Principal Associations (1), Boy Scout and Girl Scouts Associations, local Lions Clubs. Two of these offered to include information about the study in their periodicals.

A total of 459 emails were sent to secondary schools in the Republic of Ireland and 90 in Northern Ireland. Letters were sent to all schools in Galway (42) in December 2013, followed up with a personal phone call from the principal researcher. Overall the response from schools was poor. Two schools had two teachers personally interested in the study. Some schools did not recall receiving the letter or couldn’t find it. Other schools were to call back for information but did not do so. Two schools declined participation as they were already involved in other research studies and wanted to avoid student burden.

Student Services and Chaplaincies (147) were contacted in Universities in the Republic of Ireland and United Kingdom. Of these, nine responded positively and posters and brochures were sent respectively. A total of 23 charities and therapeutic services, both private and public, were contacted. Two of these responded positively and agreed to help with participant recruitment.

Foroige, a youth organisation, was asked to inform adolescents nationwide about the study. Information was sent through the portal which is the staff intranet. Information was also posted on Facebook (30 thousand followers), however, only one adolescent from this organisation took part in the study.

All registered undergraduate students at NUI Galway, as they were in the target age range (14 to 19 years), were invited to take part in the study in 2014, a total of five students responded to the email and four took part in the research. In 2015 all registered undergraduate students were emailed again, a total of eleven participants were interested in taking part. Two participants completed consent forms and then declined participation, four completed all phases of the study and others completed only some phases of the study. Psychology students were offered student credits for research participation through the Sona System Platform.

Recruitment for different types of cancer.

In an effort to improve participant recruitment it was subsequently decided to include adolescents with mothers with any type cancer. The study's name was changed to 'AMC- Adolescent Adjustment to Maternal Cancer'. Session 1 and Session 6 of the Programme were modified to include general information about cancer.

Community approach.

A community approach was once again used to promote the new version of the study. A media piece on the research and the workshops was also published in local newspapers. The principal researcher was involved again in radio interviews to promote the workshops and to promote the new version of the research study.

The principal researcher also designed a workshop for parents on communicating with children about cancer. The objective was to promote the research nationwide and establish face to face meetings with cancer centres to meet potential participants for the research. These workshops were supported by the Irish Cancer Society and this allowed an alliance with the cancer centres that were involved with the Irish Cancer Society, nine parent workshops were delivered nationwide in the following cancer centres:

LARCC Cancer Support Centre

Mullingar, Westmeath

Recovery Haven Cancer Support	Tralee, Kerry
The Gary Kelly Centre	Drogheda, Louth
Arc Cancer Support	Cork
The Cuisle Centre	Portlaoise, Laois
The Solas Centre	Waterford
Arc Cancer Support Centre	Eccles Street, Dublin
East Galway Cancer Support	Ballinasloe, Galway
Eist Cancer Support Centre	Carlow

Two different workshops were delivered. The first workshop was entitled: '*Talking with children about cancer*'. This was a two hour workshops focusing on the effect of a cancer diagnosis on children and young people. The second workshop was entitled: '*Cancer in the family, how will we cope?*'. This workshop was focused on the adjustment of adolescent children to a cancer diagnosis in the family.

The principal researcher also became a volunteer at Cancer Care West and was given permission to inform clients about the study. A total of four women with adolescents in the age range were contacted. Two agreed but in the case of one mother her adolescent declined participation.

Recruitment materials.

Recruitment materials were also modified. A new poster was designed to emphasize a family approach and to highlight that the programme was a life skills programme that would help adolescents in any difficult or stressful situation in their lives, including and beyond the experience of maternal cancer. (Appendix A).

International recruitment.

The English version of the AMC was also offered in other English speaking countries including New Zealand, Australia, United States.

In Australia a total of 15 organisations were contacted, however only one accepted participation. The Breast Cancer Organisation of Australia asked the principal researcher to complete an application of collaboration but permission was not obtained as there were doubts that the intervention would be available in the short term. The principal researcher explained that the intervention was available but no additional responses were obtained. No response was received from institutions in New Zealand (5) or the Isle of

Man (4). A total of 37 cancer centres and blogs were contacted in the United States.

The AMC Study was translated to Spanish with the objective of improving participant recruitment. Cancer centres and organisations of Spanish speaking countries were contacted including Costa Rica (14), Panama (3), Spain (2), Puerto Rico (1), Mexico (5), Chile (3), El Salvador (2), Argentina (1), Bolivia (1), Uruguay (2) and Regional organisations in Latin America (1). Of these, there were six participants in Costa Rica, zero in Panama, and two in Spain. All other countries did not respond to the emails sent.

Method

Once adolescents agreed to participate and completed consent forms online, they were asked to complete a pre intervention survey online. The scales used were the Social Network Questionnaire and the Perceived Social Support Questionnaire (Cutrona & Dolan, 2002), Adolescent Coping Orientation for Problem Experiences (A-COPE) (Patterson and Mc Cubbin, 1983), Inventory of Parent and Peer Attachment IPPA (Armsden & Greenberg, 1987), General Self-efficacy Scale (Schwarzer & Jerusalem, 1995), Depression Anxiety and Stress Scales (DASS-21) (Lovibond and Lovibond, 1995), Perceived Stress Scale (Cohen, Kamarck & Mermelstein, 1983), Feelings and Emotions (PANAS-C) (Laurent et al., 1999) and the Satisfaction with Life Scale (Diener, 1985). A description of these measures is included in chapter 4, Study 2(a).

Results

Fourteen adolescents completed the entire programme that is the pre-test, post-test and two month follow up measures. Participants ranged from 14 to 20 years of age.

Table 28: *Participant Demographic Characteristics*

Variable	<i>N</i>	%
Gender		
Male	3	21.4
Female	11	78.6
Cancer type		
Breast	9	64.3
Colon	3	21.4
Gastrointestinal	2	14.3
Country		
Ireland	11	78.6
International	3	21.4
Time since diagnosis		
0-12 months	7	50
13 – 25 months	6	42.9
26-38 months	1	7.1

Mann-Whitney U Test (Table 29) were carried out to identify if there were significant differences between adolescents ($N=26$) who completed the pre-test survey only and those who engaged in all phases of the study ($N=14$). The test identified significant differences in negative affect between the pre-test group ($Md=51.9$, $n=26$) and the pilot group ($Md=45.3$, $n=14$), $U=107$, $z=-2.13$, $p=.033$, $r=-0.3$. Adolescents who completed all phases of the study had significantly lower levels of negative affect than peers who did not.

Table 29 *Mann-Whitney U Test Result for the Baseline and the Pilot Group*

Variable	Z	p
Perceived stress	-.213	.83
Coping	-.227	.82
Perceived social support	-1.137	.26
Social network	-.589	.56
Maternal attachment	-.043	.97
Self- efficacy	-1.04	.30
Satisfaction with life	-.398	.69
Positive affect	-1.149	.25
Negative affect	-2.128	.03
Depression	-.983	.33
Anxiety	-.70	.48

Quantitative data analysis was carried out with SPSS Version 20. Descriptive statistics (mean and standard deviations) were calculated for participant scores on all scales. Non parametric statistics, specifically Friedman Test was used as the same participants were measured at three different points in time (Pallant, 2013).

Programme goals.

Adolescents were asked at the beginning of the programme to create a goal(s) for taking part in the programme, although some included goals related to their lives in general.

Table 30 *Programme Participation Goals*

Goal	N	%
Academic related goals	2	7.1
Increase cancer knowledge, contribute to research	18	64.8
Improve communication, understanding and coping related to cancer	3	10.8
Self improvement (health, communication skills)	2	7.2
Come to terms with the experience of maternal cancer	2	7.2
Improve relationship with mother	1	3.6
Total	28	100

The majority of adolescents (64.8%) wanted to increase their knowledge of cancer and contribute to research.

Evaluation of adolescent knowledge.

Prior to commencing a session, participants were asked questions about the topic of the session to determine their existing level of knowledge and understanding. These questions were focused on cancer, social support and types of behaviour. This helped determine if the information provided in the session was adequate for adolescent information needs and possible questions.

Table 31 *What is Cancer?*

What is cancer?	<i>N</i>	%
Cancer in the breast	4	14.3
Lump or tumour in breast	7	25
Damaged cells	2	7.1
Disease in part of the body	8	28.6
Change in cell mitosis	1	3.6
Abnormal or uncontrolled cell growth	5	17.9
Cells that die	1	3.6

The majority of adolescents (28.6%) defined cancer as a disease in a part of the body and 14.3% described it as cancer in the breast, as the research was initially focused only on breast cancer. The majority of adolescents did not know about the stages of cancer (42.9%) and 25% said there are four stages, which was the correct answer. All adolescents were able to describe the treatment their mother underwent; the majority reported chemotherapy and radiotherapy as the most common type.

Table 32 *What Questions do you Have About Cancer?*

What questions do you have about cancer?	<i>N</i>	%
None	9	32.1
Probability of recurrence	1	3.6
What are the causes	11	39.3
Number of people affected	2	7.1
Treatment (length)	1	3.6
Probability of having cancer themselves	1	3.6
Yes but not specified	1	3.6
Origin, prevention and treatment	2	7.1

The majority of adolescents (39.3%) wanted to know about the causes of cancer and 32.1% said they had no questions about cancer.

Table 33 *What is Social Support?*

What is social support?	<i>N</i>	%
Help others cope with problems/ difficulties	5	23.8
People helping/ supporting you	4	19
Caring for others	1	4.8
Helping, talking, listening and understanding	4	19
External supports (friends, neighbours, family, support groups)	4	19
Support from social network	2	9.5
Support from other in similar situations	1	4.8

The majority of adolescents (23.8%) defined social support as helping others cope with their problems and difficulties. Nineteen percent of adolescents described that social support types include friends, Therapist, Support groups, Teachers and Guidance Counsellor. Another 19% mentioned they knew three types but did not specify them.

Table 34 *Do you Have any Questions about Social Support?*

Do you have any questions about social support?	<i>N</i>	%
Yes	2	9.5
No	14	66.7
Possible methods	1	4.8
What is it?	4	19

The majority of adolescents (66.7%) did not have any questions about social support.

Programme Feedback

Adolescents were asked to complete five feedback questions at the end of every session as an evaluation. These were: Did you learn something about yourself?, Did you learn something new about other people?, How useful did you find this session?, What would you change? The analysis of individual sessions (Table 35) showed that 75% or more of adolescents said that they learnt something about themselves in the sessions and 66.7% or more reported that they learnt something about other people. The majority of adolescents found the sessions useful, very useful or extremely useful and 44% or more thought that the sessions were not at all difficult. Adolescents suggested that sessions should include something on the emotions of adolescents in similar situations. Some adolescents (less than 17%) provided suggestions regarding format and specific content such as less reading, more answer options, font sizes. The majority (64 % or more) did not think that any changes to the sessions were needed.

Session eight consisted of an overall evaluation of adolescents experiences in the programme. They completed open ended questions to evaluate their experience, and if they achieved the goals they established at the beginning of the programme. These questions were: The first day I, I leaned this about me, It was hard when, The happiest moment was, I felt good when, I felt proud when, The last day I, I achieved this goal.

This evaluation was very limited as adolescents interpreted the objective of this feedback as focused on their general experience of maternal cancer and not focused on the programme itself. The instructions of this

section need to be revised and improved for future applications of the programme.

Adolescents (31.3%) expressed that they had no expectations about the programme on the first day but a similar percentage (37.5%) interpreted the question incorrectly and 37.5% of adolescents expressed that through the programme they learnt about themselves and also about their coping skills and the supports available (31.3%).

Regarding the hardest moment, adolescents said they found a specific activity hard (6%), struggled to apply all the new knowledge (12.5%), turn feelings into words (6%) or nothing (6%). The remainder (69.5%) misinterpreted the question.

The happiest moment for adolescents in the programme was identifying social supports (6%), make others laugh (19%), achieving things they did not think they could do (12.5%), identify personal strengths and qualities (6%) and have a positive outlook (12.5%). Some adolescents (44%) misunderstood the question.

Adolescents (18.5%) felt good when they completed the programme, as they thought this would allow them to help other adolescents in similar situations. Adolescents liked the opportunity that the programme provided for reflection and meditation (6%), the acknowledgement of positive aspects of their lives (6%), the approval they had for their emotions (6%), the appreciation of support provided by others (6%), their acquired skills to ask for help (12.5%) and their additional knowledge about cancer (6%).

Adolescents felt proud of specific abilities they identified during their involvement in the programme such as good listening skills (6%), ability to talk about cancer (6%) and individual qualities (31%). The remainder (43%) misinterpreted or did not respond to the question.

Regarding the feedback on the last day on the programme, adolescents were able to set goals for their future (6%), valued the lessons learnt and looked forward to the future (12.5%), shared their experience of taking part in the programme with another member of their family (12.5%), adolescents felt able to ask for help (6%) and described that the increased knowledge about cancer allowed them to feel less nervous (6%). Some adolescents (57%) misunderstood the question.

Adolescents expressed that by taking part in the programme they managed to help others and improve their listening skills (12.5%), they could talk about the cancer experience with other people (18.5%), learned to relax and have a positive outlook (18.5%), increased their self understanding (12.5%) and built closer relationships (6%). Some adolescents (32%) misunderstood the question.

Table 35 *Participant Feedback on Programme Sessions 1 to 7*

<i>Session</i>		<i>1</i>	<i>2</i>	<i>3</i>	<i>4</i>	<i>5</i>	<i>6</i>	<i>7</i>
		<i>(%)</i>						
Learn something about yourself?	Yes	75	95.2	95	94.4	100	88.2	93.8
	No	25	4.8	5	5.6		11.8	6.3
Learn something new about other people?	Yes	67.9	66.7	75	66.7	88.9	76.5	81.3
	No	32.1	33.3	25	27.8	11.1	23.5	18.8
How useful did you find this session?	Not at all	3.6						
	A little	10.7	23.8	25		5.6	5.9	6.3
	Useful	50	23.8	25	38.9	22.2	29.4	31.3
	Very useful	17.9	23.8	35	33.3	33.3	23.5	31.3
	Extremely useful	17.9	28.6	15	27.8	38.9	41.2	31.3
How difficult did you find this session?	Not at all	50	57.1	65	44.4	55.6	52.9	56.3
	A little	39.3	38.1	20	44.4	38.8	29.4	31.3
	Difficult	3.6	4.8	10	11.1	5.6	17.6	12.5
	Very difficult	7.1		5				
	Extremely difficult							
What would you change?	Location of questions	3.6						
	Include emotions of adolescents in similar situations	10.7	4.8					
	Less reading, information, activities	10.7	19	15	16.6			6.3

and questions.

More facts, more information on cancer and its effects	3.6			5.6			6.3
More answer options/ activities	3.6				5.6	11.8	
Negative approach to the session	3.6						
Format (include worksheets in programme, not separately, font size)		4.8	10		5.6		6.3
Nothing	64.3	71.4	75	77.8	88.8	88.3	81.1

Table 36 *Feedback Session 8*

<i>Open ended question</i>	<i>Adolescent responses</i>	<i>N</i>	<i>%</i>
The first day I...	No expectations	5	31.3
	Change a negative experience into positive	1	6.3
	Description of their reaction to maternal diagnosis	6	37.5
	Nervous hesitant to take part	2	12.5
	Miscellaneous	2	12.5
I leaned this about me...	Maturity and knowledge	1	6.3
	Coping skills and supports available	5	31.3
	Self knowledge	6	37.5
	Permission to ask for help talk and feel bad.	3	18.8
	Realization of maternal role in their lives	1	6.3
It was hard when...	Adolescents struggled with a specific exercise in the programme	1	6.3
	Maternal diagnosis	2	12.5
	Apply new knowledge	2	12.5
	Turning feelings into words	1	6.3
	Maternal emotions and difficulties	7	44.1
	Family difficulties	1	6.3
	Assume more responsibilities due to treatment	1	6.3
	Nothing	1	6.3
The happiest moment	Feel happy, make other laugh, have positive outlook	5	31.3

was...	Awareness of social supports available	1	6.3
	Completion of maternal treatment	7	44.1
	Personal achievements and qualities	3	18.8
I felt good when...	Completed the programme	3	18.8
	Maternal well being	4	25
	Mediation reflection and positivity	2	12.5
	Cancer was over	2	12.5
	Help and support provided to them	3	18.8
	Approval of feelings	1	6.3
	More knowledge about cancer	1	6.3
I felt proud when...	Academic related achievements	1	6.3
	Positive personal qualities/ talents	7	44.1
	Ability to talk about cancer and confront emotions	2	12.5
	Maternal achievements	4	25
	NA	2	12.5
The last day I ...	Appreciate lessons learnt	2	12.5
	Set out simple goals	1	6.3
	Glad, relief, happy, good news, normal, not nervous	8	50.4
	Share experiences asked others for help	3	18.8
	NA	2	12.5

I achieved this goal...	Not yet	1	6.3
	Help and talk to others, closer relationships	6	37.5
	New skills like relax, focus on the positive, bravery, self understanding	5	31.3
	Academic achievements	3	18.8
	NA	1	6.3

Adjustment over time.

The change in scores across time for all study variables was examined. Sample size is very small so results need to be treated with caution.

Table 37 Means and Standard Deviations of Study Variables over Time

Variable	Pre test		Post test		Two month follow up		Friedman test
	Mean	SD	Mean	SD	Mean	SD	p
Satisfaction with life	24.5	7.3	23.8	6.9	25.4	6.3	> .05
Depression	9.0	8.1	9.1	10.6	7.1	9.2	> .05
Anxiety	6.3	5.1	5.9	5.4	3.1	4.5	< .001
Positive affect	51.6	10	50.5	10.2	50.8	12.2	> .05
Negative affect	46.2	9.4	50.0	10.0	47.8	13.3	> .05
Attachment	55.4	19.5	56.2	23.2	57.6	20.0	> .05
Perceived social support	41.50	4.2	42.7	5.5	41.5	5.7	> .05
Social network	7.4	4.2	6.7	3.5	7.6	3.3	> .05

Positive and negative affect scores were converted to Z-Scores and then T scores. Scores reported are standardized scores and not raw scores. One participant was excluded (N=13) from the analysis as they completed the Spanish version of the test, therefore, the scores could not be converted to Z scores because there was no mean or standard deviation values available.

The result of the Friedman Test indicated that there was a statistically significant difference in anxiety scores across the three time points $\chi^2(2, n=14) = 13.15, p < 0.01$. The inspection of the mean values

showed a decrease in anxiety levels from pre-intervention, post intervention ($Md=5.0$) and two month follow up ($Md=0.5$). There were no other significant changes in other variables over time.

General Discussion

The pilot work on the AMC Programme is very limited given the small number of participants ($N=14$) that completed all sessions and phases of the study.

The majority of adolescents that took part in the AMC Programme expressed an interest in increasing their knowledge about cancer and contributing to research. Previous studies, both qualitative and quantitative, have identified that information is very important for adolescent adjusting to parental illness (Pettersson et al., 2011; Fitch & Abramson, 2007; Davey et al., 2011; Hilton & Gustavson, 2002; Thastum et al., 2014; Lewandowski, 1996; Maynard et al., 2013; Hymovich, 1995; Kennedy & Lloyd- Williams, 2009). Dehlin and Reg (2009) identified that adolescents liked the information they received because it provided a feeling of understanding. Adams - Greenly et al. (1986) suggested adolescents may get a sense of security from the information they gather.

The feedback for all sessions was generally positive. The majority of adolescents always found the sessions useful and expressed that they learnt something about themselves and others by completing the sessions. For the first four sessions a small number of adolescents suggested that the session should have less information, questions and reading.

Adolescents did not usually suggest changes for the sessions. An important suggestion was to include information about the emotions that other adolescents in similar situation usually experience. Previous research has suggested that adolescents may struggle to deal with their emotions and wonder if their emotions are normal. Stiffler et al., (2008) and Kristjanson et al. (2004) found that adolescents wanted to know if certain feelings such as anger and guilt were normal and acceptable at a time of maternal illness, both of these studies akin to the AMC study were qualitative with a small number of participants, 8 and 31 respectively.

Adolescents reported that the AMC Programme allowed them to identify coping skills that they were not aware of and made them realize supports that were available. Bal et al. (2003), Dolan et al. (2006) and Gottlieb (1987) described a relationship between coping and social support. Social support could be defined as "social mediated coping". Cicognani (2011) found that higher perceived family support lead to more use of coping strategies and lower use of dysfunctional coping strategies in adolescents (14 to 19 years), although this finding may not be comparable to the AMC study because it was quantitative and included 342 participants.

Participants on the AMC programme suggested that they were able to ask for help when they needed it and were also able to talk about their experience with other people. This finding is similar to previous research, Issel et al. (1990) carried out 81 semi structured interviews with young people and identified that communication was difficult for adolescents, specifically regarding parental cancer. Other research studies have described the importance of factors such as communication on adolescent adjustment; however, the number of participants in these studies was also small ranging from 11 to 51. Another was a systematic review; therefore results need to be compared with caution to findings on the AMC study (Thastum et al., 2008; Maynard et al., 2013; Costas-Muñiz, 2011; Clemmens, 2009; Osborn, 2007). Gates and Lackey (1998) found that a small group of eleven young people caring for adults with cancer mentioned being aware of the help available but they did not seek that help themselves, therefore it is also important that adolescents asked for help. In the AMC study adolescents still wanted to improve family communication and relationships.

Adolescents found it most difficult to deal with maternal emotions and difficulties and they described maternal recovery as the happiest part of the experience. With a smaller sample, perhaps more comparable with the AMC Programme pilot study, Davey et al. (2011) identified that twelve adolescents struggled with changes in normal parental behaviour including irritability, impatience, moodiness and paranoia. Adolescents also described their sick parent as unavailable physically and emotionally as a result of treatment. Clemmens (2009) reported that the eleven adolescents that took part in their study were concerned as they watched their mother's illness,

fatigue and changes in her physical appearance such as hair loss and according to Stiffler, et al. (2008) the eight adolescent daughters that took part in their study mourned the loss of their mothers as they were before the breast cancer diagnosis.

Anxiety over time.

While the reduction observed in anxiety is promising, no definite conclusions can be raised about the possible influence of the programme on changes over time in adolescent adjustment. A randomized controlled trial testing the effectiveness of the AMC Programme on adolescent adjustment to maternal cancer is needed.

Previous research studies have identified that anxiety is a common response in adolescents and young people confronting parental cancer and parental illness (Visser et al., 2004; Barkman, et al., 2007; Grant & Compass, 1995; Costas-Muñiz, 2011; Compass et al., 1994; Finch & Gibson, 2009; Plumb et al., 2006; Hymovich, 1995).

Anxiety in adolescents that experience parental illness may change over time as parents complete treatments and begin to recover from illness. Clemmens (2009) identified that the completion of treatment would provide a sense of being back to normality, using a small sample. Adolescents closer to the cancer experience (Clemmens, 2009) tend to long for normality and struggle with the uncertainty of their future but several years after the diagnosis (Issel et al., 1990) adolescents do manage to come to terms with the experience of parental cancer.

Cancer knowledge and perception.

Adolescents in the AMC study seem to have general information about cancer but lack detail; this is comparable with previous research studies as Thastum (2008) and Finch and Abramson (2007) identified a strong need for information in young people that experience parental cancer but in reality they did not always have it.

Adolescents want to know about causes of cancer but others just did not have any questions. Nurses and doctors were mentioned as possible sources of information. Kristjanson et al. (2004) identified that adolescents appreciated health professionals that treated them 'as adults' and provided information in a clear and simple language. They also liked having access to

a professional's phone number but few mentioned having direct access to a nurse, social worker or physician.

Social support knowledge and perception.

Adolescents in the AMC study did not mention theory based types or sources of support. They mentioned a list of people including parents, friends, family, school and professionals. This is similar to previous findings in the literature as Dolan and Brady (2012) described that informal sources of support (friends and family) are generally preferred by young people because they are available, usually, all day at all times and constitute a natural source of help. They are also the sources which youth turn to more often as it is less stigmatising and it eliminates the potential need for 'professional help'. Professionals and teachers, however, may still play an important role. Dehlin and Reg (2009) identified that friends and family were a relief for adolescents, Friends and school were a "protective zone" as adolescents did not have to think about the illness anymore.

Research on adolescents dealing with parental cancer has identified that friends are important for adolescent coping Huizinga et al. (2011) described that friends were a way to stay in touch with their friends and have an illness 'free zone' where they could continue with their normal activities. Previous research identified that friends and parents were the ones which helped children cope the most (Forrest et al., 2009; Issel et al., 1990; Finch & Gibson, 2009; Maynard et al., 2013; Seiffge, 2004; Dehlin & Reg, 2009; Gall & Kafi, 2014).

Limitations- recruitment issues

The efficacy of the AMC Programme on adolescent adjustment could not be identified due to recruitment difficulties. Only pilot work was possible and insufficient numbers were accrued to enable inclusion of a control group in the pilot study.

There was high levels of attrition (65%) in the AMC Study overall. A total of 40 adolescents completed the survey pre test, only 28 completed Session 1 and only 14 completed the whole programme and the post test survey. Some sessions, therefore, were evaluated by more people than

others and overall the actual feedback for the programme came from a small sample.

Stanford et al. (2003) suggested that there is a lack of knowledge on the factors that may improve enrolment and retention of adolescents in longitudinal research studies. The length of the surveys and sessions might have been a reason for non participation in the AMC study, however, Hoerger (2010) suggest that the length of surveys is not a reason for participant dropout in Internet-mediated research.

The very significant recruitment challenges in the AMC study suggested that mothers are protective of their adolescent children and do not wish them to be involved in programmes dealing with sensitive and difficult issues. Previous research by Stanko and Taub (2002) reported that some parents declined participation because they wanted their children to have a 'normal life'. They also had concerns about children's ability to keep confidentiality.

The online programme had the advantage of being available any day and any time for adolescents but some mothers in the qualitative phase of the AMC Study expressed concern and mistrust towards online contexts. Perhaps given that cancer is a difficult subject, using a face to face scenario to build rapport and trust with the research team to encourage participation of adolescents would be useful. Equally a face to face trusting relationship is essential to encourage staff at Cancer Centres to promote participant recruitment. Lamb, Puskar and Tusaie-Mumford (2001) emphasized the need to consider creativity, flexibility, organizational skills and expertise with the population when carrying out research with adolescents. Overall, it is very important to make sure that potential participants understand the objectives, risks and benefits of being involved in a research study. Ulrich et al. (2010) suggested that research should be more rigorous evaluating if participants have completely understood the information provided for them in the consent form so that they can make informed decisions about participation. It was also suggested that participant burden must be evaluated and to carry out a priori analysis of patient preferences.

Some adolescents had genuine reasons for not taking part in the AMC study such as unresolved emotions and difficulties surrounding the topic and others mentioned being genuinely busy at the moment and not being able to commit. This suggests that some adolescents may require interventions or supports that take less time or are more targeted at their needs. Future research needs to determine the most suitable types of interventions for different adolescents.

Summary

A pilot study was carried out with male and female adolescents between 14 and 19 years of age who were asked to judge the appropriateness of the format, content and images of the AMC Programme. Session and activities were modified according to the feedback provided by this pilot phase. The final version of the AMC programme was completed fully by 14 participants between 14 and 20 years of age, three of whom were male. Adolescents provided qualitative and quantitative feedback at the end of every session to determine if they found it useful, difficult and suggest possible changes. They seem to lack specific information about cancer and suggested that the programme should include information about normal adolescent emotions at the time of maternal cancer. A significant decrease in anxiety levels over time was found but due to the small sample and lack of control group this finding needs to be treated with caution.

CHAPTER 5

GENERAL DISCUSSION

Overview of Findings

The AMC Study examined the experiences and determinants of adolescent adjustment to maternal cancer in an Irish and an International sample. The specific objectives of the research were to explore the subjective experience of adolescents with particular focus on perceived social support. Additionally, the research explored mothers' perceptions of their adolescent's adjustment. An online intervention to improve adolescent adjustment was designed and piloted. The research examined the role and relative impact of perceived stress, coping, perceived social support, maternal attachment and self-efficacy on adjustment (mood and wellbeing) and also explored the mediating and moderating effects of social support in the relationship between perceived stress, coping and adjustment.

The study had a mixed methods approach, including a combination of qualitative and quantitative methodologies.

Meta-ethnography on adolescent adjustment to parental cancer.

The meta-ethnography described the current state of qualitative research on adolescent adjustment to parental cancer. Overall, the experience is a challenge at an already challenging developmental stage as it has an impact on all aspects of adolescent lives including their emotions and their relationships.

Adolescent adjustment occurs from the time of cancer disclosure to treatment and beyond the completion of treatment. Adolescents lack detailed information about cancer, specifically its origins and treatments. Adolescents experience a variety of emotions including devastation, fear, upset, distress, shock, surprise, disbelief, sadness, loss, vulnerability, denial, worry, helplessness, anger, guilt, anxiety, depression, devastation and stress. Some adolescents seem to adjust successfully with no major difficulties, but others face difficulties. It is not clear what causes these differences. Treatment seems to be the time when adolescents face the reality of the illness as they visibly see the side effects on illness and treatments. Post

treatment, adolescents continue to face challenges; their levels of stress may increase due to the fear of recurrence.

Research has suggested that adolescent adjustment happens in a context where family characteristics can increase the risk of adolescent maladjustment such as poor communication, poor functioning and family separations and losses. Adolescents seem to be able to identify positive gains from their experience of parental cancer, for example, growth and maturity, increased autonomy and improved relationships in their families.

Regarding the developmental impact of parental cancer, the metaethnography suggested that adolescence is a time of independence and separation from parents, but the illness instead pulled adolescents back into their families. Adolescents have more complex cognitive abilities than young children and this allowed them to be more aware of the gains and losses of the experience which may lead to more externalizing problems. Research overall seems to show a gender imbalance, where more studies are based on the experiences of daughters and not sons, which leads to a lack of understanding of possible gender differences in adjustment.

Study 1(a): Thematic analysis of adolescent interviews.

The thematic analysis of adolescent interviews provided an overview of possible circumstances that may facilitate or challenge adolescent adjustment. A cancer diagnosis can be shocking and difficult as it is unexpected but adolescents try to face the threat they experience. Different factors increase the challenge for adolescents including the way in which the information is disclosed, providing adolescents with factual information about cancer and having open and honest communication. Treatment is difficult for adolescents as they are dealing with stress and worry of medical procedures but this could be improved if adolescents had access to medical staff that could answer their questions. After treatment adolescents are dealing with the way their ill mother and family cope at this time. Those families still struggling with financial issues and secondary effects of treatment make the experience more difficult for adolescents. Adolescents also experience additional responsibilities that are difficult to deal with but

find positive gains from it such as improved relationships and helping their ill mother.

Adolescents have different ways of coping and different information needs. Families that are more supportive and cooperative share the burden and this facilitates adolescent adjustment. Friend and community support can also be very helpful as long as adolescents can choose who they want to disclose the information to and how. Adolescents found positive gains from dealing with a challenging experience and made better decisions for their future with their acquired abilities.

Study 1(b): Interpretative, phenomenological analysis of adolescent interviews.

This analysis provided a detailed description of adolescent experiences of maternal cancer from the views of three adolescent daughters. The relationship between mothers and daughters became a caring dyad. Adolescents struggled to deal with the reality of maternal illness which led to significant behavioural and physical changes in their mums describing them as sick, scared, vulnerable, desperate, trapped and claustrophobic. Therefore, adolescents made the conscious decision to take care of their ill mothers but denied their own needs and emotions over their mother's well being.

Adolescent caring roles were influenced by different factors including family structure; less cohesive and more dysfunctional systems meant a greater caring burden for adolescents, but they were able to identify gains from their caring experiences such as closer, more intimate and stronger relationships with their mothers.

Adolescence is a time that requires young people to be independent from their families by moving away to University, but maternal cancer instead pulls them back into their families. This causes doubts and guilt in adolescents as they experience a discrepancy between their developmental needs and illness demands.

Study 1(c): Thematic analysis of maternal interviews.

Mothers explained the experience of cancer as a chronology from before diagnosis until post treatment. Mothers were very concerned with conserving and protecting their families by keeping normal routines and

spending time as a family and having fun together. Mothers also applied 'selective disclosure' which consisted of being open and honest with adolescents about cancer facts but protecting them from their own emotions of sadness and fear. Mothers were surprised at the level of coping abilities, maturity and sensitivity that adolescents showed but they were concerned about the impact that the illness could have on adolescent development.

Study 2 (a): Predictors of adolescent adjustment to maternal cancer.

This study examined the role and relative impact of perceived stress, coping, perceived social support, maternal attachment and self-efficacy on adjustment (mood and life satisfaction). Forty adolescents completed the pre-test survey.

Multivariate analysis identified that perceived stress and coping and self-efficacy significantly explained variance in positive affect. Perceived stress and coping also explained variance in negative affect. Perceived stress, coping, perceived social support, maternal attachment and self-efficacy significantly predicted variance in adolescents life satisfaction. Variables in the model failed to explain any variance in adolescent depression and anxiety levels, which may have been due to the fact that this group of adolescents were not a clinical sample, their mean scores for depression and anxiety were in the normal range.

The study identified that social support moderated the relationship between perceived stress and positive affect but this was only significant in adolescents with higher levels of social support. This relationship suggests that perceived social support can have a boosting effect for adolescent adjustment particularly for adolescents with high levels of perceived social support and low levels of perceived stress.

Study 2 (b): Design and piloting of an online intervention to enhance adolescent adjustment to maternal cancer (AMC Programme).

There is a paucity of interventions designed for adolescents facing parental cancer and those that are available are targeted at families or smaller children. Previous research has agreed that adolescent interventions should be age appropriate, provide factual information and be a safe place for adolescents to express their needs and emotions.

Adolescents described the AMC Programme as an overall positive experience. Their main motivation to take part was to obtain information about cancer and to contribute to research. The programme helped them to learn things about themselves and others but also allowed adolescents to identify more coping skills and supports that are available. They reported that they were able to ask for help and share their cancer experience with others.

Overall implications

Conflicting findings and adjustment definitions.

The impact of maternal cancer on adolescent adjustment has been examined in previous research, however, this is the first study of the experience of Irish adolescents. Previous research has produced mixed findings on the impact of parental cancer. It is difficult therefore, to definitively identify vulnerable adolescents or those at higher risk. Foran-Tuller, O’Hea, Moon and Miller (2012) suggested that mixed results may be associated with the lack of use of comprehensive measurements of symptoms and focusing on internalizing and externalizing problems only. Hoke (2001) suggested that families who were distressed were probably the ones who declined participation in the study, excluding children who were actually at risk or had adjustment problems.

Another significant source of variance in findings stems from differences in definition and measurement of adjustment. For example, Birenbaum et al. (1999) defined adjustment as altering the person-environment relationship from one that is stressful to one that is suitable for continued development. Hoke (2001) defined it as affective responses, behaviors, functioning in school and with peers. Nelson and While (2002) defined it as child self-worth and parental adjustment and finally Lewis and Darby (2003) included self esteem, behavioural problems and anxiety.

The AMC Study focused on identifying the variables that had an impact on adolescent’s adjustment and found that individual differences in perceived stress, coping, social support, attachment and self efficacy explained differences in adjustment. Findings particularly suggest that strategies that minimise stress and enhance social support could help

adjustment to maternal cancer. This identification of variables that impact adolescent adjustment is a significant contribution of the AMC Study. Predictors in the study did not play a role in distress but it can be noted that scores on depression and anxiety were not within clinical range in this group. The scales used in the AMC were all within acceptable ranges of confidence which suggests these measures are suitable for this population and can be used in future research.

A developmental approach to adolescent adjustment.

The AMC Study emphasized the need to adopt a developmental approach to understand adolescents' experiences. Not all research studies to date have included this perspective and findings have been mixed on this .

Kranttenmacher et al., (2012) described that age was not a predictive factor of children's adjustment but according to Hymovich (1993) age did determine differences. Seigffge-Krenke (1995) suggested that early adolescents seem to be a group more vulnerable to greater stress than younger children. The meta-ethnography particularly identified that previous research studies do not seem to approach this age and gender issue.

The AMC Study, particularly the qualitative section of the study, showed that adolescents are dealing with important developmental demands at the time of maternal cancer, for example, adolescents had to move away from the family home to go to college, at a time when maternal illness was pulling them back into the family. It was these contradictory developmental and illness demands that increased the burden for adolescents and created more adjustment difficulties for them (Sich, 2010).

The AMC study had more female than male participants which suggest that the knowledge of male experiences is still limited and should be addressed in future research. It is of interest that female interviews were longer, the average length of female interviews was 33.7 minutes and the average for boys was 17.6.minutes. Karlsson et al. (2013) suggested that women and girls are more inclined to talk about their feelings with others while boys would instead choose more active problem-focused strategies and this may be why more women are attracted to this type of research study and take part in interviews. Several other studies have also found the issue of gender imbalance in their research samples (Compas et al., 1996;

Grant & Compas, 1995; Heiney et al., 1997; Nelson & While, 2002; Visser et al., 2005; Welch et al., 1996; Wong et al., 2006).

In the AMC study both male and females generally used coping strategies such as having a positive outlook, trying not to worry and continuing to be involved in sports and extracurricular activities. Trust in the treatment and medical team and keeping normality in their lives was a strategy exclusively mentioned by boys. Previous research has similarly suggested that males and females use different coping strategies to deal with cancer, according to Davey et al. (2003) females; both mother and daughters tended to 'talk it out' when they were fearful or worried. Males used other coping strategies like distraction and blocking it. Other studies, however, have not identified any differences between males and females (Finch & Gibson, 2009). In the AMC study caring duties were not exclusive for boys or girls, both were concerned about keeping their mother comfortable. In a household with boys and girls it was a boy who was concerned about practical care issues (e.g. knowing if the mother had toothbrush and toothpaste). Other adolescents were more actively involved and even became their mother's full time carers, but these were females only, suggesting females are the main carers.

In the AMC study overall, there were no significant age differences in the way adolescents experienced and approached maternal cancer. In the qualitative interviews, however, some differences according to age were described, older adolescents seemed to be genuinely concerned for the well being of their younger brothers and sisters and wanted to be available to care and support them.

The chronology of maternal cancer.

The AMC Study identified that maternal cancer is not a single process but instead is described and experienced as a series of chronological phases and each one has a different challenge or demand. This chronology is evident from themes in the meta-ethnography 'an individual journey from diagnosis to the future'.

Overall, maternal cancer at diagnosis was described as very challenging and this is expressed both in the meta-ethnography and in the

AMC thematic analyses in themes such as dealing with the unexpected and facing the fear of the unexpected. Previous research described the initial phase of cancer as the most stressful one for patients and their families (Davey et al., 2003; Hilton, 1993; Northouse, 1984; Sales, 1991).

Adolescents in the current study did struggle at this stage but every stage had its own challenges.

At the time of treatment mothers face drastic physical and psychological changes that are also difficult for adolescents to deal with. Previous research described that treatment stage can materialize or make the illness experience 'real' (Hooper & Marcus, 1998; Davey et al., 2011; Finch & Gibson, 2009) when adolescents see the effects of maternal illness and the changes that occur at the time of treatment.

After treatment they deal with fear of maternal cancer recurrence or fear of getting cancer themselves. The long term impact of maternal cancer on adolescents was described in the thematic analysis as their vision of the future. Different research studies have described that fear of recurrence is almost universal in patients and their families (Sales, 1991; Davey et al., 2011; Stiffler et al., 2008; Northouse, 1984). Previous research found that some participants were hyper-vigilant to body signs and symptoms associated to cancer as they expected to get cancer themselves (Wong et al., 2009; Clarke J., 1995; Kissil et al., 2010; Davey et al., 2011).

The AMC Study, therefore, suggested that adjustment is not a single outcome, but instead adolescents are in a constant process of adjustment at every illness stage. Very few studies have taken this chronological approach to adolescent adjustment so future research should evaluate this to further understand needs at different illness stages and not just at diagnosis (Skott, 2004; Karlsson et al., 2013).

Adolescents' individual needs and skills

The AMC Study described how adolescents cope with maternal cancer and what emerged is that there were as many coping skills as there were participants, people have different needs and different ways of coping. This is a significant finding particularly for health care practitioners as there is not a single, 'normal' way for adolescents to deal with maternal cancer and they should be encouraged and allowed to choose their own coping methods

as these would probably be more effective for them. The variety in coping skills was evident from the qualitative studies, for example, some adolescents wanted to spend time alone thinking or meditating but others instead preferred to be involved in group activities such as sports. The quantitative phase of the study found that coping skills explained variance in adolescent life satisfaction and positive affect levels. Therefore, it is important to take into account not only the type of coping used, but how effective they are in helping adolescent adjustment at the time of maternal cancer. Previous research has also suggested that there are differences in adolescent needs and approaches (Patterson et al. 2013; Hymovich, 1995; Kennedy & Lloyd- Williams, 2009, Hilton and Gustavson ,2002). The AMC qualitative interviews and the AMC programme qualitative feedback showed that adolescents have a need for validation and normalization of the feelings they are experiencing at the time, which is also an important finding for health practitioners working with adolescents or their families at the time of maternal cancer. This is in line with previous research studies, where adolescents needed to normalize their emotions but also wanted or needed permission to feel strong emotions such as anger (Stiffler et al., 2008; Kristjanson et al., 2004).

Another important finding for health practitioners is that adolescents in the AMC study struggled with preconceived and negative ideas about cancer from media or TV programmes. In the AMC programme, adolescents also provided very general definitions about cancer as an ‘illness in the body’. They wanted to know more about causes, treatments and cancer stages. Adolescents seem to need factual and age appropriate information, particularly those that use intellectual mastery and information as a coping strategy. Previous research has shown that adolescent descriptions of cancer tends to be general (Rosenfeld, et al. 1983; Finch & Gibson, 2009; Forrest et al., 2009; Kissil et al., 2010) which emphasizes the importance of providing factual information that is appropriate but also of providing useful and safe sources where they themselves can do the research.

Understanding the context of adjustment.

The AMC study described, from a Family Ecology perspective and Family Systems Theory, that maternal illness can have an impact in many aspects of adolescent lives including their families, University, external supports and their relationship with hospital settings. Understanding adolescent adjustment cannot focus exclusively on individual variables as these are only one part of the adjustment process; adolescent contexts are also changed by maternal illness and in turn influence the process of adolescent adjustment to maternal cancer. Previous research has described cancer as a family experience as the impact of the illness in one member has an impact on all the family (Heiney et al., 1997; Faulkner & Davey, 2002; Hilton, 1993, Su & Ryan Wenger; 2007; Huzinga et al., 2011).

The AMC study emphasized how family structure, relationships and communication can facilitate the adjustment experience or instead become a bigger burden for adolescents. This finding is very important as adolescent adjustment cannot be understood as an exclusively individual process. There has to be understanding of their social context. It was evident that less functional families led to more difficult situations and less favourable outcomes for adolescents. Adolescents may not have personal difficulties but may be at greater risk of poor adaptation because the contexts there are in are not favourable. Previous research has also identified some of these issues (Hilton & Elfert, 1996; Edwards et al., 2008). It could be useful to include a measure of family adjustment in future research in this area.

The relevance of adjustment in context was further supported in the AMC Study by the moderating effect of social support in the relationship between stress and positive affect. This finding is relevant as it possible to improve adolescent adjustment experiences by making sure they have social support at the time of maternal illness; however, the AMC Study only found this moderating effect in positive affect and not in the other measures of adjustment.

Health care professionals, therefore, could aim to improve social support as a protective factor for adolescents experiencing maternal cancer, as previous research has shown that young people who experience parental cancer are at risk of isolation, loneliness and lacking supports (Giesbers et

al., 2010; Lewis et al., 1985; Lewandowski, 1996; Gazendam - Donofrio et al., 2011; Davey et al., 2011).

Positive gains from a negative experience.

Adolescents described the struggle and challenges they faced as a result of maternal cancer but they were also capable of identifying gains and benefits from the experience. For example, families were brought together, adolescents perceived they were more mature than their peers, they had increased appreciation for their mothers, their families and life, and had more sensitivity to others people's needs and suffering.

Previous research has also identified that adolescents are capable of identifying positive aspects in challenging experiences (Thoits, 1995; Aldwin, 2011; Buchbinder et al., 2009). In the context of parental illness, research has found that adolescents perceived they were more mature than their friends and believed that the experience also changed their values about what is right and what is wrong and even their choice of occupation for the future, and their appreciation for life (Wong, et al., 2009; Davey et al., 2005; Kissil et al. 2010; Hilton & Gustavson, 2002; Karlsson et al., 2013; Fitch & Abramson, 2007; Davey et al., 2011; Kissil et al., 2010; Dehlin and Reg, 2009). Davey et al. (2011) found that adolescents not only 'bounced back but also transformed to a higher level than that which existed before their parent's breast cancer' (p.85), including enhanced interpersonal relationships and increased personal strength.

Importantly findings suggests that adolescents do have the capacity to cope and deal with a very difficult and challenging experience. Findings show that they struggle but find the skills and talents to reconstruct their lives and find positive gains. Findings also suggest that adaptation can be improved with provision of good individual and family supports and that any interventions should take account of individual differences and be flexible or adaptable to adolescent needs and contexts.

General limitations

Due to challenging recruitment issues the study had a modest sample but also had significant attrition from adolescents and families invited to take part. Given the fairly wide ranging recruitment campaign targeted

towards adolescents and mothers with cancer, the response rate is disappointing and limits generalizability of the findings.

Hoke (2001) suggested that families who were distressed were probably the ones who declined participation in their study, excluding the experiences children who were at a higher risk of adjustment problems. Participants included in the AMC Study were also volunteers and according to Philips (2014) samples composed of volunteer participants may be biased towards more positive outcomes.

The AMC Study failed to explain variance in depression and anxiety so perhaps the measures chosen were not sufficiently sensitive to measure and predict distress in this group.

The AMC Study found a reduction in adolescent anxiety following the programme but this is very tentative given the small sample size and lack of a control group.

General recommendations

Future research.

Adolescent adjustment needs to be understood as a process. Research needs to include other stages of parental illness as research has in the main concentrated on diagnosis rather than on the treatment and post treatment phases.

Adolescent adjustment also needs to be understood in context. The AMC Study has described that maternal cancer has an impact on adolescents in varied contexts (e.g. families, friends, external supports and hospital settings). Adolescent adjustment is influenced by individual resources, particularly perceived stress, social support and self-efficacy, but also family coping and family structures in general including communication, support and the quality of relationships. Further research with larger samples is thus needed to examine the role of these variables in enhancing or minimising adaptation to maternal cancer.

Future research needs to understand the experiences of adolescent boys as well as adolescent girls. This may be achieved through the use of other methodologies, for example, participatory research or having male

researchers that may encourage male participants to share details about their experiences.

Further research could also focus on the role of the healthy parent in adolescent adjustment as the AMC Study has identified that they have a crucial supporting role for adolescents, ill mothers and families. Further research describing the adjustment of adolescents to parental cancer in an Irish context is needed and it would be worthwhile to explore adolescent adjustment when the healthy parent is female.

A randomized controlled trial methodology or a feasibility study, would help to determine the specific effects of the intervention on adolescent adjustment over time. Ideally, research may benefit from longitudinal designs that follow adolescent experiences from the beginning until years later after the completion of treatments. The AMC Study describes the different stages but they are all retrospective accounts.

The conceptualization of adolescent adjustment needs to improve to enable to comparison across studies. Cancer research may benefit from more specific tools to target adjustment to cancer and parental illness. Krauel et al. (2012) identified that tools used in research with children that experience parental cancer were not developed to measure the specific problems of these children and may not cover all relevant domains and be sensitive enough to the issues. Designing specific tools may also facilitate comparability of results across studies.

Overall this research has identified a paucity of research focused specifically on adolescent populations and few interventions and services are exclusively targeted at adolescent populations. More services tailored to adolescents with maternal cancer are needed in Ireland.

Further understanding is required on how to recruit and retain adolescents in studies with longitudinal designs. Adolescents with significantly lower levels of negative affect were the ones who engaged more but it could be argued that they were the ones who needed the intervention less. Future intervention research needs to ensure inclusion of adolescents that may be at a greater risk of psychosocial difficulties.

Summary

Adolescent adjustment to maternal cancer is a complex process that should be understood as a continuum and not as an outcome. Adolescent adjustment also needs to be understood in context as the environment can increase or instead decrease the burden of maternal illness for adolescents, those that are in more nurturing and supportive environments seemed to adjust more successfully. The current study is an important contribution to existing knowledge of adolescent adjustment to parental cancer as it provides useful insights into possible psychological predictors of adolescent adjustment to maternal cancer. The study found that those low in stress, high in positive coping, social support and self-efficacy report better affective status and life satisfaction. High levels of social support were found to moderate the relationship between stress and positive affect, suggesting a boosting effect of high levels of social support at lower levels of stress. Future studies with larger samples are needed to provide a better understanding of adjustment and how this changes over time. Adolescents may benefit from online interventions to improve their adjustment, however future research should focus on providing evidence based research to support this claim.

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APPENDIX A

Participant recruitment posters, brochure and letter



OÉ Gaillimh
NUI Galway



How do adolescents cope with maternal cancer?

What do adolescents feel and what are their needs?

How can they be supported and helped?

Maternal illness is a difficult and challenging situation and there is variability in how adolescents adjust over time to this event. Some can adapt and manage the situation but others may cope poorly or respond less well. Some adolescents may lack support in their environments and may be less able to share their feelings with others and are, therefore, more vulnerable to stressful situations. It is crucial to identify adolescents in need and to understand their experiences and provide a source of support for them to enhance their adaptation to this and other major stressors.

What is the AMC Study?

The AMC stands for ‘Adolescent Adjustment to Maternal Cancer’. This study seeks to understand the experience of adolescents between 14 and 19 years of age who have a mother diagnosed with cancer in the past 24 months. It focuses on identifying adolescent support needs and the coping strategies that helps their adjustment.

The AMC study also includes a general online life skills programme to provide skills for adolescents when they experience stressful and challenging experiences in life. The programme consists of eight sessions covering themes like social skills, social support, communication, stress management and cancer.

Who are we?

The AMC is an international study carried out by the research team at the National University of Ireland Galway. The study is a collaboration between the School of Psychology, and the Child and Family Research Centre, National University of Ireland Galway (NUIG).

The research team are Dr. AnnMarie Groarke, Head of the School of Psychology, NUIG Professor Pat Dolan, Director of Child and Family Research Centre, NUIG and Ms. Leonor Rodriguez (BA, MA) NUIG

What are we asking from you?

We would like you to help us identify adolescents between 14 and 19 years of age who have experienced maternal cancer in the previous 24 months.

You can contact adolescents individually if you consider they will benefit from the study or you can share the information on the AMC study in social media, mailing lists, periodicals, forums and/ or display our posters and brochures.

How to respond to this email?

If you are interested in helping with recruitment of mothers and adolescents to the AMC Study please contact us.

For additional information visit the AMC Study website

<http://amcstudy.wordpress.com/>

Call us or email us anytime.

Leonor Rodriguez, BA, MA

Dr AnnMarie Groarke , BA, MA, HDip Ed, PhD, AFPSsI, Chartered Psychologist

Professor Pat Dolan MLitt, PhD

Leonor Tel - 00353-85-8877718

AnnMarie Tel 00353 87 91 78166

Annmarie.groarke@nuigalway.ie



OÉ Gaillimh
NUI Galway



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

AMC

Adolescent Adjustment to Maternal Cancer

If you have been diagnosed with cancer in the
past 24 months

AND

You have an adolescent son or daughter
between 14 and 19 years of age...

The **School of Psychology, NUI Galway** wishes to recruit adolescents to take part in a study which seeks to understand their adjustment to maternal cancer and to participate in an online life-skills programme designed to help adolescents cope with this situation.

For more information please contact the research team:

Leonor Rodriguez, BA, MA
Phone: 0858877718

Dr AnnMarie Groarke, Head, School of Psychology, NUI Galway
Professor Pat Dolan, Director, UNESCO Child and Family Research
Centre, NUI Galway.

School of Psychology, NUI Galway Office Phone 091-493454

<http://amcstudy.wordpress.com/>

l.rodriquez2@nuiagalway.ie

MATERNAL CANCER....

LEARNING TOGETHER CHANGING TOGETHER GROWING TOGETHER

I learnt that when my mum got sick that nobody is free from having the chance of getting sick or anything (...)this kind of made it even more important to me just how vulnerable people are and people can get sick so quickly(...)
Irish adolescent , 17



OÉ Gaillimh
NUI Galway



IRISH RESEARCH COUNCIL
An Chomhairle um Thaisiú in Éirinn

AMC STUDY

ADOLESCENT ADJUSTMENT TO MATERNAL CANCER

The **AMC Study** is working with mothers and adolescents to understand their experiences of maternal cancer.

The **AMC Programme** is a life skills programme online designed to support adolescents during difficult and stressful times and provide them with useful coping skills for their lives:

- Assertive communication
- Stress management
- Social support
- Asking for help
- Dealing with strong emotions
- Understanding cancer



“Well I think that once you get to the stage when you feel comfortable talking about it I think it is very important to do that. I don't think I did enough of that.”
Irish adolescent 17

For more information please contact the research team:

Leonor Rodriguez, BA, MA
Phone: 0858877718

Dr AnnMarie Groarke, Head, School of Psychology, NUI Galway
Professor Pat Dolan, Director, UNESCO Child and Family Research Centre, NUI Galway.

School of Psychology, NUI Galway Office Phone
091-493454

<http://amcstudy.wordpress.com/>
l.rodriguez2@nuigalway.ie

Maternal Cancer

I think I have matured over the period of my mother's illness. I had a lot more responsibilities and because she is a single mother she has a lot of responsibilities to balance. So I think overall it has been a good growing experience for me a maturing experience.

15-18 year old daughter



Yeah, even though mothers are survivors, we are survivors too. What mothers go through we go through, they are our parents. Of course we are going to go through it with them'.

11-14 year old daughter.



FOR MORE INFORMATION CONTACT THE RESEARCH TEAM

Leonor Rodriguez, BA, MA.
Phone 085 88 777 18

Dr. AnnMarie Grogan, Head, School of Psychology, NUI Galway

Professor Pat Dolan, Director, UNESCO Child and Family Research Centre, NUI Galway

School of Psychology, NUI Galway Office
Phone 091-493454
<http://amcstudy.wordpress.com/>
Lrodriguez2@nuiagalway.ie



AMC

Adolescent Adjustment to Maternal Cancer



AMC Adolescent Adjustment to Maternal Cancer

This study is examining adolescent adjustment to maternal cancer diagnosis. It also explores the effectiveness of an online programme to help adolescents cope with this situation.



Phases of the Study

Adolescents between 14 -19 years will be asked to take part in 4 phases of the study:

1. Adolescents and mothers can volunteer to have an online or telephone interview.
2. Participants will fill in a survey online which will help understand the perceived stress and emotional impact of maternal illness on adolescents
3. Adolescents will complete an 8 week online life-skills programme designed to help them cope with illness in the family. Half will complete the intervention first and the other half later on.
4. Participants will complete the survey 2 months after the programme was completed.



Benefits

Improve adolescent well being. Provide adolescents with skills and strategies to cope successfully.



"I think it was when my mother lost her hair it was quite scary. I'm used to it now but when it first happened I was a bit scared and I didn't really tell my friends. So for about a month we didn't have anyone around and then when I told my friends I was ok about it."
(13 year old girl)

APPENDIX B

Participant information sheets and consent forms



OÉ Gaillimh
NUI Galway



AMC

Adolescent Adjustment to Maternal Cancer

PARTICIPANT CONSENT FORM

Purpose of the study

You are invited to join a study which examines the psychological impact of adjusting to maternal cancer diagnosis. This is a difficult and distressing time for you but the information you provide will be used to enhance understanding of what you are going through and to establish if a web based intervention is a good way to help adolescents facing this situation.

What will be involved if I agree to take part in this study?

If you agree to take part in this study you will be involved in 4 different phases.

The researcher will have an online video chat (SKYPE) interview with you to understand your current situation further. This session is audiotaped. Participants will fill in a survey online which will help understand the psychological impact of maternal illness on adolescents. Adolescents will complete an 8 week intervention. Half will complete the intervention first and the other half will participate in the intervention later on. The survey will be filled in again at the end of the intervention and at a six month follow up.

Can I withdraw from the study?

Even if you decide to take part in all phases of this study you are free to withdraw at any stage without having to explain why and there will be no consequences for you or your family.

Confidentiality

All the information you provide will be anonymous. Your name or family name will not appear in any report resulting from this study. A research

number will identify you in the databases. Findings will only be reported as group data.

However the researcher must break confidentiality if:

- 1) Your physical and emotional wellbeing is at risk and another adult (parent, guardian) has to be informed to guarantee your safety.
- 2) You are being harmed or in risk of being harmed by issues specified in the Child Protection Policy NUI Galway (2011) and the “Child First”- National Guidelines for the Protection and Welfare of Children.

However, **the researcher will always inform you first** about this situation and the procedure that has to be followed after the situation has been reported.

If you have any queries please contact the researcher, Leonor Rodriguez E. Phone number 0858877718 or email l.rodriquez2@nuigalway.ie. Or contact Dr. AnnMarie Groarke, Head of School, School of Psychology, NUI Galway annmarie.groarke@nuigalway.ie

**Adolescent Adjustment to Maternal Cancer
PARTICIPANT CONSENT FORM**

	Place a circle round either	
	Yes	No
1. I confirm that I have read and understood the information sheet about the study which is examining the psychological impact of adjusting to maternal cancer diagnosis.	Yes	No
2. I am satisfied that I understand the information provided and have had enough time to consider the information.	Yes	No
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	Yes	No
4. I understand that any information I give to the researcher is anonymous and will be treated with confidence.	Yes	No
5. I understand that I can ask the researcher questions about the study at any time.	Yes	No
6. I confirm that I have competent reading writing and comprehension skills in the English language to be able to take part in this online study.	Yes	No
7. I confirm that I have access to the internet and parental/adult permission to use it for the purpose of this research project.	Yes	No

Name: _____

Signed: _____

Date: _____

Please send back one signed copy of this Consent Form. The other copy is for you to keep.



AMC

Adolescent Adjustment to Maternal Cancer

PARTICIPANT INFORMATION SHEET

I am inviting you to take part in a research study: ‘Adolescent Adjustment to Maternal Cancer’. This Information Sheet provides a description of the study. Please read it carefully before you decide to take part.

If you still have any questions or doubts the researcher will be happy to answer them for you.

Purpose of the study

This study examines the psychological impact of adolescent’s adjustment to maternal cancer diagnosis. It also explores the effectiveness of a web based intervention for adolescents in this situation.

What will you take part in?

Adolescents between 14 and 19 years of age will take part in 4 different phases:

1. Some adolescents (8 to 11) will have an online or telephone interview with the researcher. The interview will help the researcher understand the experiences and social support needs of adolescents adjusting to maternal cancer. This data will help inform the appropriateness of the proposed intervention for this specific context.
2. All adolescents will complete the AMC Survey online. These are scales which provide general information on the adolescent’s everyday life, including: relationships with parents, friends, siblings as well as feelings, emotions, thoughts, self perception and difficulties.
3. Adolescents will be part of an 8 week online intervention (AMC Intervention). Each weekly session has a specific theme: cancer, social support, self perception, staying calm, assertiveness, emotions, communication and asking for help. All sessions provide

information on these themes and include activities based on them. Half of adolescents will complete the Intervention first, and the second half will complete it later on.

4. Adolescents will complete the AMC Survey again, just after the AMC Intervention has finished and two months later.



Benefits of taking part

All the information provided by participants will increase understanding of the psychological and emotional impact on adolescents when their mother has been diagnosed with cancer. This study will also determine if a web based intervention is an effective way to help adolescents when facing this situation.

Risks of taking part

You may feel distressed or upset whilst participating in this study as this may be a difficult and sensitive topic for you.

If this is the case, the researcher will give you information on services that can provide emotional and psychological support if you need it.

How will my identity be protected?

All the information you provide will be stored and analyzed anonymously. Your name or family name will not appear. You will receive a research identification number that nobody else will know. You and your family won't be identified in any reports or articles resulting from this study, all results will be reported as group data only.

Confidentiality will only be broken if your mental and/or physical health are at risk or you are involved in an issue specified in the Child Protection Policy NUI Galway (2011) and the “Children First”- National Guidelines for the Protection and Welfare of Children. You will be the first one informed if this is the case.

Do I have to take part?

It is your decision to be part of this study. If you decide to take part you will be given this Information Sheet to keep and you will also be asked to sign a Consent Form. Even if you sign, you are free to withdraw at any time, without giving a reason. Withdrawing will not affect your rights or your family's in any way. Additionally, you can also explicitly ask that you would like your data to be removed from research databases.

If you have any questions or comments you can contact the researcher by email l.rodriguez2@nuigalway.ie or by phone 0858877718. Or contact Dr. AnnMarie Groake, Psychology, NUI Galway. annmarie.groarke@nuigalway.ie

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

Thank you for reading this!



Adolescent Adjustment to Maternal Cancer

ADULT CONSENT FORM

Purpose of the study

You are invited to allow your adolescent son/ daughter to be involved in a research study which is examining the psychological impact of adolescent's adjustment to maternal cancer. This is a difficult and distressing time for you and them but the information provided will enhance our understanding of what he or she is going through and establish if a web based intervention is a suitable way to support adolescents facing this situation.

What will be involved if I agree to take part in this study?

If you allow your adolescent to take part in this study he/she will be involved in 4 phases:

1. The researcher will have a telephone or online video chat interview with him/her to understand the current situation further. This session is audiotaped.
2. Adolescents will fill in a survey online which will help understand the psychological impact of maternal illness on adolescents.
3. Adolescents will complete an 8 week intervention. Half will complete the intervention first and the other half will participate in the intervention later on.
4. The survey will be filled in again at the end of the intervention and at the two months follow up.

Can I withdraw from the study?

Even if adolescents agree to take part in this study your son/ daughter is free to withdraw at any stage without having to explain why and there will be no consequences for you or them.

Confidentiality

All the information that you and your son/ daughter provide will be anonymous and confidential. Your name and their name will not be revealed, only a research number will be used in databases. All results will only be reported as group data.

However, confidentiality must be broken if:

- 1) The adolescent's physical and/or emotional wellbeing is at risk and another adult (parent, guardian) should be informed to guarantee their safety.
- 2) The adolescent has been harmed or is at risk of being harmed by issues specified in the Child Protection Policy NUI Galway (2011) and the "Child First"- National Guidelines for the Protection and Welfare of Children.

Adolescents **will be informed first** about this and the researcher will then proceed to report the situation.

If you have any further queries please contact the researcher, Leonor Rodriguez E. Phone number 0858877718 or email l.rodriguez2@nuigalway.ie. Or contact Dr. AnnMarie Groarke, Head of School, School of Psychology, NUI Galway. annmarie.groarke@nuigalway.ie

**Adolescent Adjustment to Maternal Cancer
ADULT CONSENT FORM**

Place a circle
round either

- | | | |
|---|-----|----|
| 1. I confirm that I have read and understood the information sheet about the study which is examining the psychological impact of adolescent's adjustment to maternal cancer diagnosis. | Yes | No |
| 2. I am satisfied that I understood the information provided and have had enough time to consider the information. | Yes | No |
| 3. I understand that my participation and my adolescent's participation is voluntary and that I am free to withdraw at any time, without giving any reason and without having my legal rights affected. | Yes | No |
| 4. I understand that any information I give to the researcher will be treated in the strictest confidence. | Yes | No |
| 5. I understand that I can ask the researcher questions about the study at any time. | Yes | No |
| 6. I confirm that my adolescent son/daughter has competent reading writing and comprehension skills in the English language to be able to take part in this online study. | Yes | No |
| 7. I confirm my adolescent son/daughter has access to the internet and has my permission to use it for the purpose of this research project. | Yes | No |

Name: _____

Signed: _____

Date: _____



Adolescent Adjustment to Maternal Cancer

ADULT INFORMATION SHEET

I am inviting you to allow your adolescent son/daughter to take part in a research study: ‘Adolescent Adjustment to Maternal Cancer’. This Information Sheet provides a description of the study. Please read it carefully before you decide.

If you still have any questions or doubts the researcher will be happy to answer them for you.

Purpose of the study

This study examines the psychological impact of adolescent’s adjustment to maternal cancer diagnosis. It also explores the effectiveness of a web based intervention for adolescents in this situation.

What will you take part in?

Adolescents between 14 and 19 years of age will take part in 4 different phases:

1. Some adolescents (8 to 11) will have an online interview with the researcher using Skype. The interview will help the researcher understand the experiences and social support needs of adolescents adjusting to maternal cancer. This data will help inform the appropriateness of the proposed intervention for this specific context.
2. All adolescents will complete the AMC Survey online. These are scales which provide general information on the adolescent’s everyday life, including: relationships with parents, friends, siblings as well as feelings, emotions, thoughts, self perception and difficulties.
3. Adolescents will be part of an 8 week online intervention (AMC Intervention). Each weekly session has a specific theme: cancer, social support, self perception, staying calm, assertiveness,

emotions, communication and asking for help. All sessions provide information on these themes and include activities based on them. Half of adolescents will complete the Intervention first, and the second half will complete it later on.

4. Adolescents will complete the AMC Survey again, just after the AMC Intervention has finished and two months later.



Additionally, mothers will complete an information sheet including socio demographic information and illness characteristics.

Benefits of taking part

All the information provided by participants will enhance understanding of the psychological and emotional impact on adolescents when their mother has been diagnosed with cancer. This study will also determine if a web based intervention is an effective way to help adolescents when facing this situation.

Risks of taking part

Adolescents may feel distressed or upset whilst participating in this study as this may be a difficult and sensitive topic for them.

If this is the case, the researcher will provide information on services that supply emotional and psychological support if needed.

How will my identity be protected?

All the information provided will be stored and analyzed anonymously. Adolescent names and family names will not appear. Families will only have a research identification number that nobody else will know so they won't be identified in any reports or articles resulting from this study, all results will be only reported as group data.

Confidentiality will be broken if the mental and/or physical health of the participant is at risk or the participant is involved in an issue specified in the Child Protection Policy NUI Galway (2011) and the "Children First"-National Guidelines for the Protection and Welfare of Children. You will immediately be informed if this was the case.

Do I have to take part?

It is your decision to allow your adolescent to be part of this study. If you agree, you will be given this Information Sheet to keep and you will also be asked to sign a Consent Form. Even if you sign, you and your adolescent are free to withdraw at any time, without giving a reason. Withdrawing will not affect your rights or your family's in any way. Additionally, you can also explicitly ask that you would like your data to be removed from research databases.

If you have any questions or comments you can contact the researcher by email l.rodriquez2@nuigalway.ie or by phone 0858877718. Or contact Dr. AnnMarie Groake, Psychology, NUI Galway. annmarie.groarke@nuigalway.ie

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

Thank you for reading this!



**OÉ Gaillimh
NUI Galway**



Adolescent Adjustment to

Maternal Breast Cancer

MATERNAL INTERVIEW

PARTICIPANT CONSENT FORM

Purpose of the study

You are invited to join a study which examines the psychological impact of adjusting to maternal breast cancer diagnosis. This is a difficult and distressing time for you and your family but the information you provide will be used to enhance understanding of what you are going through and to analyze the relationship between adolescent experiences of maternal breast cancer and these experiences from their mum's point of view.

What will be involved if I agree to take part in this study?

If you agree to take part in this study you will be asked to complete a telephone or face to face semi structured interview with the researcher. These interviews will be recorded and the scripts will be transcribed for analysis.

Can I withdraw from the study?

Even if you decide to take part of this study you are free to withdraw at any stage without having to explain why and there will be no consequences for you or your family.

Confidentiality

All the information you provide will be anonymous. Your name or family name will not appear in any report resulting from this study. Findings will only be reported as group data.

If you have any queries please contact the research team, Leonor Rodriguez. Phone number 00353858877718 or email l.rodriguez2@nuigalway.ie. Or contact Dr. AnnMarie Groarke, Head of School, School of Psychology, NUI Galway annmarie.groarke@nuigalway.ie

AMBC
Adolescent Adjustment to Maternal Breast Cancer
PARTICIPANT CONSENT FORM

**Place a circle
round either**

Yes No

- | | | |
|---|-----|----|
| <p>1. I confirm that I have read and understood the information sheet about the study which is examining the psychological impact of adjusting to maternal breast cancer diagnosis.</p> | Yes | No |
| <p>2. I am satisfied that I understand the information provided and have had enough time to consider the information.</p> | Yes | No |
| <p>3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.</p> | Yes | No |
| <p>4. I understand that any information I give to the researcher is anonymous and will be treated with confidence.</p> | Yes | No |
| <p>5. I understand that I can ask the researcher questions about the study at any time.</p> | Yes | No |

Name: _____

Signed: _____

Date: _____

Please send back one signed copy of this Consent Form. The other copy is for you to keep.



Adolescent Adjustment to Maternal Breast Cancer

MATERNAL INTERVIEW

PARTICIPANT INFORMATION SHEET

I am inviting you to take part in a research study: ‘Adolescent Adjustment to Maternal Breast Cancer’. This Information Sheet provides a description of the study. Please read it carefully before you decide to take part.

If you still have any questions or doubts the researcher will be happy to answer them for you.

Purpose of the study

This study examines the psychological impact of adolescent’s adjustment to maternal breast cancer diagnosis. It also explores the effectiveness of a web based intervention for adolescents in this situation.

Study 2 will specifically contribute to identify the perception of mothers diagnosed with breast cancer on the process of adjustment of their adolescent sons and daughters and analyze the relationship between adolescent experiences of maternal breast cancer from their mum’s point of view. Study 2 will also identify the needs and social support needs that mothers have identified in their adolescent children in the process of adjustment to maternal breast cancer.

What will you take part in?

Women (N= 8-10) diagnosed with breast cancer in the previous 24 months, who have adolescent children (14 to 19 years) will be invited to take part of a face to face or telephone interview with the researcher. These interviews will be recorded and the scripts will be transcribed for analysis.

Benefits of taking part

All the information provided by participants will increase understanding of the psychological and emotional impact on adolescents when their mother has been diagnosed with breast cancer, identify their needs and their social support needs as well as identify ways to provide for those needs and improve their adjustment to maternal illness.

Risks of taking part

You may feel distressed or upset whilst participating in this study as this may be a difficult and sensitive topic for you.

If this is the case, the researcher will give you information on services that can provide emotional and psychological support if you need it.

How will my identity be protected?

All the information you provide will be stored and analyzed anonymously. Your name or family name will not appear. You and your family won't be identified in any reports or articles resulting from this study, all results will be reported as group data only.

Do I have to take part?

It is your decision to be part of this study. If you decide to take part you will be given this Information Sheet to keep and you will also be asked to sign a Consent Form. Even if you sign, you are free to withdraw at any time, without giving a reason. Withdrawing will not affect your rights or your family's in any way. Additionally, you can also explicitly ask that you would like your data to be removed from research databases.

If you have any questions or comments you can contact the researcher by email l.rodriguez2@nuigalway.ie or by phone 0858877718. Or contact Dr. AnnMarie Groake, Psychology, NUI Galway.

annmarie.groarke@nuigalway.ie

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

Thank you for reading this!



**OÉ Gaillimh
NUI Galway**



APPENDIX C

Adolescent Adjustment to Maternal Cancer

PROTOCOL FOR DISTRESSED PARTICIPANTS

The following is a procedural protocol for assisting participants who may become distressed while taking part in any of the four phases of this study.

1. Online survey

Every participant (adolescent, mother) can inform the researcher about being distressed or upset by phone, email or video conferencing.

The researcher will immediately:

1. Ask the participant which method they prefer to use to speak further about the problems or issues they are facing.
2. Researcher and participant can decide if another person (parent, guardian, or partner) should be informed of the situation to ensure the participant's safety and wellbeing.
3. If the situation persists, parents or guardians can decide to seek further help from their local general practitioner (GP) or any of the services provided in this protocol.
4. Ask the participant if it would be ok to call them later in the day or the next day to make sure they are doing well.
5. Participants can choose to withdraw from the study. They can also choose to withdraw their previous data from the research databases.

2. Online interviews

If a participant becomes distressed or upset during the interview they can inform the researcher immediately. The researcher will also be aware of physical signs of distress or discomfort from the participant and stop the interview immediately.

The researcher will:

1. Ask the person if they would like to take a break and if they would like to switch off the recorder.
2. Allow the person to withdraw from the group and speak apart with the group's co leader.
3. If the person continues to be upset, ask them if they would like to end their participation in the group and if they would like the researcher to call someone to spend time with them, such as a parent, guardian, family member or mentor.
4. Before leaving, ask the person if it would be ok to call them later in the day or the next day to make sure they are doing well.
5. If the participant continues to be distressed the researcher will follow points 3, 4 and 5 from the online survey protocol

3. Web based programme

Every participant (adolescent, mother) can inform the researcher about being distressed or upset by phone, email or video conferencing.

The researcher will immediately:

1. Ask the participant which method they prefer to use to speak further about the problems or issues they are facing.
2. Researcher and participant can decide if another person (parent, guardian, or partner) should be informed of the situation to ensure the participant's safety and wellbeing.
3. If the situation persists, parents or guardians can decide to seek further help from their local general practitioner (GP) or any of the services provided in this protocol.
4. Ask the participant if it would be ok to call them later in the day or the next day to make sure they are doing well.
5. Participants can choose to withdraw from the study. They can also choose to withdraw their previous data from the research databases.



**OÉ Gaillimh
NUI Galway**



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

STRESS MANAGEMENT PROCEDURES

GENERAL STRATEGIES TO MINIMIZE PARTICIPANT STRESS

- a) The interviewer must be trained to handle psychological distress and be sensitive to statements and/or behaviours which may suggest the interview is too stressful.
- b) Researcher has to make sure the adolescent is comfortable in the setting.
- c) Provide breaks during stressful data collection procedures.
- d) Divert attention from the distressing topic, for example talk about something the adolescent enjoys or likes.
- e) Consistent monitoring of participant emotional reactions.
- f) Determine if the adolescent wants support from another person, for example inform the parents or somebody they know, or provide information on professional help available.
- g) Provide information on available psychological or social services.

(Draucker, Martsof & Poole, 2009; Alderson & Morrow 2011)

PHASE 1: INTERVIEWS

PRIOR TO THE INTERVIEW

1. Prior to interview, the researcher will rule out individuals who seem to be experiencing acute emotional distress as the interview would only aggravate the situation.
2. Adolescents will be asked: “Are there any reasons you can think of that might make participating in this interview about your experience of maternal breast cancer too stressful for you?” (Draucker, Martsof & Poole, 2009)

If the answer was YES, the researcher will express concern and conduct a safety assessment with the following questions:

- a) Tell me what thoughts you are having.
- b) Tell me what you are feeling right now.

- c) Do you feel you are able to continue your day?
- d) Do you feel safe?
- 3. Participants will be encouraged to disclose these feelings to an adult (parent/caregiver) which they can trust and confide with so they seek appropriate help together.
- 4. Participants will be encouraged to contact his/her mental health care provider or they will be offered appropriate psychological referral.
- 5. The researcher will remain with the adolescent until they reach a stable emotional state.

DURING THE INTERVIEW

- 1. If the interview becomes distressful for participants they can be offered a break or divide the interview into different sessions.
- 2. The research can provide the adolescent with simple exercises that can help reduce the level of stress for example breathing exercises or simple relaxation exercises if the participant is willing to use the techniques.
- 3. If the level of distress is too distressful the researcher will ask the participant if they wish to terminate.
- 4. The researcher will encourage the adolescent to contact another person they can trust and confide with so they seek appropriate help together.
- 5. The researcher will remain with the adolescent until they reach a stable emotional state.

PHASE 2: SURVEY

PRIOR TO COMPLETING THE SURVEY

Prior to completing the survey online adolescents are reminded:

- 1. Participation is voluntary.
- 2. They are allowed to withdraw from the study at any point and decide whether their data is removed from the databases.
- 3. Adolescents are encouraged to contact the researcher if they experience any kind of distress or problems or have any questions.

DURING THE SURVEY

If an adolescent informs the researcher of distress the researcher will follow the distress protocol and get immediately in contact with the adolescent.

1. The researcher will conduct the safety assessment:
 - a) Tell me what thoughts you are having.
 - b) Tell me what you are feeling right now.
 - c) Do you feel you are able to continue your day?
 - d) Do you feel safe?
2. The research can provide the adolescent with simple exercises that can help reduce the level of stress for example breathing exercises or simple relaxation exercises if the participant is willing to use the techniques.
3. If the level of distress is too distressful the researcher will ask the participant if they wish to inform another person of the situation.
4. The child can identify a person known to them which they trust or would like to seek help from or the researcher can suggest specialists to the child and his/her parents or guardians, these are included in the Distressed Participant Protocol.
5. The researcher will remain with the adolescent until they reach a stable emotional state.

PHASE 3: PROGRAMME

PRIOR TO EACH SESSION OF THE ONLINE INTERVENTION

Adolescents are reminded:

1. Participation is voluntary.
2. They are allowed to withdraw from the study at any point and decide whether their data is removed from the databases.
3. Adolescents are encouraged to contact the researcher if they experience any kind of distress or problems or have any questions.

DURING THE INTERVENTION

If an adolescent informs the researcher of distress the researcher will follow the distress protocol and get immediately in contact with the adolescent.

1. The researcher will conduct the safety assessment:
 - a) Tell me what thoughts you are having.
 - b) Tell me what you are feeling right now.
 - c) Do you feel you are able to continue your day?
 - d) Do you feel safe?
2. The research can provide the adolescent with simple exercises that can help reduce the level of stress for example breathing exercises or simple relaxation exercises if the participant is willing to use the techniques.
3. If the level of distress is too distressful the researcher will ask the participant if they wish to inform another person of the situation.
4. The child can identify a person known to them which they trust or would like to seek help from or the researcher can suggest specialists to the child and his/her parents or guardians, these are included in the Distressed Participant Protocol.
5. The researcher will remain with the adolescent until they reach a stable emotional state.

PHASE 4: SURVEY

The same procedure will be followed as for phase 2 for subsequent occasions in which participants will complete the online survey.



**OÉ Gaillimh
NUI Galway**



IRISH RESEARCH COUNCIL
An Chomhairle um Thaighde in Éirinn

AMC Adolescent Adjustment to Maternal Cancer

CONTACT INFORMATION SHEET

The following is a list of national organizations that offer **free and confidential** support services. If you are distressed or upset please don't hesitate to get in contact with them.

1) Child Line

Support for young people up to 18 years of age

Phone: 1800 666 666. Or a free text message: send the word "Talk" to 50101.

Website: <http://www.childline.ie/Home.aspx>

2) Society of Saint Vincent de Paul

Support Services Phone: 09326293

Website: www.svp.ie

3) Samaritans

Emotional Support Services Phone: 1850 60 90 90

Website: www.samaritans.org

4) Aware

Mental Health Support Phone: 1890 303 302

Website: www.aware.ie

5) Jigsaw Galway

Support service for young people

Phone 091 549 252 Website: www.jigsaw.ie



**OÉ Gaillimh
NUI Galway**



**Adolescent Adjustment to Maternal Cancer
PROTOCOL FOR DISTRESSED PARTICIPANTS
MATERNAL INTERVIEWS**

The following is a procedural protocol for assisting participants who may become distressed while taking part of this study.

If a participant becomes distressed or upset during the interview they can inform the researcher immediately. The researcher will also be aware of physical signs of distress or discomfort from the participant and stop the interview immediately.

The researcher will:

1. Ask the person if they would like to take a break and if they would like to switch off the recorder.
2. Allow the person to withdraw and speak about the situation.
3. If the person continues to be upset, ask them if they would like to end their participation and if they would like the researcher to call someone to spend time with them, such as a family member or partner.
4. Before leaving, ask the person if it would be okay to call them later in the day or the next day to make sure they are doing well.
5. Participants can choose to withdraw from the study. They can also choose to withdraw their data from the research databases.



STRESS MANAGEMENT PROCEDURES

- a) The interviewer must be trained to handle psychological distress and be sensitive to statements and/or behaviours which may suggest the interview is too stressful.
- b) Researcher has to make sure the adolescent is comfortable in the setting.
- c) Provide breaks during stressful data collection procedures.
- d) Divert attention from the distressing topic, for example talk about something the adolescent enjoys or likes.
- e) Consistent monitoring of participant emotional reactions.
- f) Determine if the adolescent wants support from another person, for example inform the parents or somebody they know, or provide information on professional help available.
- g) Provide information on available psychological or social services.

(Draucker, Martsolf & Poole, 2009; Alderson & Morrow 2011)

PRIOR TO THE INTERVIEWS

6. Prior to interview, the researcher will rule out individuals who seem to be experiencing acute emotional distress as the interview would only aggravate the situation.
7. Participants will be asked: “Are there any reasons you can think of that might make participating in this interview about your experience of breast cancer too stressful for you?” (Draucker, Martsolf & Poole, 2009)

If the answer was YES, the researcher will express concern and conduct a safety assessment with the following questions:

- a) Tell me what thoughts you are having.
- b) Tell me what you are feeling right now.
- c) Do you feel you are able to continue your day?
- d) Do you feel safe?

8. Participants will be encouraged to disclose these feelings to an adult (psychologist/ partner/ friend) which they can trust and confide with so they seek appropriate help together.
9. Participants will be encouraged to contact his/her mental health care provider or they will be offered appropriate psychological referral.
10. The researcher will remain with the adolescent until they reach a stable emotional state.

DURING THE INTERVIEWS

- a) If the interview becomes distressful for participants they can be offered a break or divide the interview into different sessions.
- b) The research can provide the participant with simple exercises that can help reduce the level of stress for example breathing exercises or simple relaxation exercises if the participant is willing to use the techniques.
- c) If the level of distress is too distressful the researcher will ask the participant if they wish to terminate.
- d) The researcher will encourage the participant to contact another person they can trust and confide with so they seek appropriate help together.
- e) The researcher will remain with the participant until they reach a stable emotional state.



AMC Adolescent Adjustment to Maternal Cancer

CONTACT INFORMATION SHEET

The following is a list of national organizations that offer **free and confidential** support services.

If you are distressed or upset please don't hesitate to get in contact with them.

1) Society of Saint Vincent de Paul

Support Services Phone: 09326293

Website: www.svp.ie

2) Samaritans

Emotional Support Services Phone: 1850 60 90 90

Website: www.samaritans.org

3) Grow

World Community Mental health Movement in Ireland

Tel: 1890474474 Website: <http://grow.ie/get-help-now/>

4) National Cancer Helpline

Tel: 1 800 200 700 Mon- Thurs 9am-7pm. Fri (9am-5pm)

helpline@irishcancer.ie

5) Cancer Care West Support Centre

72 Seamus Quirke Road, Galway Tel: 091540040

info@cancercarewest.ie

APPENDIX D

Adolescent social support and needs interview script

1. What are you currently concerned about?
2. Do you have enough people in your life with whom you can talk to about these concerns?
3. What are your roles/responsibilities in your house?

Have you noticed changes in these roles or responsibilities recently?

4. Have you noticed changes in your usual activities since your mothers' diagnosis and treatment (Sports, school, family time, friends time, others)
5. What activities have you done recently to relax and/or have fun?
6. Did you get all the support you expected from family, school, community, friends others?

Did you get support when you asked for it?

What strategies do you use when you need to ask for help?

7. What kind of support did you feel you needed the most?
 - a) Tangible/ Concrete (visible, practical, like loaning a book to a friend)
 - b) Emotional (feelings, relationships, like talking to a friend)
 - c) Esteem (positive characteristics people recognise in you)
 - d) Advice (help with a decision or provide information)
8. Who informed you about your mothers' cancer diagnosis (father, mother, sister, brother, another family member, teacher, friend, health staff)?
9. How did you cope/deal with your mothers' diagnosis?

Is there anything in particular that has helped you through this time?

What do you think could help you even more?

Do you have a person (s) to talk to about the cancer experience?

10. Where did you look for information about cancer and/or treatment (father, mother, sister, brother, another family member, teacher, friend, health staff, books or didn't look for information)?
11. Have you noticed changes in the relationship with your mother since diagnosis?
- 18 Has the experience of maternal cancer made you realise who you can really count on?
- 19 Has this experience of having a mother diagnosed with cancer affected or changed people around you in ways you didn't expect or understand?
- 20 What would you recommend to other adolescents facing the same experience as you?
- 21 How can health professionals (physicians, nurses, psychologists) help you?

APPENDIX E

Maternal social support and needs interview script

How did your adolescent(s) find out about your illness?

What do you think your adolescent(s) knows or understands?

What or who was your adolescent(s) source of information?

What changes have you noticed in your family since diagnosis?

Have you noticed any changes in your adolescent(s) behaviour since diagnosis?

What were the specific roles of each family member before the diagnosis, did this change? If so, how?

Did you notice any changes in the daily life or activities that your adolescent(s) did before?

What strategies did they use to cope, relax or have fun?

What do you think has been the most challenging part of this experience for your adolescent(s)?

What or who has helped your adolescent in this process?

Has your relationship with your adolescent(s) changed since the diagnosis? If so, how?

Is there anything else you would like to tell me about the experience of cancer on your adolescent(s)?

What would you recommend to other mothers facing the same experience as you?

How can health professionals (physicians, nurses, psychologists) help you and your adolescent?

APPENDIX F

Family Questionnaire

AMC STUDY FAMILY QUESTIONNAIRE

Family Questionnaire

Please read all questions carefully. Fill in all questions. There are no wrong answers.

ALL INFORMATION YOU PROVIDE IS CONFIDENTIAL AND WILL ONLY BE USED IN THIS RESEARCH FOR CONTACT PURPOSES. All information will be securely stored and properly disposed according to the NUI Galway 'Data Protection Act'.

***1. Name**

***2. Family name**

***3. Email**

***4. Relationship to child**

Biological parent

Adoptive parent

Step parent

Foster parent

Other

Other (please specify)

***5. What is your country of birth?**

***6. what is the country of birth of your adolescent?**

***7. How many sons and/or daughters do you have in total?**

***8. Which type of school your son/daughter goes to:**

Public

Semi private

Private

Other

Other (please specify)

AMC STUDY FAMILY QUESTIONNAIRE

***9. What is your date of birth? (Day/Month/Year)**

***10. Current Address**

***11. The household is:**

- Owned
- Rented
- Shared
- Mortgaged
- Borrowed
- Other

Other (please specify)

***12. Number of people living in the house**

***13. What is your current marital status?**

- Married
- Single
- Separated
- Divorced
- Widow
- Currently in a relationship
- Other

Other (please specify)

AMC STUDY FAMILY QUESTIONNAIRE

***14. What is your situation regarding work?**

- Employee (apprenticeship/ community employ)
- Self employed
- Farmer
- Student full-time
- On state training scheme
- Unemployed/ Actively looking for a job
- Long term sickness/ disability
- Home duties
- Retired
- Other

Other (please specify)

***15. What is the highest level of education you have completed to date?**

- Primary or less
- Intermediate/ Junior/ Group certificate or equivalent
- Diploma/ Certificate
- Primary degree
- Postgraduate/ Higher degree
- Refusal
- Other

Other (please specify)

***16. Is your family time enjoyable?**

- No
- Yes

***17. Do you feel family time is less enjoyable in the last weeks?**

- No
- Yes

Household Chores

AMC STUDY FAMILY QUESTIONNAIRE

***18. Cooking**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***19. Ironing**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***20. Laundry**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***21. Cutting grass**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***22. Looking after the car**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***23. Children school work**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

AMC STUDY FAMILY QUESTIONNAIRE

***24. Bring children to doctor/ hospital**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***25. Wash dishes**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***26. Painting**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***27. Vacuum/ cleaning**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***28. Taking bins out**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***29. School runs**

- Mother
- Other
- Father (partner)
- Mother and father (partner)

AMC STUDY FAMILY QUESTIONNAIRE

30. Runs to extracurricular activities and friend's households.

- Mother
- Other
- Father (partner)
- Mother and father (partner)

***31. Besides cancer, do you have any other chronic physical or mental health issue?**

- No
- Yes

32. If yes, please name the illness/ diagnosis

33. Time since diagnosis

***34. What is your cancer diagnosis (type)?**

***35. Cancer date of diagnosis (Day/Month/Year)**

***36. Are you currently undergoing treatment?**

- Yes
- No

AMC STUDY FAMILY QUESTIONNAIRE

***37. What is/ was your treatment for cancer? (Please select as many as you need).**

- Surgery
- Mastectomy
- Axillary lymph node removal
- Lumpectomy
- Radiation
- Chemotherapy
- Hormonal therapy
- Targeted therapy
- Other

Other (please specify)

AMC STUDY FAMILY QUESTIONNAIRE

***38. What side effects have you experimented? (Please choose as many as you need)**

- Anaemia
- Fatigue
- Fertility issues
- Hair changes/loss
- Infection
- Memory loss
- Menopause symptoms
- Mouth/ throat sores
- Nail changes
- Nausea
- Neuropathy
- Diarrhoea
- Taste and smell changes
- Vomiting
- Weight changes
- Bone loss/ osteoporosis
- Heart problems
- Vision/ eye problems
- Armpit dysfunction
- Lowered white cells counts
- Lung problems
- Skin reactions
- Mood swings
- Other

Other (please specify)

39. What is your cancer grade? (If you know it)

Thank you!

Thank you very much.

If you have any questions or comments you can contact the researcher by email l.rodriguez2@nuigalway.ie or by phone 0858877718. Or contact Dr. AnnMarie Groake, Psychology, NUI Galway. annmarie.groarke@nuigalway.ie

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact 'the Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for

APPENDIX G**AMC Survey****Adolescent Coping Orientation for Problem Experiences ACOPE
(Patterson & Mc Cubbin, 1987)****When you face difficulties or feel tense, how often do you...**

	Never	Hardly	Sometimes	Often	Most of the time
	1	2	3	4	5
Go along with parent's requests and rules	1	2	3	4	5
Read	1	2	3	4	5
Try to be funny and make light of it all	1	2	3	4	5
Apologize to people	1	2	3	4	5
Listen to music-stereo, radio	1	2	3	4	5
Talk to a teacher or counsellor at school about what bothers you	1	2	3	4	5
Eat food	1	2	3	4	5
Try to stay away from home as much as possible	1	2	3	4	5
Use drugs prescribed by doctor	1	2	3	4	5
Get more involved in activities in school	1	2	3	4	5
Go shopping, buy things you like	1	2	3	4	5
Try to reason with parents and talk things out, compromise	1	2	3	4	5

Try to improve yourself (get body in shape, get better grades, etc.)	1	2	3	4	5
Cry	1	2	3	4	5
Try to think of the good things in your life	1	2	3	4	5
Be with a boyfriend or girlfriend	1	2	3	4	5
Ride around in the car	1	2	3	4	5
Say nice things ("warm fuzzies") to others	1	2	3	4	5
Get angry and yell at people	1	2	3	4	5
Joke and keep a sense of humour	1	2	3	4	5
Talk to a minister/priest/rabbi	1	2	3	4	5
Let off steam by complaining to family members	1	2	3	4	5
Go to church	1	2	3	4	5
Use drugs (not necessarily prescribed by a doctor)	1	2	3	4	5
Organize your life and what you have to do	1	2	3	4	5
Swear	1	2	3	4	5
Work hard on school work or school projects	1	2	3	4	5
Blame others for what's going on	1	2	3	4	5
Be close with someone you care about	1	2	3	4	5
Try to help other people	1	2	3	4	5

solve their problems					
Talk to your mother about what bothers you	1	2	3	4	5
Try, on your own, to figure out how to deal with your problems or tension	1	2	3	4	5
Work on a hobby you have (sewing, biking, etc.)	1	2	3	4	5
Get professional counselling (not a school teacher or school counsellor)	1	2	3	4	5
Try to keep up friendships or make new friends	1	2	3	4	5
Tell yourself the problem(s) is not important	1	2	3	4	5
Go to a movie	1	2	3	4	5
Daydream about how you would like things to be	1	2	3	4	5
Talk to a brother or sister about how you feel	1	2	3	4	5
Get a job or work harder at one	1	2	3	4	5
Do things with your family	1	2	3	4	5
Smoke	1	2	3	4	5
Watch T. V.	1	2	3	4	5
Pray	1	2	3	4	5
Try to see the good things in a difficult situation	1	2	3	4	5
Drink beer, wine, liquor	1	2	3	4	5

Appendices

Try to make your own decisions	1	2	3	4	5
Sleep	1	2	3	4	5
Say mean things to people, be sarcastic	1	2	3	4	5
Talk to your father about what bothers you	1	2	3	4	5
Let off steam by complaining to your friends	1	2	3	4	5
Talk to a friend about how you feel	1	2	3	4	5
Play video games (Space Invaders, Pac-Man), pool, pinball, etc.	1	2	3	4	5
Do a strenuous physical activity (jogging, biking, etc.)	1	2	3	4	5

Perceived Stress Scale (Sheldon & Cohen, 1983)

The questions in this scale ask about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
	0	1	2	3	4
In the last month how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
In the last month how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
In the last month how often have you felt nervous and “stressed”?	0	1	2	3	4
In the last month how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
In the last month how often have you felt that things were going your way?	0	1	2	3	4
In the last month how often have you found that you could not cope	0	1	2	3	4

with all the things that
you had to do?

In the last month how often have you been able to control irritations in your life?	0	1	2	3	4
--	---	---	---	---	---

In the last month how often have you felt that you were on top of things?	0	1	2	3	4
--	---	---	---	---	---

In the last month how often have you been angered because of things that were outside of your control?	0	1	2	3	4
--	---	---	---	---	---

In the last month how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4
--	---	---	---	---	---

Social Network Questionnaire, Perceived Social Support

(Cutrona and Dolan, 2002)

In answering the next 4 questions, please think about your current relationships with your friends. If you feel a question accurately describes your relationships with your friends, you would say “yes.” If the question does not describe your relationships, you would say “no.” If you cannot decide whether the question describes your relationships with your friends, you may say “sometimes.”



1. Are there friends you can depend on to help you, if you really need it?

NO

SOMETIMES

YES



2. Do your relationships with your friends provide you with a sense of acceptance and happiness?

NO

SOMETIMES

YES



3. Do you feel your talents and abilities are recognised by your friends?

NO

SOMETIMES

YES



4. Is there a friend you could trust to turn to for advice, if you were having problems?

NO

SOMETIMES

YES



In answering the next set of questions, please think about your current relationships with your parent(s)/carer.

5. Can you depend on your parent(s)/carer to help you, if you really need it?

NO

SOMETIMES

YES



6. Do your relationships with your parent(s)/carer provide you with a sense of acceptance and happiness?

NO

SOMETIMES

YES



7. Do you feel your talents and abilities are recognised by your parent(s)/carer?

NO

SOMETIMES

YES



8. Could you turn to your parent(s)/carer for advice, if you were having problems?

NO

SOMETIMES

YES



In answering the next set of questions, please think about your current relationships with your brother(s) and/or sisters(s).

Again mark either No Sometimes or YES

9. Can you depend on your brother(s)/sister(s) to help you, if you really need it?

NO

SOMETIMES

YES



10. Do your relationships with your brother(s)/sister(s) provide you with a sense of acceptance and happiness?

NO

SOMETIMES

YES



11. Do you feel your talents and abilities are recognised by your brother(s)/sister(s)?

NO

SOMETIMES

YES



12. Could you turn to your brother(s)/sister(s) for advice, if you were having problems?

NO

SOMETIMES

YES



In answering the next set of questions, please think about your current relationships with any other adult person in your community for example a teacher, sports coach or other adult who you know and who supports you.

13. Can you depend on other adult(s) you know to help you, if you really need it?

NO **SOMETIMES** **YES**



14. Do your relationships with this adult(s) provide you with a sense of acceptance and happiness?

NO **SOMETIMES** **YES**



15. Do you feel your talents and abilities are recognised by this adult?

NO **SOMETIMES** **YES**



16. Could you turn to another adult for advice, if you were having problems?

NO **SOMETIMES** **YES**

ID REF. No : _____

DATE : _____

TIME 1

SOCIAL NETWORK QUESTIONNAIRE

(Cutrona and Russell 1981; with amendments by Dolan 2002)

INSTRUCTIONS: Please list below under “NAME”;

- First, the people you see and spend time with during a typical week. You only need to write first names or initials of all the people you see and talk to during a normal week. This would include the people you live with.
- Second, any other people whom you consider your close friends (not already listed). A close friend is a person with whom you really communicate and in whom you can confide about feelings and personal problems. The friendship is valued because of the warmth, caring, and emotional sharing it provides.
- Third, the people whom you consider your casual friends (not already listed). These are people with whom you mainly do activities such as shopping, school work, sports activities, etc
- Fourth, any relative to whom you feel close (not already listed).
- Finally, if there are other important people in your life that have not already been noted, please write them under “NAME” also.

NAME	A	B	C

The following questions should be answered for each person you've just listed. Score your response next to each name. The column letters refer to the questions below.

A

A. Does "NAME" live in your home?

✓ = YES

X = NO

B

B. What is "NAME"'s relationship to you?

01 = MOTHER

02 = FATHER

03 = CARER/ STEP-PARENT OR FOSTER PARENT

04 = BROTHER/SISTER

05 = OTHER RELATIVE

06= CLOSE FRIEND

07 = OTHER FRIEND

08 = OTHERS IN RESIDENTIAL SETTING (NOT LISTED AS FRIENDS)

09 = PROFESSIONAL PERSON (PLEASE LIST TYPE)

10 = OTHER PERSON, PLEASE STATE

C

C. Is most of your contact with "NAME" positive (make you feel good), or negative (make you feel bad)?

1 = BAD

2 = HALF AND HALF

3 = GOOD

DASS 21

Please read each statement and circle a number 0, 1, 2, or 3 which indicates how much the statement applied to you *over the past week*.

There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

0 Did not apply to me at all

1 Applied to me to some degree, or some of the time

2 Applied to me to a considerable degree, or a good part of time

3 Applied to me very much, or most of the time

- | | | | | |
|---|---|---|---|---|
| 1. I found it hard to wind down. | 0 | 1 | 2 | 3 |
| 2. I was aware of dryness in my mouth. | 0 | 1 | 2 | 3 |
| 3. I couldn't seem to experience any positive feeling at all. | 0 | 1 | 2 | 3 |
| 4. I experienced breathing difficulty (e.g. excessively rapid breathing, breathlessness in the absence of physical exertion). | 0 | 1 | 2 | 3 |
| 5. I found it difficult to work up the initiative to do things. | 0 | 1 | 2 | 3 |
| 6. I tended to over – react to situations. | 0 | 1 | 2 | 3 |
| 7. I experienced trembling (e.g. in the hands) | 0 | 1 | 2 | 3 |
| 8. I felt that I was using a lot of nervous energy. | 0 | 1 | 2 | 3 |
| 9. I was worried about situations in which I might panic and make a fool of myself. | 0 | 1 | 2 | 3 |
| 10. I felt that I had nothing to look forward to. | 0 | 1 | 2 | 3 |
| 11. I found myself getting agitated. | 0 | 1 | 2 | 3 |
| 12. I found it difficult to relax. | 0 | 1 | 2 | 3 |
| 13. I felt down – hearted and blue. | 0 | 1 | 2 | 3 |

Appendices

14. I was intolerant of anything that kept me from getting on with what I was doing.	0	1	2	3
15. I felt I was close to panic.	0	1	2	3
16. I was unable to become enthusiastic about anything.	0	1	2	3
17. I felt I wasn't worth much as a person.	0	1	2	3
18. I felt I was rather touchy.	0	1	2	3
19. I was aware of the action of my heart in the absence of physical exertion (e.g. sense of heart rate increase, heart missing a beat).	0	1	2	3
20. I felt scared without any good reason.	0	1	2	3
21. I felt that life was meaningless.	0	1	2	3

Feelings and Emotions (PANAS-C)

(Laurent J, Catanzaro S., Joiner T., Rudolph K., Potter K., Lambert S., Osborne L. & Gathright T, 1999)

This scale consists of a number of words that describe different feelings and emotions.

Read each item and then circle the appropriate answer next to that word.

Indicate how much you have felt this way during the past few weeks.

	Not much or not at all	A little	Some	Quite a bit	A lot
Interested	1	2	3	4	5
Sad	1	2	3	4	5
Frightened	1	2	3	4	5
Alert	1	2	3	4	5
Excited	1	2	3	4	5
Ashamed	1	2	3	4	5
Upset	1	2	3	4	5
Happy	1	2	3	4	5
Strong	1	2	3	4	5
Nervous	1	2	3	4	5
Guilty	1	2	3	4	5
Energetic	1	2	3	4	5
Scared	1	2	3	4	5
Calm	1	2	3	4	5
Miserable	1	2	3	4	5
Jittery	1	2	3	4	5
Cheerful	1	2	3	4	5
Active	1	2	3	4	5
Proud	1	2	3	4	5
Afraid	1	2	3	4	5
Joyful	1	2	3	4	5
Lonely	1	2	3	4	5
Mad	1	2	3	4	5

Appendices

Fearless	1	2	3	4	5
Disgusted	1	2	3	4	5
Delighted	1	2	3	4	5
Blue	1	2	3	4	5
Daring	1	2	3	4	5
Gloomy	1	2	3	4	5
Lively	1	2	3	4	5

Inventory of Parent and Peer Attachment

(Gay C. Armsden and Mark T. Greenberg, 1987)

Each of the following statements asks about your feelings about your mother, or the woman who has acted as your mother. If you have more than one person acting as your mother (e.g. a natural mother and a stepmother) answer the questions for the one you feel has most influenced you.

Please read each statement and circle the ONE number that tells how true the statement is for you now.

	Almost never or never true	Not very often true	Sometimes true	Often true	Almost true or always true
1. My mother respects my feelings	1	2	3	4	5
2. I feel my mother does a good job as my mother.	1	2	3	4	5
3. I wish I had a different mother.	1	2	3	4	5
4. My mother accepts me as I am.	1	2	3	4	5
5. I like to get my mother's point of view on things I'm concerned about.	1	2	3	4	5
6. I feel it's no use letting my feelings show around my mother.	1	2	3	4	5
7. My mother can tell when I'm upset about something.	1	2	3	4	5
8. Talking over my problems with my	1	2	3	4	5

mother makes me feel ashamed or foolish.					
9. My mother expects too much from me.	1	2	3	4	5
10. I get upset easily around my mother.	1	2	3	4	5
11. I get upset a lot more than my mother knows about.	1	2	3	4	5
12. When we discuss things, my mother cares about my point of view.	1	2	3	4	5
13. My mother trusts my judgment.	1	2	3	4	5
14. My mother has her own problems, so I don't bother with mine.	1	2	3	4	5
15. My mother helps me to understand myself better.	1	2	3	4	5
16. I tell my mother about my problems and troubles.	1	2	3	4	5
17. I feel angry with my mother.	1	2	3	4	5
18. I don't get much attention from my mother.	1	2	3	4	5
19. My mother helps me	1	2	3	4	5

to talk about my difficulties.					
20. My mother understands me.	1	2	3	4	5
21. When I am angry about something, my mother tries to be understanding.	1	2	3	4	5
22. I trust my mother.	1	2	3	4	5
23. My mother doesn't understand what I'm going through these days.	1	2	3	4	5
24. I can count on my mother when I need to get something off my chest.	1	2	3	4	5
25. If my mother knows something is bothering me, she asks me about it.	1	2	3	4	5

Satisfaction with Life Scale

(Diener et al., 1985)

Below are five statements that you may agree or disagree with. Using the 1 - 7 scale below, indicate your agreement with each item by placing the appropriate number on the line preceding that item. Please be open and honest in your responding.

- 7 - Strongly agree
- 6 - Agree
- 5 - Slightly agree
- 4 - Neither agree nor disagree
- 3 - Slightly disagree
- 2 - Disagree
- 1 - Strongly disagree

___ In most ways my life is close to my ideal.

___ The conditions of my life are excellent.

___ I am satisfied with my life.

___ So far I have gotten the important things I want in life.

___ If I could live my life over, I would change almost nothing.

General Self-Efficacy Scale
(Schwarzer & Jerusalem, 1995)

For each of the following statements, please circle the choice that is closest to how true you think it is for you. The questions ask about your opinion.

There are no right or wrong answers.

	Not at all true 1	Hardly true 2	Moderately true 3	Exactly true 4
I can always manage to solve difficult problems if I try hard enough.	1	2	3	4
If someone opposes me, I can find the means and ways to get what I want.	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals.	1	2	3	4
I am confident that I could deal efficiently with unexpected events.	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations.	1	2	3	4
I can solve most problems if I invest the necessary effort.	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities.	1	2	3	4

When I am confronted with a problem, I can usually find several solutions.	1	2	3	4
If I am in trouble, I can usually think of a solution.	1	2	3	4
I can usually handle whatever comes my way	1	2	3	4
I can always manage to solve difficult problems if I try hard enough.	1	2	3	4

APPENDIX H
AMC Programme

AMC PROGRAMME: CANCER SESSION 1
WELCOME TO SESSION 1
<p>1. Please remember your participation in this study is voluntary.</p> <p>2. You may withdraw from the study at any moment and this will not have any consequences for you or your family.</p> <p>3. As this is an online individual study, please contact the researcher by any of the means provided (email, telephone) if you experience any distress or problems that limits or impedes your participation.</p> <p>4. If you have any questions or queries please contact the researcher.</p> <p>*1. What is your research identification number?</p> <input style="width: 100%; height: 20px;" type="text"/>
KNOWLEDGE CHECK
<p>These questions are about cancer. Try to fill in as many as you can.</p> <p>YOU ARE NOT EXPECTED TO KNOW ALL THE ANSWERS!</p> <p>Please don't worry if you don't and just say so.</p> <p>By the end of this programme you will be able to answer them so don't worry.</p> <div style="text-align: center; margin: 10px 0;">  </div> <p>*2. What is cancer?</p> <input style="width: 100%; height: 20px;" type="text"/> <p>*3. Do you know how many grades of cancer are there?</p> <input style="width: 100%; height: 20px;" type="text"/> <p>*4. What treatment has your mother undergone?</p> <input style="width: 100%; height: 20px;" type="text"/> <p>*5. What questions do you have about cancer?</p> <input style="width: 100%; height: 20px;" type="text"/> <p>*6. Who do you think can help you answer these questions?</p> <input style="width: 100%; height: 20px;" type="text"/> <p>*7. Who would you ask?</p> <input style="width: 100%; height: 20px;" type="text"/>
WHAT IS CANCER?
Empty space for the 'WHAT IS CANCER?' section

AMC PROGRAMME: CANCER SESSION 1

Like any other living thing, the human body is made up of more than 200 different cell types (brain cells, lung cells, blood cells).

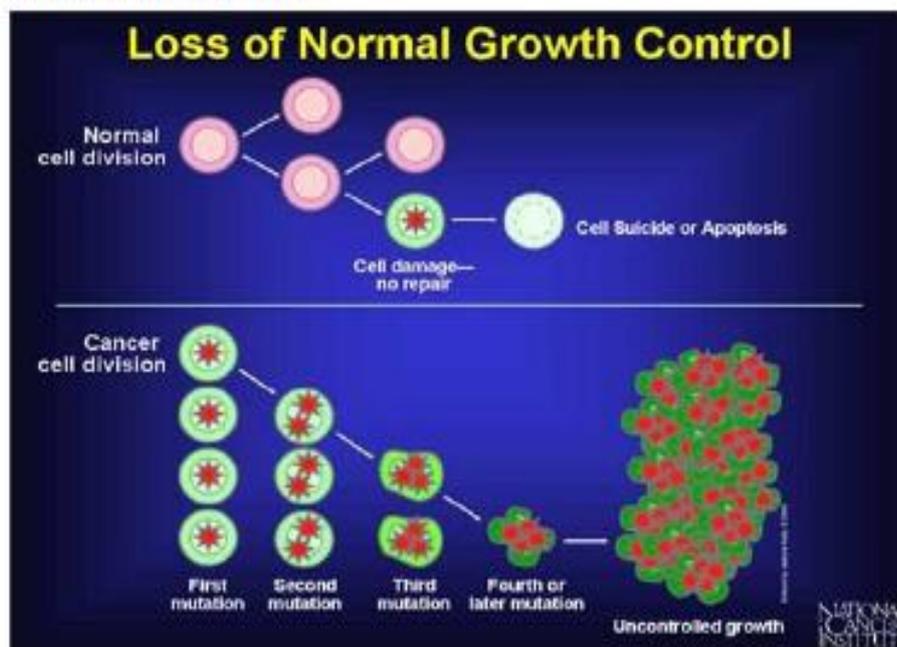
All cells go through a cycle in which they grow and multiply. However this process is controlled. Ideally only healthy cells are allowed to multiply and abnormal or damaged cells would be detected and stopped from dividing.

The genetic information in charge of the cell cycle might become damaged, leading to a faulty process and the cell will multiply at the wrong time or the wrong place leading to cancer.

Cells can support and accumulate a certain amount of damage over time, however eventually these may become cancer cells, multiply and form a tumour. Cancer cells can separate from the tumour and enter the blood stream or the lymphatic system, and travel around the body causing damage to other parts (metastasis).

(Cancer Research UK, 2009)

What are abnormal cells?



Abnormal cells are cells which don't look or behave like healthy cells in your body.

TYPES OF CANCER

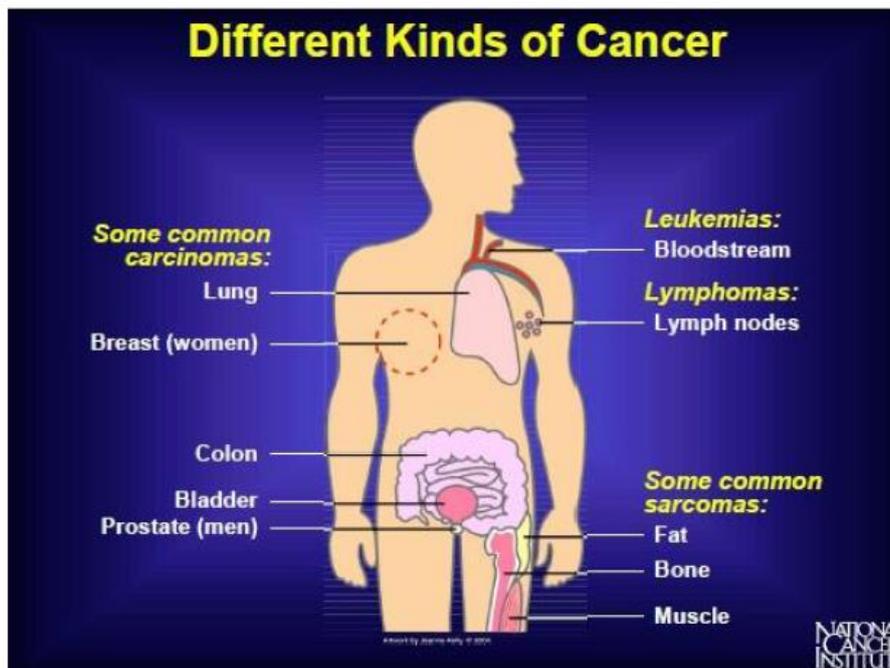
There are several types of cancers for example lung cancer, cancer of the larynx, liver cancer, pancreatic cancer, small bowel cancer, gall bladder cancer, amongst others.
(www.rprap.uk)

AMC PROGRAMME: CANCER SESSION 1

CANCER	DEFINITION
Bowel Cancer	Cancer located in any area of the large intestine, specifically colon, rectum or appendix.
Breast Cancer	Cancer in cells of the breast. It can occur in females and males.
Lung Cancer	Cancer in the cells of the lungs. There are two types: small cell and non-small cell.
Prostate Cancer	Cancer cells in the prostate, a small gland located below the bladder and surrounding the tube that carries urine from the bladder through the penis.
Leukaemia	Cancer of the white small cells which are made in the bone marrow.
Lymphoma	Cancer in the lymphatic system that is part of the immune system which protects the body from illnesses.
Brain tumours or Central Nervous System	Cancer in the brain or spinal cord.
Germ cell tumours	Cancer located in the reproductive organs.
Melanoma	Type of skin cancer.
Thyroid cancer	Cancer in the thyroid gland that controls the use of energy in the body, makes proteins and is in charge of the body's sensitivity to hormones.

TYPES OF CANCER

Cancer can originate in many parts of the body and would have a different classification depending on where it is located.



AMC PROGRAMME: CANCER SESSION 1

TYPES	DEFINITION
Carcinomas	Cancer originates on the cells that cover external and internal body surface. example, lung, breast and colon.
Sarcomas	Cancer is found in the supporting tissues of the body like bones, cartilage, connective tissue and muscle.
Lymphomas	Cancer originates in the body's immune system like lymph nodes.
Leukaemia	Cancer of the immature blood cells that grow in the bone marrow and spread in the blood stream.

REDUCING THE BURDEN- CANCER RESEARCH

1. Research can help people understand the risk factors associated with cancer and it can also help to determine the efficacy of interventions to prevent and manage the illness.
2. Research helps understand illness behaviour and characteristics and this allows the creation of new treatments and medicine that have improved the possibilities of treating cancer and try to save more people over the years.

Some of the strategies that could help reduce and control cancer are:

Evidence based strategies for cancer prevention.
 Early detection of cancer.
 Appropriate management of patients and their families.

Cancer survival rates worldwide are improving. According to Cancer Research UK, cancer survival rates have doubled in the last 40 years.

The AMC Study is seeking to understand the experience of women, families and adolescents who are experiencing a cancer diagnosis. Your support and input will help women, families and adolescents to have better experiences through this situation.



EARLY DETECTION

What is early detection?

Early diagnosis consists of being aware of early signs and symptoms to avoid advanced stages of the illness.

What is screening?

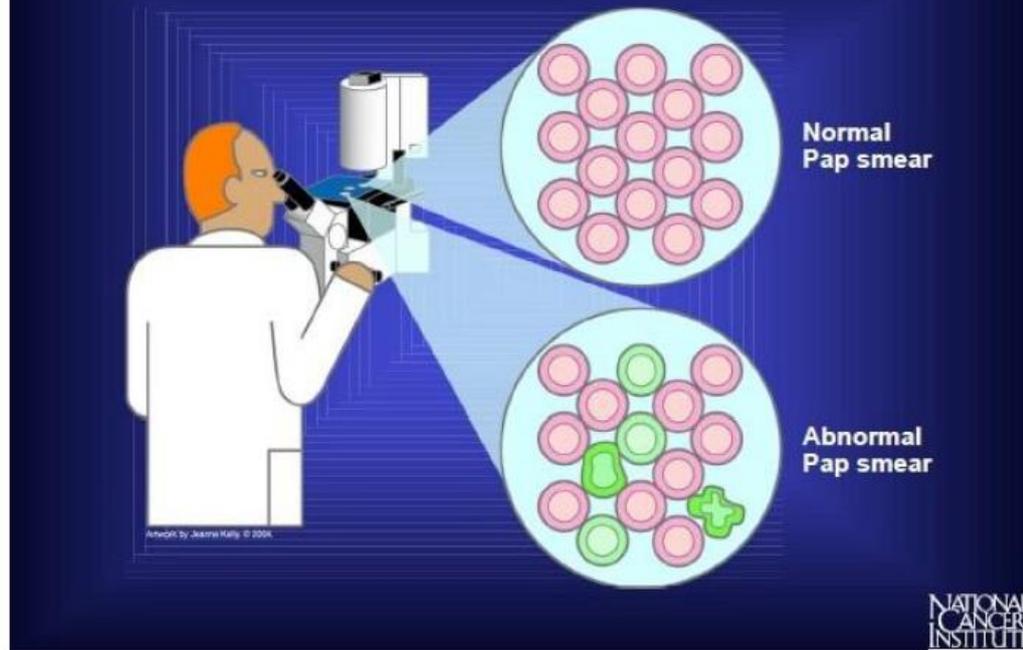
Screening is a systematic application of a test in a population to identify possible abnormalities and refer the person to diagnosis and treatment as soon as possible, if required.

Some of the test available that you might have heard of are:

1. PAP test for cervical cancer.
2. Mammography screening for breast cancer.

AMC PROGRAMME: CANCER SESSION 1

Cervical Cancer Screening



What is a biopsy?

A biopsy is carried out to determine the presence of cancer by looking at a sample of tissue under a microscope (For leukaemia, a blood sample is used for the same purpose). This test can determine whether the tumour is malignant (cancer) or benign.

Cancer Grades

Based on the microscopic appearance of cancer cells, doctors can assign a numerical 'grade' to the cancer which is based on the possible behaviour of a tumour in response to treatment.

Cancers with higher abnormal cell appearance and greater numbers of dividing cells tend to grow faster and spread more easily. Lower grade numbers (I and II) are cancers with fewer cell abnormalities than those with higher grades (III and IV).



ADULT CANCERS

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According to 'CanTeen Australia', these are the most common types of cancer in adults.

CANCER	DEFINITION
Bowel Cancer	Cancer located in any area of the large intestine, specifically colon, rectum or appendix.
Breast Cancer	Cancer in cells of the breast. It can occur in females and males.
Lung Cancer	Cancer in the cells of the lungs. There are two types: small cell and non-small cell.
Prostate Cancer	Cancer cells in the prostate, a small gland located below the bladder and surrounding the tube that carries urine from the bladder through the penis.
Leukaemia	Cancer of the white small cells which are made in the bone marrow.
Lymphoma	Cancer in the lymphatic system that is part of the immune system which protects the body from illnesses.
Brain tumours or Central Nervous System	Cancer in the brain or spinal cord.
Germ cell tumours	Cancer located in the reproductive organs.
Melanoma	Type of skin cancer.
Thyroid cancer	Cancer in the thyroid gland that controls the use of energy in the body, makes proteins and is in charge of the body's sensitivity to hormones.

CANCER IN WOMEN WORLDWIDE

Many adolescents around the world are also facing the situation of their mother's diagnosis with cancer.

Adolescents can react in different ways some may feel good, relax and calm while others may feel worried, angry sad or anxious. These feelings can even change, there may be good days and bad days as well.

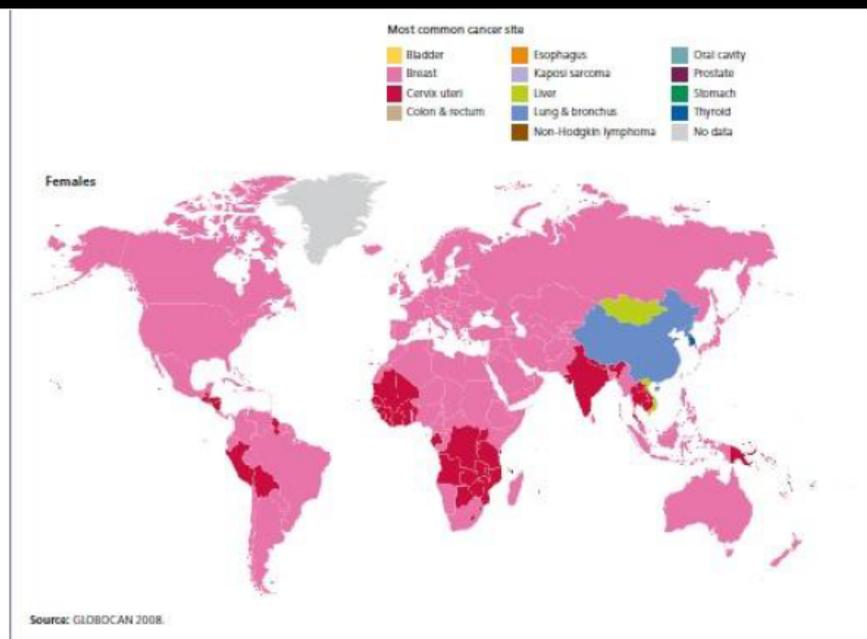
The World Cancer Research Fund International determined the most common types of cancer in women worldwide.

Breast cancer was the most common cancer, representing 25% of all new cancer diagnosis in 2012. Exclusively female cancers like cervical cancer represented 8% of all cancer in the same period.

The Top 10

1. Breast
2. Colorectal
3. Lung
4. Cervix uteri
5. Stomach
6. Corpus uteri (endometrium)
7. Ovary
8. Thyroid
9. Liver
10. Non Hodgkin

AMC PROGRAMME: CANCER SESSION 1



CANCER TREATMENTS

Specific treatments for cancer are carefully selected and usually involve one or a combination of different treatments such as surgery, radiotherapy or chemotherapy.

The main objective of treatment is to cure the illness, prolong life and improve the patient's quality of life.

Patients and their families can benefit from psychological support.



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TREATMENT	DEFINITION
Surgery	Surgery can help diagnose, treat or prevent cancer. Surgery could remove the affected area before it has spread to other parts of the body, increasing the chances of cure.
Chemotherapy	Special drugs/ medicines to treat cancer. Affects healthy cells causing side effects.
Radiation Therapy	High energy particles or waves are targeted to destroy cancer cells.
Targeted Therapy	Involves the use of drugs or substances to identify and destroy cancer cells.
Immunotherapy	The body's own immune system is used to fight the cancer. Also called Biologic Therapy or biotherapy.
Hyperthermia	Further research is required but delivery of heat, hyperthermia is being used to fight different cancer types.
Stem Cell Transplant	Bone marrow transplants include peripheral blood, bone marrow and cord blood transplants that are used to treat cancers.
Photodynamic Therapy	Drugs called photosensitizing agents and light are used to kill cancer cells. These drugs are activated by specific types of light.
Laser	Laser is a powerful beam of light which can be very precise and used instead of scalpels for very precise and delicate surgical interventions for some cancers. Some treatments may be short term only so treatment may need to be repeated.

SIDE EFFECTS

All people respond differently to treatment, depending of the types and characteristics of treatment received but also on each person's body function.

Some of the side effects common to several types of treatment are:

Weakness, fatigue, anaemia, diarrhoea, hair loss, memory loss, weight changes, nail changes, skin changes, bone loss, heart and vision difficulties, pain, discomfort, blisters, vomit, nausea, cough, bone loss and headache.

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HOW CAN I HELP?

Your role as an adolescent is to:

1. Go to school.
2. Do your homework.
3. Keep in contact with your friends and spend time with them.
4. Have some fun for example watch a comedy show.
5. Stay fit and healthy: relax, play sports, get enough sleep, eat and drink well.
6. Avoid risky behaviours: smoking, drinking and/or drugs.



HOW CAN I HELP MY MOTHER

1. Spend time with her when you do your homework or just be there in silence.
2. Express your love and care.
3. Bring water, a small snack or a meal.
4. Talk to you mother about what you did during the day, keep a journal together, draw or write about what you share with each other.
5. Help with your brothers and sisters if you feel like it: play games, read books together.

Don't be afraid to ask her how you can help. You know her better after all!



PLEASE REMEMBER...

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- 1.You deserve to have specific and honest information.
- 2.You are entitled to your privacy; you can decide who you want to talk to.
- 3.It is important for you to spend time with your friends, keep up with your school work, go to social activities and have some fun.
- 4.You may feel that you need to be taken care of and not just be responsible for taking care of others, you can be taken care of and your needs fulfilled.
- 5.You can ask for help or advice from the medical team, family, friends, neighbours, teachers, coaches, nurses, guidance counselors or members of your religious community.
- 6.It is healthy to cry and express your feelings if you want to and with people you feel comfortable and good with. You might be feeling scared, guilty, angry, neglected, lonely, embarrassed. Your feelings are valid and important.
- 7.You can be involved in your mother's treatment if you want to.
- 8.You are not alone.
- 9.You are not to blame.
- 10.You don't have to feel always positive and cheerful, especially when you don't feel like it.
- 11.Some of the information you may have read or heard may not apply to you mother. All cases are different.
- 12.Getting back to "normal" life may be difficult and even take a long time. It may even not happen as you expect it.



YOUR GOALS

I would like you to set up a goal (goals) you would like to accomplish by the end of this programme.

It can be related to any aspect of your life but it has to be important to you and realistic.

These tips can help you...



AMC PROGRAMME: CANCER SESSION 1

MAKING SMART GOALS

What do you think makes a good goal?

Good goals should be realistic and achievable it might mean setting a series of small goals that help us make progress towards achieving a larger goal.

These SMART strategies may help you to decide what makes a good goal and how you can improve your goal making skills and achieve them!

S- Specific

M- Measurable

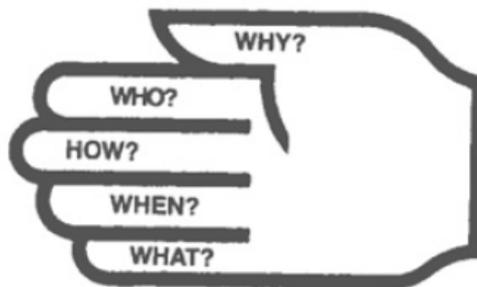
A- Achievable

R- Realistic

T- Time-bound

How to set SMART goals: The five friends.

The five friends is a simple formula to set goals.



Think about the:

WHY? The reasons for working towards a goal

WHO? The person who will carry out the plan

HOW? The step-by-step actions required

WHEN? The time within which each step will be done and the goal achieved

WHAT? The resources needed to achieve the goal

THINKING EXERCISE

1. What parts of our life do you need to develop goals and plans for?
2. How will the "five friends" help you achieve your goals?
3. How can the "five friends" be useful in your life?
4. Are having goals important in life? Why or why not?

AMC PROGRAMME: CANCER SESSION 1

SETTING MY GOALS WORKSHEET

	GOAL	WHY	WHO	HOW	WHEN	WHAT
PERSONAL						
FAMILY						
EDUCATION						
WORK						
FINANCIAL						
FRIENDS						
HEALTH						

1. Add any extra areas of your life that you would like to set goals for in the blank spaces.



You can use the worksheet attached to your email to complete this task.

FEEDBACK

***8. What is your goal (goals) in this programme?**

***9. Did you learn something about yourself in this session?**

Yes

No

Other (please specify)

***10. Did you learn something new about other people?**

Yes

No

Other (please specify)

***11. How useful did you find this session?**

Not at all

A little useful

Useful

Very useful

Extremely useful

Other (please specify)

AMC PROGRAMME: CANCER SESSION 1

*12. How difficult did you find this session?

- Not at all
- A little difficult
- Difficult
- Very difficult
- Extremely difficult

Other (please specify)

*13. What would you change to improve this session?

CONTACT INFORMATION

If you have any problems or queries please don't hesitate to contact me:

Email: l.rodriquez2@nuigalway.ie
Skype: Leonor_AMBC
Phone: 0858877718

THANK YOU!

You will receive by email the link to the next session shortly!



Session 2

AMC SESSION 2

WELCOME TO SESSION 2!

1. Please remember your participation in this study is voluntary.
2. You may withdraw from the study at any moment and this will not have any consequences for you or your family.
3. As this is an online individual study, please contact the researcher by any of the means provided if you experience any distress or problems that limits or impedes you participation.
4. If you have any questions or queries please contact the researcher.

***1. What is your research identification number?**

KNOWLEDGE CHECK

These questions are about social support.

Try to fill in as many answers as you can.

YOU ARE NOT EXPECTED TO KNOW ALL THE ANSWERS!

Please don't worry if you don't, just say so.

You are involved in a learning process that will make this information easier for you.



***2. What do you think social support is?**

***3. How many types of social support do you know?**

***4. What type of social support can you provide?**

***5. How many sources of social support do you have?**

***6. Why is social support important?**

***7. Do you have any questions about social support?**

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*8. Who might help you answer these questions?

WHAT IS SOCIAL SUPPORT?

Social support means the acts we do to give or get help from other people. This can include words, actions and feelings.

Social support relates to reduced stress and good coping in life.

Social support is the psychological and emotional, informational, and practical (tangible) benefits we receive from our personal relationships.



"I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel".

Maya Angelous



WHY IS SOCIAL SUPPORT IMPORTANT?

Social support impacts people's self-esteem, self-identity, self-efficacy, intimacy accomplishment and warmth.

It can help you:

- Feel good.
- Buffer stress.
- Enhance mental health.
- Increase your ability to cope.

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In stressful situations social support becomes very important as it has emotional and psychological effects like:

- Consolation
- Comfort
- Alleviation of loneliness

People can provide concrete (tangible) help for us like:

- Help with household chores (cooking a meal, cleaning, lend a book)
- Financial assistance



WHO ARE TYPICAL MEMBERS OF A SOCIAL SUPPORT NETWORK?

- Family members (parents, siblings, aunts, cousins)
- Close friends
- Acquaintances (church, school, clubs)
- Pets

CAN SOCIAL SUPPORT BE NEGATIVE?

YES

- When the type of support somebody offers you is not the support you need you might feel distressed.
- When people try to get TOO involved and make decisions for you.
- If someone becomes increasingly critical it may cause tension and stress in the relationship.



WHAT CAN YOU DO?

- Learn to identify the types of support some people can provide for you, some are better at some than others.
- Before you reach out for help, think of who might be able to address your needs, increasing your chances of success.
- Don't be afraid of speaking up to achieve a shared construction of the situation.
- There is no "ideal" support system as specific situations have specific demands. People's needs may change during their life course. Don't be afraid to develop new relationships according to your new needs and the resources available for you.

TYPES OF SOCIAL SUPPORT

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	TYPE OF SUPPORT	DEFINITION
T	Tangible /Concrete support	Visible, practical and physical forms of help like loaning a book to a friend or helping a friend tidy up their room.
	Emotional support	Involves feelings and intimate relationships. For example listening to your best friend when they need to talk.
E	Esteem support	Involves what other people think about you and all the positive characteristics you have
A	Advice support	Helping people with a decision or providing information.

QUALITIES OF SOCIAL SUPPORT



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	QUALITY OF SUPPORT	DEFINITION
C	Closeness	Feelings of ease, comfort and familiarity towards people in the social network.
A	Admonishment (non criticizing)	Criticism from someone in the social network might make a person feel bad or inadequate.
R	Reciprocity	Extent to which favours provided by others can be returned. It is the balance of taking and giving within the social network.
D	Durability	People need to be reasonably sure that they will receive support when they ask for it.

HOW DO I IMPROVE MY SOCIAL SUPPORT?

Several strategies can be used to improve the quality of your social support network.

1. Asking for help.
2. Break down social support into individual components.
 - Seek information.
 - Request practical (tangible) help.
 - Request friends and family for time to spend together on illness related activities and also leisure activities.
 - Communicate feelings and needs directly.
 - Try to explore new ways of sharing feelings and receiving support.



MY SOCIAL SUPPORT NETWORK

Your social support network is typically made of your family, friends, neighbours and even your pets.

However, people don't provide you with the same kind of support. You may feel closer to some and turn to different

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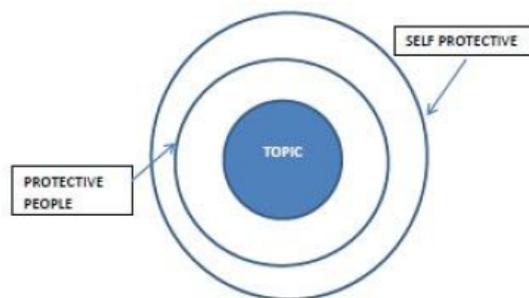
people in different occasions. As you remember, this is the quality of social support.

These activities will help you identify the people in your network, the types of support they provide and the quality of that support.



EXERCISE: SAFETY MAP

1. Take a sheet of paper.
2. Write an important problem, situation or topic you are facing.
3. On the next circle write the name of people that are protective of you and support you in that situation.
4. In the external circle write names of people you feel you should be self-protective of at this moment.



RELATIONSHIPS

Read the following statements and try to think about what the answers mean to you.

1. What is a relationship?
2. What are the different types of relationships that young people find themselves in?
3. Why do people get into relationships?



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Think, or write down, all the things that are needed to keep a ship afloat and moving.

Like a ship needs calm seas, fuel, a solid hull or base to keep afloat. Certain things are needed to keep relationships "afloat".

Think about all the things that are needed for a strong and healthy relationship (of any kind) and things that may ruin a relationship.

FOR EXAMPLE:

STRONG HEALTHY RELATIONSHIPS NEED...	THINGS THAT RUIN A RELATIONSHIP....
<ul style="list-style-type: none"> • Respect • • • • • 	<ul style="list-style-type: none"> • Dishonesty • • • • •

RELATIONSHIPS

Relationships can be of many kinds, they are not always romantic. Relationships are any kind of interaction or connection with others.

Young people may be involved in relationships with peers, friends, parents, adult relatives, siblings, teachers, community or with a girlfriend or boyfriend.

Healthy and strong relationships are usually based on respect, empathy, genuineness, values, attitude and communication.

Respect

Respect is shown through attitudes and behaviour. The other person must feel valued, worthwhile, and important. Negative criticism, name-calling, and ridiculing are destructive. Useful ways to show respect include being there when needed, listening carefully to what is said, and responding accordingly.

Empathy

This means trying to understand another person's position, that is, trying to see situations from the other person's point of view. This shows a deeper understanding, particularly if communicated back to the other person using different words to make sure you understand.

Genuineness

Being genuine involves being yourself and having positive self-esteem.

Values and Attitudes

Successful friendships/relationships are often based on the individuals having similar values. Two people will continuously be in conflict if their values about most things differ. Values can change over time, owing to changing circumstances, etc. This may have an effect on a relationship.

Communication

Humans communicate verbally and non-verbally. Verbal communication is talking. Non-verbal communication, also known as body language, is shown by listening, smiling, frowning, nodding, body posture, etc. Communication reveals how one individual feels about another.

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TIPS TO REMEMBER!



No two people are the same. We therefore need to compromise and understand each other's differences for relationships to be successful.

Respect and communication are two important factors needed to build a good relationship

We have to be honest with ourselves and those we have a relationship with. We can say when things are going right and when we are unhappy about something.

We need to assess our relationships and decide whether they are good or bad for us.

Everyone deserves good relationships. Each of us has a clear idea of what we would like in a friend or partner, and we must be able to hold onto that.

Remember that the best relationships result from each person working hard at giving the best of themselves at all times.

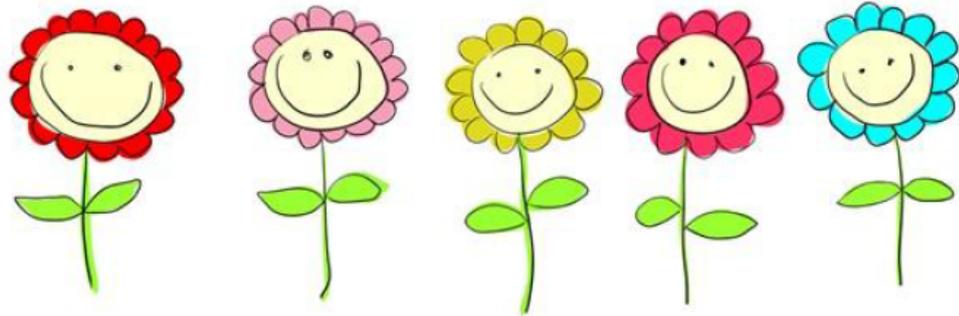
EXERCISE: MY FRIENDS

1. Take a sheet of paper. Divide it in three parts (or a word document if you prefer).
2. Make a list of friends that nurture you.
3. Next to your friends write down what type of support are they more likely to provide for you (tangible, emotional, esteem, advice).
4. On the third column write which qualities you think you have in that relationship (closeness, reciprocity, admonishment, durability).

***9. Which traits do you admire on friends that nurture you?**

***10. Which of their characteristics really help you?**

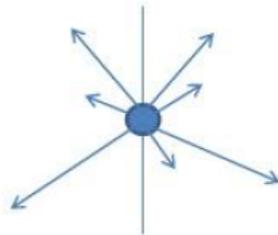
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EXERCISE: THE WHEEL

1. Think of 6 to 10 people that are important to you.
2. Draw a wheel with spikes of different lengths.
3. At the end of each spike, write the names of the people you thought of.

The people who are most important to you usually are on the spikes closer to you.
The position of people varies over periods of time.



*** 11. How much has it changed over the last months?**

*** 12. How would you like it to be?**

*** 13. What can you do to change it?**

EXERCISE: WHILE WE HAVE BEEN TOGETHER

1. Think about an important person in your life.
2. Think about the relationship you have with this person and what it means to you.
3. Complete the following statements.

You may share this with your person or you might just keep it to yourself.

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- The thing that made me most angry was:
- The funniest thing was:
- The thing I regret most:
- I was upset when:
- The most interesting thing was:
- The thing which made me most nervous was:
- The most valuable experience was:
- My best memory is:
- The thing I would like to repeat the most is:
- The thing which interested me least was:
- The thing which made me angry with myself was:
- The thing I would like to do more of is:
- The thing I would like to do less of is:
- The thing that made me happy was:



EXERCISE: MY FRIEND

1. Call a friend who treats you really well.
2. Let them know why they are important to you.

You may also agree on meeting to do something you enjoy together (watch a movie, play, meet for tea/coffee)

***14. How does this person help you accomplish things?**

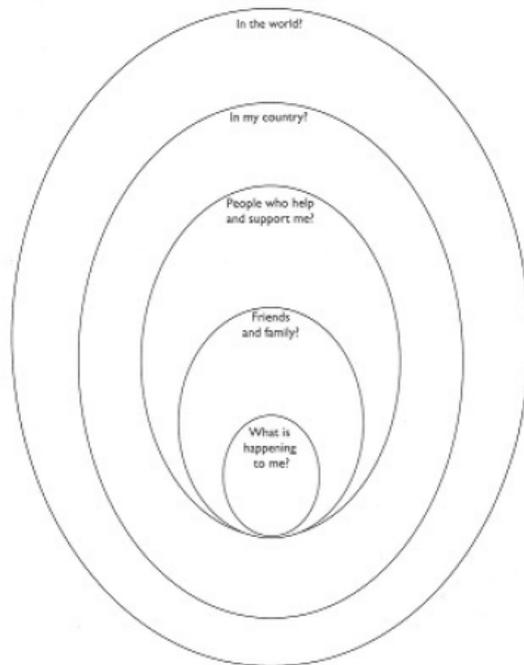
***15. How does he or she provide support for you?**



MY CIRCLE OF LOVED ONES

Identify people who are within your circle of loved ones, including parents, carers, close friendships or people that love you and write their name in this circle.

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***16. Who is in your circle and why?**

***17. How do you show your love to them?**

***18. How do they show their love to you?**

EXERCISE: MESSAGE SHEET

In order to grow in relationships with one another, it is important to practice the skill of providing honest and constructive feedback.

When facing difficult times it is helpful to share information about things you like or dislike about each other's way of dealing with the situations you face.

1. Choose a person you would like to help or understand better at this moment.
2. Print or write the following message sheet and share it with the person you chose.
3. Fill your own message sheet and share it as well, only if you want to.

TO:.....

FROM:.....

1. I like it when you do these things.....

Please keep doing them!!

2. Please do more of the following.....

3. Please do less of these things.....

4. Please think about starting to do these things.....

AMC SESSION 2



FEEDBACK

***19. Did you learn something about yourself in this session?**

Yes

No

Other (please specify)

***20. Did you learn something new about other people through these activities?**

Yes

No

Other (please specify)

***21. How useful did you find this session?**

Not at all

A little useful

Useful

Very useful

Extremely useful

Other (please specify)

***22. How difficult did you find this session?**

Not at all

A little difficult

Difficult

Very difficult

Extremely difficult

Other (please specify)

AMC SESSION 2

***23. What would you change to improve this session?**

CONTACT INFORMATION

If you have any problems or queries please don't hesitate to contact me:

Email: l.rodriquez2@nuigalway.ie

Skype: Leonor_AMBC

Phone: 0858877718

THANK YOU

You will receive by email the link to the next session shortly!



Session 3

AMC SESSION 3**WELCOME TO SESSION 3!**

1. Please remember your participation in this study is voluntary.
2. You may withdraw from the study at any moment and this will not have any consequences for you or your family.
3. As this is an online individual study, please contact the researcher by any of the means provided if you experience any distress or problems that limits or impedes your participation.
4. If you have any questions please contact the researcher.

***1. What is your research identification number?**

EXERCISE: ME

You need a tape recorder or the video/ audio device on your computer or your mobile phone.

This task is very simple. You will press record and start talking about yourself, like when you meet someone for the first time. You can say anything you like, as long as it is about you. At first, social barriers are likely to inhibit you but, after a while, these are eased and you are likely to start talking openly.

You may, if you wish, play the record back once you have finished.

**2. What surprised you during this exercise?**

3. What did you learn/like about the description when you played it back?

EXERCISE: NEWS OF THE YEAR

1. Imagine you are a reporter who has been given the task of writing an article on the news of the year. People will buy the newspaper and read the news.

2. Think about an item of media news, but this time it will be personal news. It can be news that you find both easy or hard to share.

3. Try to write an article about this news: what happened, when did it happen, who is involved, how did you feel then, how do you feel now.

AMC SESSION 3



4. Did this exercise help you in any way? How?

TIP: PERCEPTION CHECK

These strategies can help you when you are trying to make sure you have understood other people's feelings.

A perception check has three parts:

1. You describe what the other person's feelings are.
2. You ask whether or not your perception is accurate.
3. You refrain from expressing approval or disapproval of the feelings.



MY FRIENDSHIP SKILLS

Social skills can help us maintain and foster positive relations that help our well-being. If we are more aware of the motives and feelings of ourselves and others can help us deal more authentically with other people. People who have good social skills can be good at friendship. Look at the friendship qualities below and rate yourself against each one.

FRIENDSHIP SKILLS WORKSHEET

Think about your own friendship skills.
(You can use the worksheet attached to your email to complete this task)

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QUALITY	1	2	3	4	5
Show interest in what people do					
Good at giving compliments					
Have a pleasant expression					
Laugh at people's jokes					
Kind					
Ask, not demand, to join in					
Offer to help others					
Invite people to do things					
Hang around where other students are					
Welcoming to other students					
Good at thinking of interesting things to do					

Once you completed the worksheet...

Select three areas in which you would like to improve.

***5. What would you like to do?**

***6. How would you like to achieve it?**

***7. Who might support you and help you in this?**

EXERCISE: BODY BEAUTIFUL

Our bodies are made of many different parts. Each person can contribute to other people with his/her own special talents and abilities.

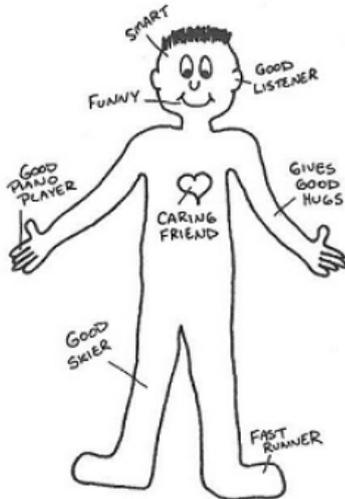
You can do this activity by yourself or ask another person (friend/bother/ sister/ cousin) to help you.

1.You can take a big piece of paper and trace your silhouette (you will lie down on the floor so you need someone

AMC SESSION 3

else's help for this).

2. Write in each body part one or several positive things you can do with it. (For example on the arms write 'give hugs', on the ears 'good listener').



A DAILY ACT OF KINDNESS

Authentic acts of kindness and empathy are good ways to act and respond to other people, this also contributes to developing positive relationships in our lives.

This would allow us to be able to see a situation from someone else's point of view ('walk in their shoes') to be able to provide the support they may need and help them make things better.

Try to intentionally carry out an act of kindness every day for one week. Record your act of kindness every day, including what it was, what happened and the thoughts and feelings this had in you.



DAILY ACT OF KINDNESS WORKSHEET

You can use the worksheet provided to complete this task if you want.

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	Act of kindness- what was it?	Outcome- what happened?	Review- my thoughts and feelings
MONDAY			
TUESDAY			
WEDNESDAY			
THURSDAY			
FRIDAY			
SATURDAY			
SUNDAY			

TIPS: SELF-TALK

Self-talk is a cognitive skill which can help you stay calm in stressful situations or exchanges with other people. Your task is to write down more self-praise phrases that you already use or that you would like to use more often. Feel free to add more lines if you need them.

TALKING NICE TO YOURSELF

Some examples are:

- "Hang in there, stay calm"
- "That was all right, I said in my mind and I didn't give up or get too upset"
- _____
- _____
- _____
- _____
- _____
- _____
- _____

Listen to the audio recording "Affirmations for Stress Management". The file is attached in the email for this session. If you have any problems, let me know!



AMC SESSION 3

FEEDBACK

***8. Did you learn something about yourself in this session?**

Yes

No

Other (please specify)

***9. Did you learn something new about other people through these activities?**

Yes

No

Other (please specify)

***10. How useful did you find this session?**

Not at all

A little useful

Useful

Very useful

Extremely useful

Other (please specify)

***11. How difficult did you find this session?**

Not at all

A little difficult

Difficult

Very difficult

Extremely difficult

Other (please specify)

***12. What would you change to improve this session?**

CONTACT INFORMATION

If you have any problems or queries please don't hesitate to contact me:

Email: l.rodriquez2@nuigalway.ie

Skype: Leonor_AMBC

Phone: 0858877718

Session 4

AMC SESSION 4**WELCOME TO SESSION 4**

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4. If you have any questions please contact the researcher.

*** 1. What is your research identification number?**

BE CALM BEFORE YOU TALK!

Staying calm is both an interpersonal and a cognitive skill that can help your relationships with other people.

If you engage in a discussion and you are not calm, you might end up screaming, fighting and not finding any good solutions.

Relaxation and meditation are strategies that can help you feel calm when you are feeling stressed, angry or distressed.

Here are several exercises that you can try, starting from the most simple to more complex. Not all exercises suit all people so try to figure out which one works best for you.

The more you practice, the easier it will become!

**EXERCISE: QUICK RELAXATION ROUTINE. THE QUICK FIX.**

1. Tune in to your breathing. Take one deep breath in, hold it, then tell yourself to let go as you breathe out. Breathe naturally for a while, repeating the instruction to let go with every outward breathe. Choose an instruction that fits for you: "Keep calm", "Hang in there", "Take it slow", "Let it go", etc.
2. Tense up and then relax a single muscle group such as your hand, foot, or stomach. When you let go, try to let all the unnecessary tension slip away.
3. Drop your shoulders.

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'When I just want to relax I just turn on the classical station and just lay down close my eyes and relax, meditate, and do yoga'.
15-18 year old daughter.

Listen to the audio recording attached for this session " Stress Management for Teens".

Look for a comfortable quiet place where you can concentrate and relax!!

If you have any problems please let me know!



TIP: RELAXING PHRASES

These phrases can help you focus your attention when relaxing. Choose the phrase that works better for you and concentrate on only one per exercise if you want.

1. I feel very relaxed.
2. I am starting to feel relaxed.
3. I feel my feet heavy and relaxed.
4. I feel my ankles, knees and hips heavy, relaxed and comfortable.
5. I feel my chest and stomach relaxed.
6. I feel my hands, arms and shoulders relaxed and comfortable.
7. I feel my body heavy, comfortable and relaxed.
8. My hands and arms are heavy and warm.
9. My whole body is relaxed.
10. Heat is flowing in my hands.
11. I feel my body comfortable, relaxed and calm.
12. My mind is calm.
13. I separate my thoughts and feel calm and relaxed.
14. I can see myself in the back of my mind relaxed, comfortable and calm.
15. My mind is calm.
16. I am enjoying these sensations.
17. The energy in my body makes me feel light and full of life.

AMC SESSION 4



BENEFITS OF RELAXATION AND MEDITATION

BENEFITS OF RELAXATION AND MEDITATION

- Physiological effects: heart and breathing rate slows down, oxygen consumption decreases by 20%, alpha (relaxation) activity in the brain.
- Get rid of stress and tension.
- Help you feel better in general.
- Impact on people's health. It helps in the treatment of chronic diseases like migraine, diabetes and heart disease, as well as anxiety, depression and many other issues.



EXERCISE: PASSIVE RELAXATION

- Choose a nice comfortable place where you will have no interruptions.
- Sit down with your arms and legs extended. Loosen your clothes if you have to, until you feel completely comfortable.
- You can close your eyes or fix them in a single point over the roof above you.
- You will begin to relax. All your muscles will begin to loosen, from your feet all the way up to your head, after a few seconds, focus your attention on your breathing.
- Breathe trying to let the air in slowly and deeply. Feel your stomach as it fills up with air. When you exhale, try to take double the time that you take to inspire.
- Pay close attention to the moment when the air comes out and when the air comes in.
- Fix your attention in your breathing, your tensed muscles, the sound of the air around you, the feeling of air coming in and out of your body, the movement or the tightness in your chest, check the humidity in your nose and any sensation in your body.
- Continue to breathe in and out.
- Fix your attention in one phrase or one image that you enjoy, for example the word serenity, relaxation, tranquility. Continue to let the air out gently.
- Choose only one phrase at a time and fix your attention on it.
- It is normal to hear distracting sounds, voices or thoughts in your mind, let them come and be part of your respiration cycle.
- Some people like to choose images and sensations from comfortable and nice places. Keep these images in your mind and enjoy them for a few more moments.

AMC SESSION 4

- Take all the time you need. Start moving your body slowly, your hands, your feet. Check how you are feeling at this moment. Slowly get ready to come back to the room and open your eyes.
- The exercise has ended.



EXERCISE: PROGRESSIVE RELAXATION

- Sit down comfortably, with your back straight, your feet touching the floor and your knees slightly separated.
- Try to wear comfortable clothes that don't exert any pressure on any part of your body.
- You will work with different muscles in your body, relaxing and contracting them. Make sure you can handle the tension so it shouldn't be painful.

Procedure:

- Straighten your right arm in front of you. Close your fist tightly, more tightly, much tighter. Pay close attention to the tension you achieved in your arm and fist.
- Lose your fist slowly and pay attention to what happens, what sensations did you notice, how does your skin feels.
- Let your muscles relax, let them loose, don't exert any force. Compare your sensation now to the one you had a few moments ago.
- Repeat the same exercise with your left arm.
- Now try doing the exercise with both arms at the same time.
- Now rest and breathe deeply.
- Proceed to tense and relax the muscles of your face.
- Lift your eyebrows, keep the tension for a while. Fix your attention on the tension and release it slowly. Pay attention to all the changes and sensations you are feeling.
- Continue with the muscles of your head, neck and jaw.
- Lift your shoulders as if you wanted to reach your eyebrows with them.
- Repeat the movement once more. Breathe deeply and exhale slowly through your mouth.
- Continue with the muscles of your chest and down to your stomach. Notice the tension and the relaxation sensations.
- Now raise your toes up like if you were trying to reach your knees. Raise your legs slowly and notice the tension.
- Relax your muscles and let them come back to their original position.
- Push your ankles strongly against the floor. Notice the sensations you feel in your legs. Let your muscles relax slowly.
- To finish, the exercise, inhale through your nose and exhale through your mouth. Repeat the exercise five times. Take your time and slowly come back to this moment.
- The exercise has finished.

WHAT IS MEDITATION

Meditation is essentially a nonjudgmental attempt to focus your attention on one thing at a time.

Mantra meditation

This is the kind of meditation you make when you concentrate on one word, syllable or group of words at a time.

AMC SESSION 4

These exercises can help you begin with meditation:

- Gazing at a fixed object for example a candle flame or a flower.
- Concentrate on the inhalation and exhalation process of your own breathing.



Listen to the meditation attached for this session: "Guiding Star Meditation".



EXERCISE: STILL QUIET PLACE

I would like to share one of my favourite places with you. I call it the Still Quiet Place. It's not a place you travel in a car, train, or plane. It's a place inside you that you can find by just closing your eyes. Close your eyes and take some slow, deep breaths. See if you can feel a kind of warm, happy smile in your body. Do you feel it? That is your Still Quiet Place. Take some deeper, slow breaths and really snuggle in. The best thing about your Still Quiet Place is that it is always inside of you. And you can visit it whenever you like. It is nice to visit your Still Quiet Place and feel the love that is there. It is especially helpful to visit your Still Quiet Place if you are feeling angry, sad, or afraid. The Still Quiet Place is a good place to talk with these feelings and make friends with them. When you are in your Still Quiet Place and talk to your feelings, you may find that you feelings are not as big and powerful as they seem.



EXERCISE: THE SEAWEED MEDITATION

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Pretend that you are a seaweed beneath the sea. Your feet are rooted in the soft white sand. You move with the waves, but your feet stay still on the ground. Pretend that your arms and head any upper body are being moved gently by warm, green-blue water. Notice how your body feels as it is moved slowly and gently by the waves. Now pretend that there's a wind making bigger waves in the sea, and your body moves a little faster, a little more wildly. Back and forth, and swirling in circles. Keep your feet on the ground. Notice how your body feels as you are moved about by the waves.

The storm is passing, and the waves begin to calm. Little by little, let your seaweed body move slower, and slower as the waves move slower and slower. Practice this for a few moments until you are still. Notice how your body feels as you slow down.



EXERCISE: STILL QUIET SHIP

When you are angry, close your eyes, and imagine you are in a huge sailing ship that is heavy and safe in the water. Outside the porthole of your ship is the sky, and it is stormy. Imagine that your feelings and thoughts are the storm clouds – you can watch them safely from inside your ship. Each time a thought, or picture in your mind shows up, place it on a storm cloud, and watch it move on the wind. You are on a wide ocean, and the sky touches the sea all around you. You are close to storm clouds, but you are safe in your steady ship. Watch what they do outside the porthole. What do they look like? Are they moving slowly or quickly? Is there lightning? Thunder? Rain? How they move, and when they come and go.



EXERCISE: INNER PEACE AFFIRMATIONS FOR GROWING UP IN A CRAZY WORLD.

Listen to the "Inner Peace- Affirmations for Growing Up in a Crazy World". This meditation can help you soften angry or critical regards to other people and help you relax.

Don't forget to tell me how you felt while you did this exercise and any of the others you tried!

AMC SESSION 4



Inner Peace Affirmations for Growing Up In a Crazy World

I choose compassion, instead of violence.
I choose tolerance and understanding instead of hatred.
I choose peace instead of fringe or anger.
I choose faith, instead of fear.
I am a peaceful and a compassionate person.
I look for the peaceful and the beautiful things that are all around me.
I look for the good in other people and for the good inside of me.
I am kind to people, even when they don't deserve it.
I carry competence with me.
Instead of waiting for things to happen to me, I go out and make a difference in the world around me.
When I feel worried about how everything will work out, I am free to choose to just trust that somehow it will.
I trust my instincts. I will know what to do in each moment as it arises.
The most important decision is always the one that lies directly in front of me.
My power and peace are in the present, I chose, in this moment, to be at peace.
I let go of things that I can't control, and embrace the things that I can control.
I can control how I treat myself and others in each moment.
I can control my thoughts, I can relax my mind and body.
I accept the things that I cannot change.
I don't have to figure everything out right now.
For the next few minutes take some time to relax your body and your mind.
Think about the person, the best part of you wants to become.

STOP AND LISTEN!

At any given time there are many sounds that can be heard by the human ear. Some people find it more easily to concentrate on a single sound while others may get easily distracted and may miss out on information that someone else is giving.
Before you can support someone, you have to listen carefully to what they need. Listening is a basic skill for successful communication.

AMC SESSION 4



EXERCISE: SOUNDS AROUND

1. Choose a place you like, preferably outdoors.
2. Carry a pen or pencil and a notebook with you or something to write on.
3. Listen carefully and try to identify any sounds you hear and write them down.
4. After 10 or 20 minutes you will have a very long list.



***2. Where you surprised at the number of sounds you heard?**

***3. Do you feel that you are a good listener? Why or why not?**

***4. How do you think you may become a better listener?**

RATE YOUR OWN LISTENING SKILLS

You can rate your listening skills with this scale. You are not expected to be perfect, this is only to identify areas in which you can improve if you would like to.

4=always, 3= most, 2= sometimes and 1= never

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1. I look the speaker in the eye when he or she is talking.
2. I can pay attention even if the subject bores me.
3. I wait for the speaker to finish before responding.
4. I keep an open mind and do not respond negatively to others' ideas or feelings.
5. I do more listening than talking.
6. I give the speaker my full attention. I do not look at my watch, fidget, do something else at the same time.
7. I use good non-verbal responses, for example nodding, smiling, leaning forward.
8. I give brief verbal responses, for example 'uh-huh' and 'mmm'.
9. I ask for clarification if I am unsure about what has been said.
10. I try to understand the speaker's feelings.

Now add up your score! Total= _____

How did you score?

10-19 Your listening skills can improve. You will improve. Get practising- you'll soon notice an improvement.

20-30 You are doing well but you can improve more.

Over 30 Congratulations! You are an excellent listener. Have a look to see if there are any areas you could improve on even more.

FEEDBACK

*5. Did you learn something about yourself in this session?

Yes

No

Other (please specify)

*6. Did you learn something new about other people through these activities?

Yes

No

Other (please specify)

AMC SESSION 4

*7. How useful did you find this session?

- Not at all
- A little useful
- Useful
- Very useful
- Extremely useful

Other (please specify)

*8. How difficult did you find this session?

- Not at all
- A little difficult
- Difficult
- Very difficult
- Extremely difficult

Other (please specify)

*9. What would you change to improve this session?

CONTACT INFORMATION

If you have any problems or queries please don't hesitate to contact me:

Email: l.rodriquez2@nuigalway.ie
Skype: Leonor_AMBC
Phone: 0858877718

THANK YOU

You will receive by email the link to the next session shortly!

Session 5

AMC SESSION 5

WELCOME TO SESSION 5!

1. Please remember your participation in this study is voluntary.
2. You may withdraw from the study at any moment and this will not have any repercussions for you or your family.
3. As this is an online, individual study, please contact the researcher by any of the means provided if you experience any distress or problems that limits or impedes you participation.
4. If you have any questions or doubts please contact the researcher as well.

***1. What is you research identification number?**

KNOWLEDGE CHECK

These questions are about your usual behaviour. Try to fill in as many answers as you can.

YOU ARE NOT EXPECTED TO KNOW ALL THE ANSWERS!

Please don't worry if you don't.

You are involved in a learning process that will make this information easier for you.

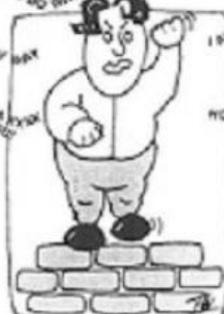
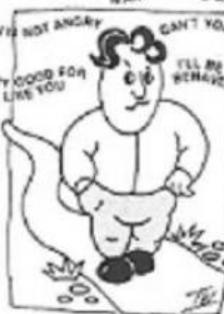


BEHAVIOUR TYPES

Please look at the examples provided of assertive, non-assertive and passive behaviours. As well as the worksheet provided.

Once you can identify them, you can start working towards being more assertive

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<p style="text-align: center;">DIRECT AGGRESSION</p>  <p style="text-align: center;">BOSSY ARROGANT BULLDOZING INTOLERANT OPINIONATED OVER-BEARING</p>	<p style="text-align: center;">INDIRECT AGGRESSION</p>  <p style="text-align: center;">SARCASTIC DECEIVING AMBIGUOUS INSINUATING MANIPULATIVE GUILT INDUCING</p>
<p style="text-align: center;">PASSIVITY</p>  <p style="text-align: center;">WAITING MOANING HELPLESS SUBMISSIVE INDECISIVE APOLOGETIC</p>	<p style="text-align: center;">ASSERTIVENESS</p>  <p style="text-align: center;">DIRECT HONEST POSITIVE ACCEPTING RESPONSIBLE SPONTANEOUS</p>

***2. Which do you think is your behaviour type?**

- Direct aggression
- Indirect aggression
- Passivity
- Assertiveness

ASSERTIVENESS

Assertiveness is a skill that will help you communicate more effectively with other people, express your feelings and ideas more freely and will allow you to have a balance between give and take in your relationships.

Assertiveness will therefore have a direct impact on the quality of your social support as it will improve the closeness and reciprocity of your interactions with friends and family.

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Assertiveness is based on a basic principal: if people can't communicate their intentions clearly, interpersonal conflict and stress will arise.

Assertive people can:

- Stand up for their rights without violating other people's rights.
- Express their likes and dislikes more easily.
- Openly disagree.
- Be less self-conscious when talking about themselves.



EXERCISE: ROLE PLAY SCRIPT

Listen to these recordings, they are meant to help you identify different types of behaviours and role modeling of more assertive behaviours.

SITUATION 1

You invited a friend for dinner at your house. She just arrived but she is an hour late and didn't call you to let you know. You are upset and you tell them:

- 1-Come in. Dinner is served.
- 2-You have no shame, how do you dare arrive this late. It's the last time I am inviting you over.
- 3-I have been waiting for an hour, I would have liked you to call to tell me you would be late.

SITUATION 2

You bought a pair of shoes yesterday and today the soles are falling off. You go to the store and explain what has happened to the sales man. He tells you this can be fixed very easily and you can do it yourself at home. You tell him:

- 1.Thank you. Goodbye.
- 2.Give me another pair right now. Who do you think I am a shoemaker?
- 3.That is an option, but I'd like you to change them for me, I want another pair of shoes please.



BEHAVIOUR GRID

This grid will help you identify the signals in your body that are associated to a specific behaviour type.

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You can identify these signs and avoid the effects of aggressive and not assertive behaviours.

BEHAVIOUR GRID			
	NOT ASSERTIVE	ASSERTIVE	AGGRESSIVE
	Too little, too late or never.	Enough appropriate behaviours at the right moment.	Too much, too soon, or too much too late.
BODY LANGUAGE	Eyes face down, weak voice, agitation, weak gestures, deny importance to the situation, evasion of the situation, "fake" laughter	Direct eye contact, fluid voice; erect posture, honesty, direct answers to the situations, loose hands.	Fixed look, loud voice, threatening gestures, dishonesty, intimidating posture.
VERBAL	Maybe, I guess, I wonder if, would you mind?, don't you think, it's really not important, don't be upset.	I feel, I think, I want, let's do, how can we deal with this?, what do you think?, What do you feel?	It would be better if you, you should, you must, you have to be kidding me, if you don't do it..., you don't know, you are so wrong.
EFFECTS	Conflict in the relationship, depression, loneliness, poor self-image, loose opportunities, loose tension, loose control, anger, not liked by the self or by others.	Solves issues, feels comfortable with other people, satisfaction, relaxed, in control, opportunities, like the self and others, good for the self and others.	Conflicts in the relationship, guilt, frustration, poor image of the self, tension, loneliness, lack of control, anger, doesn't like others.

Source: Caballo (1993) p.227

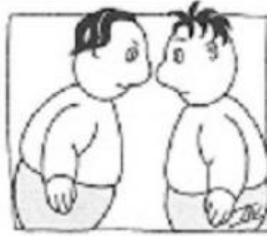
BODY LANGUAGE

Identify the body language of assertiveness and put it into practice.

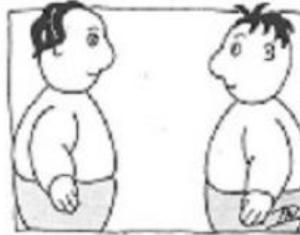
Look around at different people interacting, even if you can't hear their conversation.

Can you identify their behaviour just by their body language?

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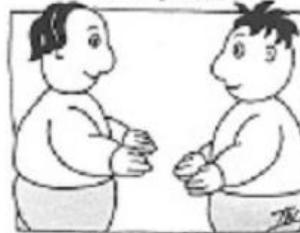
BODY SPACE
Respect other's space.
Too-close? Too far?



ASSERTIVE STANCE
Stand tall.
Hold your head high.
Feel strong and equal.
Believe in yourself.



FACIAL EXPRESSION
Is your face saying what you are saying?
GESTURES
Avoid fidgeting.
Use appropriate gestures.



EYE CONTACT
Look at the person – not at the ground.
Avoid a fixed stare.
Use a comfortable, direct gaze.



INTONATION
Be interesting not monotonous.
Avoid sarcasm.



VOLUME
Adjust your volume control.
Check your speed.

EXERCISE: BEHAVIOUR TYPE

Identify the following behaviour types.

Read each statement carefully and then choose what type of behaviour it may be.



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SITUATION 1

A neighbour calls at your house to ask you to help with the school fair.

RESPONSE

I'd like to help you with the fair, but I'm not sure if I'm free then. I'll get back to you tomorrow.



***3. This situation corresponds to which type of behaviour?**

- Direct aggression
- Indirect aggression
- Passivity
- Assertiveness

SITUATION 2

The television maintenance person promises to return the following day with your television. When he doesn't you ring the shop to complain.

RESPONSE

I'm fed up with your awful service- I won't buy anything from you ever again!

***4. This situation corresponds to which type of behaviour?**

- Direct aggression
- Indirect aggression
- Passivity
- Assertiveness

SITUATION 3

You are served a cold cup of tea in a cafe.

RESPONSE

You say nothing to the waitress but pull a face when you drink the tea.



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***5. This situation corresponds to which type of behaviour?**

- Direct aggression
- Indirect aggression
- Passivity
- Assertiveness

SITUATION 4

Your friend telephones you and chats for a long time. You would like to finish the conversation.

RESPONSE

I'm ever so sorry, but I'm going to have to go: the cat's just been sick and my mum is calling me for dinner. I'm really sorry, I hope you don't mind.

***6. This situation corresponds to which type of behaviour?**

- Direct aggression
- Indirect aggression
- Passivity
- Assertiveness

TIP: ASSERTIVE RIGHTS

I have the right:

- To say "I don't know"
- To say "no"
- To have an opinion, and to express it.
- To have feelings, and to express them.
- To make my own decisions, and deal with the consequences.
- To change my mind.
- To choose how to spend my time.
- To make mistakes.



MY EMOTIONS: ANGER

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Anger is a human emotion, like any other emotion it is allowed and normal to feel angry sometimes. Anger is a reaction that is learned, experience tells us when, where and how to express anger. This means that the way we deal with anger can also be changed for better ways to handle it.



WHAT MAKES YOU ANGRY?

Think for a moment about the things that make you angry. Some people might include frustration, disappointments, pain, deadlines, lack of understanding, and intolerance amongst others.

Maternal breast cancer may or may not be on your list.

HOW DO YOU EXPRESS ANGER?

There are different ways to express anger. Some people may talk about it openly, others decide to keep it to themselves, however some others may explode with anger verbally or emotionally.

EXERCISE: I AM ANGRY!

1. How do you think the messages you received when you were a child had an impact on this situation?
2. How did you choose to express your anger?
3. How did you feel about being angry and expressing it?
4. What reaction did you get from other people?
5. Did you feel better or worse after expressing your anger?
6. What do you like about the way you express your anger?
7. Would you be willing to improve your ability to recognize and express your anger?



EMPOWERING OR DISEMPOWERING ANGER

Anger, depending on how you deal with it, may provide ways to empower you or instead it may disempower you.

EMPOWER

Stand up for yourself

Protect others

Go after things you really want

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DISEMPOWER
 Too upset to deal with things
 Withdraw from a situation
 Feel embarrassed by your reaction



TIP: ANGER AWARENESS

Next time you start to notice you are getting angry ask yourself ASAP:

		DEFINITION
A	Awareness	Who or what is really angering me?
S	Source	Why am I angry? What is the real source?
A	Alternatives	What do I want to do? Do I have alternatives for accomplishing it?
P	Plan	What is my plan of action?

TIP: DETECTING ANGER

These activities which may help you recognize anger and decide whether to act or wait:



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1. Recognize body signals

When we are angry our body reacts with different symptoms like increasing blood pressure, increase blood flow, increase heart rate, increase muscle tension and sweating. You can learn to recognize these signs in your own body.

When you start to feel angry try this:

- a) Breathe slowly and deeply.
- b) Picture a stop sign in your mind and really stop for a moment.
- c) Take at least five more big breaths.

2. Time out

When you recognize that you are getting angry, say to yourself: 'I am starting to get angry, I need a time out'.

- a) Look for a place where you can actually be calm for an hour or for as long as you need to (inside or outside your house).
 - b) Do an activity that may relax you for example the exercises you learned or practice a sport you like.
 - c) Come back, if you find that you are ready to talk or solve the situation and other people are ready too, go ahead, otherwise keep waiting for a good moment.
3. Go for a walk or run.



4. Listen to your favourite music



POSSIBLE RESPONSES TO ANGER WHICH MAY BE SUITABLE FOR YOU

ABCDEFGHI

A-ssertive behaviour: tell the person how you feel; ask for what you need.

B-lowing up.

C-ooling down.

D-efusing: find an unbiased, third party negotiator.

E-motion-focused behaviour: exercise, relax, elicit support from friends and family express your emotions in a safe

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way.

F-ocus on incompatible behaviour.

Let it G-o (If it is appropriate, its not the same as stuffing)

H-umour: joke and laugh.

I-nformation seeking: ask for advice, search for more information.



FEEDBACK

***7. Did you learn something about yourself in this session?**

Yes

No

Other (please specify)

***8. Did you learn something new about other people through these activities?**

Yes

No

Other (please specify)

***9. How useful did you find this session?**

Not at all

A little useful

Useful

Very useful

Extremely useful

Other (please specify)

***10. How difficult did you find this session?**

Not at all

A little difficult

Difficult

Very difficult

Extremely difficult

Other (please specify)

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***11. What would you change to improve this session?**

CONTACT INFORMATION

If you have any problems or queries please don't hesitate to contact me:

Email: l.rodriquez2@nuigalway.ie

Skype: Leonor_AMBC

Phone: 0858877718

THANK YOU

You will receive by email the link to the next session shortly!



Session 6

AMC SESSION 6

WELCOME TO SESSION 6!

1. Please remember your participation in this study is voluntary.
2. You may withdraw from the study at any moment and this will not have any consequences for you or your family.
3. As this is an online individual study, please contact the researcher by any of the means provided if you experience any distress or problems that limits or impedes you participation.
4. If you have any questions please contact the researcher.



***1. What is your research identification number?**

I CAN TALK ABOUT CANCER

1. Before you decide to talk make a plan or write it down. Decide on the topics or questions you may have.
2. Decide on the best time and place to meet with the people or person you want to talk to.
3. Look for solutions together.
4. Try to keep these talking sessions at least one time a day. This will get much easier with practice.



TIP: STICKING TO IMPORTANT POINTS

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- Step 1: Decide what you want to say.
 Step 2: Express this clearly.
 Step 3: Think of as many other ways of expressing your decision as you can.



EXERCISE: TALKING TO MY FRIENDS ABOUT CANCER

1. Your friends may not know what to say to you.
2. Your friends may feel better if you speak first, but only if you feel like it.
3. Make a list of fun things you might enjoy doing.
4. Talk to your friends and spend time with them.
5. Sometimes old friends move on and may have very little in common with you, don't be afraid to meet new people.

Try to think of a friend you like and trust and tell them something about the cancer experience you are going through, as much or as little details as you wish.



I DON'T FEEL LIKE TALKING!

1. You don't have to be always positive and cheerful, especially when you don't feel like it.
2. If you don't want to talk try something like: "Thanks for asking about my mum, but would it be ok if we talked about this later?"

Some people may say mean things or jokes.

You can choose to ignore the remarks or tell someone about it if you are being bullied or hurt.

Try saying something like:

"My mum has cancer, it is not funny, how would you feel if it was you?", "That's enough."

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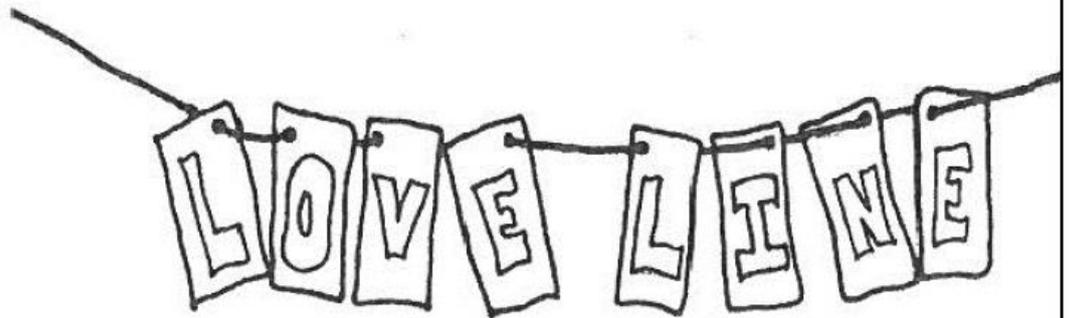


EXERCISE: LOVE LINE

This activity can go on for a short time or it can continue for a longer time.

Choose a good moment or a special occasion to hang your love line.

1. Place you mum's name in an envelope.
2. Punch a hole in the corner of sets of cards or pieces of paper.
3. Inform everyone that is important to you and your mother that whenever they have free time they may use the cards to write a nice note or comment.
4. Attach the cards/ papers to a string and place it along a wall or between two chairs so that the middle section is hanging free for her to read.



THINGS I CAN DO FOR MY MUM WHEN SHE IS IN THE HOSPITAL

PLEASE REMEMBER TO ASK A MEMBER OF MEDICAL STAFF IF YOU CAN DO THIS AND IF IT IS SUITABLE FOR YOUR MOTHER'S CURRENT HEALTH CONDITION.

1. Celebrate someone's birthday by having a party in your mother's room. Bring an extra gift if your mother wants to give it to the person you are celebrating for.
2. Bring family photos and put them in the room. Photograph people, pets or places your mother might like.
3. Make or bring a large calendar or poster board and write what is happening each day on it.

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4. Prepare and celebrate holidays together, bring decorations to the room.
5. Make recordings of greetings from loved ones who can't visit as often. You may also want to share sounds you liked from the surroundings like a bird singing.
6. Send cards frequently so your mum looks forward to mail-delivery time.
7. Bring greeting cards (with stamps) so your mum can send them to relatives and friends. You can even help her write them.
8. Bring flowers, leaves or branches from your own garden (or the photos if you can't bring flowers or plants to the hospital).
9. Stop by the room to let your mother see you on your way to prom or a party.
10. Bring someone new to visit (neighbours, one of your friends, one of your mother's friends). Make sure she is happy to receive visits that day!
11. Be sensitive to your mother's energy level. Offer to watch TV, listen to radio if she seems tired. Sit without talking, just keep her company.
12. Sit down next to your mother instead of standing up and talking over her. It will be more comfortable for her to communicate that way with you.



GIFT IDEAS (In a wide range of prices!)

These are some ideas of gifts you can buy or even make or decorate yourself:

1. A nice journal or diary.
2. A voucher for a nice cafe.
3. DVDs or books.
4. An audio book.
5. Subscription for a newspaper or magazine.
6. Organic and not scented shower gels, shampoo, hand cream.
7. Organic oils.
8. Slippers, bathrobes, pajamas in cheerful colours.
9. Book of crosswords, quizzes, word searches.
10. Voucher for a beauty treatment.
11. Meditation CD.
12. Voucher for a personal shopper.
13. Nuts, seeds, dried fruit (all natural, no salt or other additives included)
14. Gently scented flowers like freesia, daffodils and sweet pea.
15. A voucher for a night away (with friends, partner, family)

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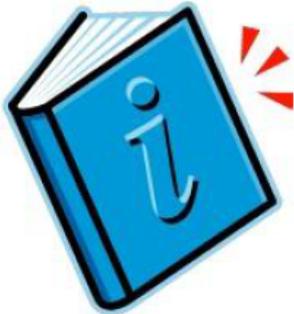


THE RIGHTS OF FAMILY MEMBERS

I have the right to enjoy my own good health without feeling guilty. It is not my fault that someone I love has cancer.



I have a right to know what is going on in our family. I have a right to be told the truth about the cancer in words I can understand.



I do not always have to agree with someone because they have cancer. I can get angry without feeling guilty because sickness does not stop someone from being a real person.

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I have a right to feel what I feel , not what someone else says I "should" feel.



I have the right to look after my own needs. I am permitted to take "time out" from the cancer without feeling disloyal.

I have a right to get outside help for the patient if I cannot manage all the responsibilities of home care myself.



I also have a right to get help for myself, even if others in my family choose not to get help.

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FEEDBACK

***2. Did you learn something about yourself in this session?**

Yes

No

Other (please specify)

***3. Did you learn something new about other people through these activities?**

Yes

No

Other (please specify)

***4. How useful did you find this session?**

Not at all

A little useful

Useful

Very useful

Extremely useful

Other (please specify)

***5. How difficult did you find this session?**

Not at all

A little difficult

Difficult

Very difficult

Extremely difficult

Other (please specify)

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***6. What would you change to improve this session?**

CONTACT INFORMATION

If you have any problems or queries please don't hesitate to contact me:

Email: l.rodriquez2@nuigalway.ie

Skype: Leonor_AMBC

Phone: 0858877718

THANK YOU

You will receive by email the link to the next session shortly!



Session 7

AMC SESSION 7**WELCOME TO SESSION 7!**

1. Please remember your participation in this study is voluntary.
2. You may withdraw from the study at any moment and this will not have any consequences for you or your family.
3. As this is an online individual study, please contact the researcher by any of the means provided if you experience any distress or problems that limits or impedes you participation.
4. If you have any questions please contact the researcher.

***1. What is your research identification number?**

KNOWLEDGE CHECK

I would like you to think about the answers for these questions:

***2. What does asking for help mean to you?**

***3. Who would you ask for help?**

***4. How do you usually ask for help?**

***5. How many people do you have in your life that will help you if you need it?**

WHY IS ASKING FOR HELP IMPORTANT?

People don't always know if you need something, even if they know you very well.

Remember that assertive people are those who can clearly communicate what they want, feel and need. This way you may increase your chances of actually getting the help you need, whether you are asking for tangible, emotional, esteem or advice support.

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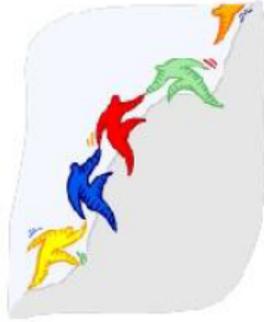
TIP: HOW TO ASK FOR HELP

1. Recognize that you need help and/or support.
2. Identify which people may help you in difficult times.
3. Choose the right help for the right situation.
4. Approach the person
Say hello
Make your petition clear and specific.
Explain why it is important to you.
Use a nice and polite tone so other's feel comfortable.
Ask, don't demand.
5. Thank and appreciate the help provided.
6. If a person says no, don't get upset. Look for other options.
Try to explain yourself further. Try to explain why this is important to you.



PROVIDE HELP

AMC SESSION 7



YOU CAN PROVIDE HELP WHEN:

1. Recognize the other person needs help.
2. Listen carefully to what is being said.
3. Make sure you understand the petition.
4. Think if you are the right person to provide help.
5. If the petition is not direct but if it is clear that the person needs help, approach the person and ask them.
6. Help the person in a way they feel comfortable and you as well.

YOU CAN'T PROVIDE HELP WHEN:

1. Petitions are not reasonable or they are excessive.
2. You don't know or can't do what they asked for.

Specify your reasons to say no.
Apologize to the person asking for help.
Suggest who else may be willing to help.

EXERCISE: MY HELP JOURNAL

Keep a record of how many times you asked for help during the day and how many people asked you for help.



***6. Who did you ask for help?**

***7. How did you do it?**

***8. How did it make you feel?**

***9. How many people asked you to help them?**

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***10. How did you feel helping others?**

LAUGHTER LOG

Humour can see us through a variety of difficult and complex situations as well as help reduce stress. Bringing smiles to our face and to other people is important and something we should engage in on a regular basis.



WHAT MAKES US LAUGH?

Think about and identify different things that make you laugh and record them.

LAUGHTER LOG WORKSHEET

Take one week. Keep a record of all the times that you laughed – either quietly or out loud.

Rate each time and rate it in the feel-good factor (out of 10, 10 is the best laugh ever!!).

	Why?	Feel good factor (out of 10)
MONDAY		
TUESDAY		
WEDNESDAY		
THURSDAY		
FRIDAY		
SAFFRDAY		

You can use the worksheet attached if you want to.

***11. How did these situations helped you?**

***12. How did this help other people around you?**

MAKING OTHERS SMILE AND FEEL HAPPY

What can you do for others? How can you do this?

Identify the key people in your life. Record their names on the Post-it notes and then write down your ideas as to how you can make them smile and feel happy. The go for it! Spread the happiness!

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(You can use the worksheet attached if you want)



FEEDBACK

***13. Did you learn something about yourself in this session?**

Yes

No

Other (please specify)

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***14. Did you learn something new about other people through these activities?**

Yes

No

Other (please specify)

***15. How useful did you find this session?**

Not at all

A little useful

Useful

Very useful

Extremely useful

Other (please specify)

***16. How difficult did you find this session?**

Not at all

A little difficult

Difficult

Very difficult

Extremely difficult

Other (please specify)

***17. What would you change to improve this session?**

CONTACT INFORMATION

If you have any problems or queries please don't hesitate to contact me:

Email: l.rodriguez2@nuigalway.ie

Skype: Leonor_AMBC

Phone: 0858877718

THANK YOU!

You will receive by email the link to the next session shortly!

Session 8

AMC SESSION 8**WELCOME TO SESSION 8!**

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4. If you have any questions please contact the researcher.

***1. What is your research identification number?**

SURVIVING MY MOM'S BATTLE WITH CANCER

My name's Ralph Crespo. I'm a 16-year-old.

Four years ago, my mom was diagnosed with breast cancer.

If I'd known then what I know now, things might have been a little bit better. If you're a teen dealing with a similar situation, I hope my story will help you. And if you have a friend with a parent who's ill, maybe this story can help you help your friend. Here's what happened.



This is a true story written by a 16 year old adolescent about his experience of maternal breast cancer.

A 16 YEAR OLD TELLS HIS STORY

As soon as I walked through the door, I knew something was wrong.

My mom was sitting on the couch in our living room, and she was totally still. She looked really sad.

"Mom, what's wrong?" I asked. She didn't answer.

I asked again. "Mom, tell me!" Still, she stayed silent.

Worried, I went to my bedroom and closed the door. A while later, I peeked out through a crack in the door, and I saw that my mom was crying. My mother hardly ever cries, so I knew something serious was going on.

Later that day, she finally told me. "I have breast cancer," she said. "But it's nothing to worry about."



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FRIGHTENED FAMILY

Then, my dad came home. He sat down and started talking to my mom. Then they hugged and he started crying. That was the first time I'd ever seen my father cry. I was stunned.

I was 12 when this happened, and I didn't really know what cancer was.

I was terrified that my mom was going to die. Shortly after she was diagnosed, my mom had surgery to have the cancer removed. My aunt came from the Dominican Republic to take care of me and my sister, who was 8 at the time. It felt weird coming home from school and not seeing my mom. Every time the phone rang, I was sure that it was bad news.

When my mom came home about a week later, she still seemed really sick.

My little sister didn't know my mom had cancer. My parents had decided to keep it from her because they thought telling her would add more stress to the situation. But she could tell something was wrong. She'd ask me, "What's wrong with Mom? Why is everybody crying?"

I would get frustrated. I'd be like, "leave it alone." But she'd ask again and again. I think the whole thing made me closer to her, though, because I had to protect her. I'd play house with her -- do whatever she wanted to make her feel better

STAYING CLOSE TO HOME

After she healed from the surgery, my mother started radiation treatments to kill any cancer that might be left in her body. The treatments made her really tired. Seeing her made me worry even more. I started just staying home with her. It was summer, and I'd spend all day in her room. My mom would tell me to go out and enjoy myself, but I couldn't. My friends would come around and they'd ask, "What's up? Why don't you go out anymore?" I didn't want to talk about it, because every time I did, I'd start crying.

They knew something was wrong with my mom, but that was it.

When school started in the fall, it was hard. I'd always had an 85 or 90 average, but that year I dropped down to 65 or 70 -- barely passing. And I did something that I really

regret now: I quit playing football. My whole family used to go to games, and I knew it wouldn't be like that anymore.

Also, I had this sense that my mom would pass away while I was playing a game and I'd never get to say goodbye.



RESEARCH PROJECT

As my mom was finishing radiation treatments -- and I saw that she still seemed pretty healthy -- I started handling things better. I decided to find out more about my mom's cancer. So when I got a computer for Christmas, I researched breast cancer online. I was so relieved to discover that it's a disease that can be controlled and cured, especially in the early stages, and my mom luckily caught hers early.

Then I joined a group at school called Sparks. It's a group in which kids help other kids. I felt more comfortable telling those kids what was going on. I learned that other people have problems, too, and that talking about things can really help. I even met one girl whose mom also had breast cancer, and now our moms are friends!

By eighth grade, my grades started improving and life was starting to feel normal. Still, my mom was depressed. She was afraid the cancer was going to come back. Then, that summer, we spent two months in the Dominican Republic.

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While we were there, the pressure just went away and she got happy.



LIFE GOES ON

Now, four years after my family is doing great. At her latest check-up, she got a clean bill of health. Of course I'm not glad she got sick, but good things did come of it. My family is closer and I've grown up a lot. My mom is more open-minded too. She tells me you only live once. She's going to tell me right from wrong and let me make my own decisions. Because of all I've been through, I try to do the right thing.

If anyone reading this has a parent who's sick, here's my advice: Learn about the illness.

The more information you have, the better. Don't throw away activities you're involved with the way I threw away football.

It's normal to feel low, but remember, your life isn't over.

Don't lose hope.

MY JOURNEY

I would like you to share your feelings and thoughts about your experience in this programme.

Fill in the spaces provided with your experience in these weeks and please share it with me.



***2. The first day I:**

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***3. I learned this about myself:**



***4. It was hard when:**

***5. The happiest moment was:**

***6. I felt good when:**



***7. I felt proud when:**

***8. The last day I:**

***9. I achieved this goal (goals)....**

***10. I did not achieve this goal (goals)....yet!**

APPENDIX I

Bioecological Models of maternal cancer (IPA Analysis)

