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Developing guidelines for best practices that address the transition of adolescents with Cystic Fibrosis from a paediatric to an adult healthcare setting in Ireland

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Publications arising from the thesis

1. Al-Yateem, N (2012) The effect of interview recording on quality of data obtained: A methodological reflection. Nurse researcher, 19 (4) 31-35

2. Al-Yateem, N (2012) Child to Adult: Transitional care for young adults with Cystic Fibrosis (CF). British Journal of Nursing, 21 (14), 850-854

3. Al-Yateem, N (2012) Developing guidelines for best practice for adolescents with CF during transition from children to adult health care settings, submitted for publication in Nursing Children and Young People Journal (formerly Paediatric Nursing Journal)

Abstract

Background: Ireland has the highest rate of Cystic Fibrosis (CF) in Europe and in the world. However, there is a strong evidence to suggest that the Irish transition service for adolescents with CF from a child to adult setting warrants further service improvement, particularly in terms of clinically relevant guidelines that can shape care planning and service delivery.

Objectives: To develop relevant and feasible guidelines for the transition care of CF children in Ireland. The proposed guidelines are intended to emanate from an initial evaluation of the transition service, an investigation into the subjective experience of transition of CF patients and their personal needs, and finally an interrogation of relevant health professional practice in relation to transitional care.

Methodology: A sequential exploratory mixed method design guided this study. The first qualitative phase employed in-depth interviews to explore CF adolescents and young adult experiences about the current transition service, followed by focus group interviews with healthcare professionals to discuss the reported CF patients needs and suggest interventions that address them. Finally, a survey questionnaire formulated on the data gathered during the first qualitative phase and tested for its validity was used in the second quantitative phase, the goals of which were to explore the opinions of a larger sample of CF service stakeholders about the relevancy and feasibility of the suggested guidelines for clinical practice.

Results: The in-depth interviews revealed 4 main themes, the amorphous service, sharing knowledge, the need to be involved in care, and easing the transition process. While the focus group interview revealed the need to follow a systematic approach of care (assessment, planning, implementation, and evaluation), to include a developmentally appropriate approach, providing transitional care in an environment appropriate to the unique stage of development , and train healthcare professionals in issues related to adolescence and transition process. Participants in the survey questionnaire agreed on 37 proposed guidelines out of a possible 54 as either highly important or important and highly feasible or feasible. These guidelines reflect the needs reported by CF patients and the healthcare professionals as suggested elements of care essential to a safe and secure clinical transition that meets the diverse needs of those living with a chronic and life limiting illness.

Chapter 1: Introduction and background

1.1 Introduction

Nursing and health care management provided for patients with complex health problems is often carried out during periods of transition. These periods may be characterised by instability, in the patient's own life or in their family's life. Transition where it is possibly continuous and un-anticipated can be overwhelming (Meleis, 1994; Kralik, 2006; Meleis, 2010).

For individuals with chronic and life limiting illnesses such as cystic fibrosis (CF), managing periods of transition in their lives and coping with their illness can be extremely difficult. Cystic fibrosis is a life limiting genetic illness that starts from birth and lasts for the duration of the patient's life. This illness can be a significant burden on the life of the patient and their family, and has to be managed with a complex course of treatments, during which potentially serious complications can occur. For adolescents with CF, the 'ordinary' changes that their lives go through at that age - such as going to school, developing into adolescence, starting college, starting relationships - can be complicated and compounded by their illness(Chick and Meleis, 1986; Meleis, 1991; Blum *et al*., 1993; McDonagh, 2005; Kralik, 2006; Meleis, 2010).

For an adolescent suffering with CF, this period in their life can represent a time when multiple sources of distress are present. To combat this, it is necessary to weigh up the different needs of individual patients, and consider the different tasks (illness-related or otherwise) that must be accomplished in order to best serve their health. These tasks may require extra effort, careful preparation and competent management from patients, their families, and their healthcare providers. The ultimate goal for any healthcare provider should be to achieve the best possible outcomes during these periods of transition and to decrease any potentially negative consequences.

1.1.1 Thesis outline

The thesis is outlined as follows.

Chapter 1: introduction and background chapter, where an introduction and background are presented along with the study's purpose, its aims, associated questions, and finally, the importance of the study.

Chapter 2: the literature review chapter will discuss current literature and available research about different aspects of adolescence, the effects of chronic and life limiting illnesses and transition on adolescents, and the transition process and its components.

Chapter 3: the research framework chapter presents the philosophical and methodological approaches used in this research.

Chapter 4: the research methods chapter presents the research methods used in this study.

Chapter 5: the interview and focus groups findings chapter will report the findings of the qualitative interviews phase of the study.

Chapter 6: the survey findings chapter will report the findings of the quantitative survey phase of the study.

Chapter 7: the comparison of findings from interviews data and questionnaire data chapter compares the findings of the quantitative survey phase of the study.

Chapter 8: the discussion chapter will critically discuss the results and findings of this study in the context of the wider international literature.

Chapter 9: the study's recommendations for transition service guidelines chapter will present the study recommendations, and proposed guidelines for the transition service for healthcare professionals.

1.2 Cystic fibrosis – definitions and presentation

Cystic fibrosis is an irreversible autosomal recessive genetic disease, a progressive and life-limiting illness that affects individuals from birth. In this condition "premature death is inevitable and long periods of intensive treatment aimed at prolonging life and allowing participation in normal activities is anticipated" (ACT, 2012)

This disease is considered the most common chronic and life-limiting condition that affects children on an international level, and specifically for the purpose of this study, in Ireland. Cystic fibrosis results in generalised dysfunction of the exocrine glands that affect multiple organ systems in the body, including the sweat glands, respiratory system, and the gastrointestinal tract. The main signs and symptoms of CF are listed as follows.

- Thick, tenacious secretions in the bronchioles and alveoli leading to repeated infections, obstructive changes in the lungs such as wheezy respirations; a dry, non-productive, paroxysmal cough; dyspnoea; and tachypnoea, all leading eventually to severe atelectasis and emphysema.
- Poor weight gain and poor growth, resulting from the obstruction of the pancreatic ducts which lead to a deficiency of trypsin, amylase and lipase. The absence of these enzymes prevents the conversion and absorption of fat and protein in the intestinal tract.
- Clotting problems, retarded bone growth and delayed sexual development in both males and females as a result of the deficiency of fat-soluble vitamins (A, D, E and K).Males have been found to have congenital bilateral absence of the vas deferens, causing sterility. Females may experience secondary amenorrhea but can reproduce.
- Increased risk of hyponatremia, hypochloremia, and arrhythmias, especially in hot weather, all resulting from increased concentrations of sodium and chloride in the sweat (McGee, 1992; Goljan, 2007; Rosaler, 2007; Bjorklund, 2009).

The treatment of CF aims to help children lead as normal a life as possible. The treatment includes: generous salting of foods and sodium supplements, especially in hot weather; pancreatic enzyme replacement; a low fat but high protein and calorie diet; supplements of fat-soluble vitamins (A, D, E and K); management of pulmonary dysfunction including physiotherapy, postural drainage and breathing exercises; and nebulisers as part of the range of treatment.

The consequences of CF as a chronic, life limiting and debilitating disease are varied, and include: arthritis, atelectasis, biliary disease, bronchiectasis, cardiac arrhythmias and corpulmonale, clotting problems, dehydration, delayed sexual development, azoospermia in males, secondary amenorrhea in females, diabetes, distal intestinal obstructive syndrome, electrolyte imbalances, gastro-oesophageal reflux disease, hepatic disease, cirrhosis, portal hypertension, oesophageal varices, malnutrition and pneumonia (McGee, 1992; Goljan, 2007).

1.3 Significance of cystic fibrosis within the Irish context

Ireland has the highest rate of CF in the world (World Health Organisation, 2004; Cystic Fibrosis Registry of Ireland, 2006), with one case in every 1,800 people. This incidence is higher than the United Kingdom (1 in 2,600), the United States of America (1 in 3,500), and Australia (1 in 2,500) (World Health Organisation, 2004).

According to the 2006 report of the Cystic Fibrosis Registry of Ireland, there are 40 babies born with CF every year. The majority of those children will live into adolescence, and increasingly into their fourth and fifth decades due to progress that has been achieved in the management of the disease (Figure 1).

The growing number of CF patients who live into adulthood indicates the need for an effective transition service between paediatric and adult CF institutions, in addition to a comprehensive adult medical CF service, especially within the acute hospital service (Pollock, 2005; CFRI, 2006; Health Service Executives, 2009).

Despite the highest incidence rate for CF in the world, the service in Ireland is still reported as being underdeveloped and needing considerable improvement (Radio and Television of Ireland, 2007; Pollock, 2005; CFRI, 2006; Health Service

Executive, 2009).

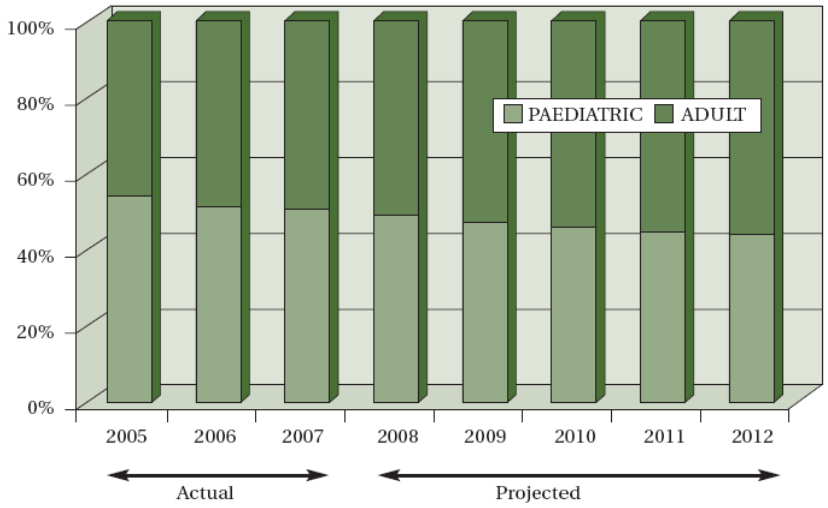


Figure 1- Projected ratio of adult to paediatric CF population until 2012, used with permission from CFRI (CFRI Annual Report, 2006)

1.4 The adolescent developmental stage

Researchers have described adolescence as a transitional period during which adolescents develop their coping mechanisms, decision-making abilities and independence skills (Arnett, 2000). It has been described as a period extending from the onset of puberty until early adulthood, with most in agreement that this period is poorly defined by a particular age point, especially for those with chronic and life limiting illnesses (Jessor, 1984; Singer, 1984; Nielson, 1991; Millstein, 1993).

Initially, Levinson (1978) described this period of life (extending from 17 to 22) as the "early adult transition". During this period, adolescents experience a considerable amount of change and instability while trying to achieve the task of moving into the adult world and building a stable life structure.

Later, researchers described two stages for this period; adolescence and young adulthood. They then divided adolescence into early, middle or late, with distinct concerns and interests for the adolescent during these specific phases (Nielson, 1991; Singer, 1984; Millstein, 1993; Jessor, 1984). Other authors, like Arnett (2000), have argued for a third unique developmental stage of "emerging adulthood", which

extends between the late teens and early twenties. He described this period as distinct and characterised by change and exploration of possible life directions. In this way, Arnett added another distinct developmental stage to the previous literature to establish the stages of adolescence (early, middle and late), emerging adulthood, and finally, young adulthood (Arnett, 2000) as shown in Figure 2.

Figure 2- Developmental stages of the transitional period extending from adolescence to adulthood (Arnett, 2000 P.469)

According to Schumacher and Meleis (2010), adolescence is considered one of the important transitions in a person's life, and needs to attract greater attention from researchers due to the amount of change and adjustment that takes place.

Generally, researchers agree on the transitional nature of this period, and that it requires a person to make decisions and choices that will determine his or her future life. This transitional stage is one of a series of "passages" that take place throughout an individual's life, which is, according to Van Gennep (1960), made up of successive stages, both endings and beginnings.

Within this study terms adolescents and young adults were used to refer to some of the study participants. The term adolescents was used to refer to those still in a children's hospital and who are candidates for transfer to adult services, while young adults was used to refer to those who have already been transferred to adult services and are starting to assume the responsibilities expected from them as adults.

1.4.1 Social and developmental consequences of cystic fibrosis for adolescents and young adults

Cystic fibrosis as a life limiting disease has serious effects on child health and well being, especially during adolescence, when the CF-associated health issues are accompanied by other developmental and social role changes that occur

concurrently. Simultaneous life transitions in addition to health-illness transitions (the need for a particular treatment, changing treatment, undergoing a diagnostic procedure, being admitted to hospital) and organisational transitions (the need to move to a new CF treatment centre) may put the adolescent under a considerable amount of stress (Thomas and Gaslin, 2001; Moos, 2002; Schmidt *et al.*, 2003; Michele and Sawyer, 2005). These transitions can also increase the chances of his/her failure to fulfil all these roles and carry out all these transitions competently (Somerville, 1997; Watson, 2000; Kipps *et al.*, 2002; Annunziato *et. al*. 2007; Rutishauser *et al*., 2010).

The unsuccessful management of the many transitions that take place in the lives of CF adolescents and young adults may expose them to potentially negative consequences, ranging from unnecessary psychological stress to even more serious complications, such as premature death (especially in post-transplant patients). Evidence suggests that the inability of adolescents with chronic and life limiting illnesses to carry out these transitions successfully will be costly in terms of increased healthcare expenditures, and will lead to increased usage of the health care system, increased admissions, and increased demands on medical and nursing staff (Sommerville, 1997; Watson, 2000; Wysocki *et al*., 1992; Meleis, 2000; Rutishauser *et al*., 2010; Meleis, 2010).

1.5 The cystic fibrosis service in Ireland

The effects of chronic and life limiting illnesses such as CF on Irish adolescents were noted in Ireland by a recent report for the Department of Health and Children (DOHC) on the topic of chronic illness across the life spectrum (DOHC, 2008). The report noted that 77% of service activity and expenditure in the healthcare system is caused by chronic and life kimiting illnesses. The report also noted that chronic and life limiting illness is the major cause for mortality (86%) and illness in the country. The report called for national and international initiatives to tackle chronic illnesses and decrease the related burden on the healthcare system (DOHC, 2008). The nature of such a generic report reflects the predominantly older adult population, for whom chronic illness is the greatest challenge. The needs of adolescents with chronic and life-limiting illness remain underreported.

Current services are based on shared care, where main CF treatment centres and smaller health centres closer to CF patients' homes share the care provided for CF patients. Furthermore, the shared care model requires careful co-ordination between the different involved hospitals to ensure quality service provision. This model of care is reportedly inferior to a centralised model, where all the care provided for CF patients is provided in a specialised centre (HSE, 2009).

Although CF is a disease that is of significant importance to the Irish population, the current CF service in Ireland does not appear to achieve its desired service goals (Pollock, 2005; RTE show – Prime Time, 2007, 2008; HSE, 2009). The existing CF service focuses on the paediatric population, leaving an imbalance between the numbers of the paediatric centres compared with the number of centres offering care for adults. Furthermore, these centres are inadequately staffed, underdeveloped, and lack the necessary medical cover to manage the increasing numbers of CF adults with multiple needs (Pollock, 2005).

In summary, CF is a life limiting illness that is common in Ireland. The treatment regime is laborious, and the illness itself characterised by the occurrence of potentially serious complications. The complexity of disease management is further complicated when the adolescent is also going through other transitions. For the adolescent to master all the changes and transitions competently, they must be well-prepared, and healthcare professionals must be equipped with interventions and practices that can assist adolescents by creating conditions conducive to a healthy transition (Meleis, 2000, 2010). This was endorsed by the national policy on palliative care for children with life limiting conditions like CF. This policy recommends the need to establish a committee to oversee the development of a cohesive and integrated palliative care service based on population needs for children and parents (DOHC, 2009).

This study will focus on the transition experience for adolescents with CF from the paediatric to the adult healthcare setting. The aim is to produce guidelines for interventions that reflect the diversity and complexity of this transition experience; guidelines that can help health professionals competently deliver their care to the adolescent population. Many previous studies have explored the theoretical aspect of

the transition from the adolescent, parental and the healthcare professional perspectives without giving attention to this aspect which has real ability to improve adolescent health outcomes (Scal, 2002; Reiss, 2005; Farrant and Watson, 2004; McDonagh, 2005; Por, 2004).

1.6 Developing the transition service through care guidelines

The development of the transition service for CF patients, as is the case for the different nursing and healthcare interventions, requires not only knowledge about the patients' needs during these periods, and the factors that affect these needs, but also a deliberate effort to improve clinical practice through well-proposed and well-designed healthcare interventions. Such interventions that aim to organise and coordinate the healthcare service are usually referred to as service guidelines or care pathways (Vanhaecht *et al.,* 2009).

The principle behind developing service guidelines and care pathways, as reported in the literature, is that simply having knowledge about effective care rarely leads to an improvement in practice (WHO, 2004; Davies, 2006). Knowledge about elements of effective care should be complemented by an effort to translate this knowledge into practical interventions that can be implemented into clinical practice.

The need to design care guidelines and pathways, especially for chronic and life-limiting conditions, is reported in the literature (Davies, 2006; ACT 2007), and their benefits in organising and coordinating – and thus improving – the care provided for patients is evident (Vanhaecht *et al.* 2009).

Therefore, the development of guidelines was the main goal of this study, following the identification of the elements of the transition service from those involved in it. The choice of service guidelines over care pathways was based on its ability to allow some flexibility for healthcare professionals in different clinical CF settings in Ireland to adopt and implement as much as they can from these guidelines, based on their service resources and configuration.

1.7 The study

The purpose, importance, aims of and approaches to the study will now be discussed, as well as a summary of the questions that the study is seeking to answer.

1.7.1 Purpose of the study

Cystic fibrosis has a multi-system nature and requires a complex treatment regimen. It has a wide-ranging effect on the patient's life (in terms of their study, work, and relationships) and has the potential to be life-threatening and life-limiting due to complications. All these aspects of the illness mean there is a need to foster a multi-disciplinary approach to care management. Such an approach would enhance the transition experience, and mitigate against the profound effect that CF can have on an adolescent's ability to live well (Graue *et al*., 2003; Palmer and Boisen, 2002; Somerville, 1997; Schmidt *et al*., 2002; Kyngas, 2000).

The purpose of this study is to understand the experience of transition for adolescents and young adults with CF, and to produce guidelines for best practice for healthcare professionals working both in the child and adult health services during periods of transition between the two settings. The guidelines proposed would be informed by the views and experiences of affected adolescents and their parents or guardians, all within the context of the Irish healthcare system. Parents were involved in this study due to their significant experience in the provision of care for their children in the paediatric CF setting, and due to the role that they can play in the adolescents' transition to the new setting.

1.7.2 Importance of the study

There is limited evidence in the literature on issues of service delivery, and limited practical nursing interventions regarding the transition service from a paediatric to an adult healthcare setting for adolescents with CF. The need to improve the transition service by different means continues to be emergent and persistent, and particularly focuses on developing guidelines for practice (While, 2004; Reiss, 2005; Lotstein *et al*., 2008; Steinbeck *et al*., 2008; Tuchman *et al*., 2010; Towns and Bell, 2011).

Current literature covering the transition of adolescents with CF and other chronic and life limiting illnesses has provided theoretical information about the experience of adolescents, families and healthcare professionals during the transition between different services (e.g. Abdale *et al*., 1994; Palmer and Boisen 2002; Brumfield and Lansbury 2004; Shaw *et al*., 2004; Tuchman and Britto 2008). However, no guidelines have been developed for translating this information into actual interventions that help providers deliver the best possible practice at the proper time. This gap in practice has led some authors to the conclusion that appropriate healthcare transition is still an unfulfilled promise to adolescents with special healthcare needs, despite many years of discussion about transition services (While, 2004; Reiss, 2005; Lotstein *et al*., 2008; Steinbeck *et al*., 2008; Rapley and Davidson, 2009; Rutishauser *et al*., 2010; Tuchman *et al*., 2010; Towns and Bell, 2011). It is suggested that the absence of structured delivery plans and guidelines leads to the failure of the healthcare providers to give desired or effective transitional services.

In addition, the absence of a comprehensive model for best practice that guides the clinical service means that existing service models tend to focus on one aspect of the transition and ignore others (While, 2004), thus ignoring the complex and comprehensive nature of transition and the need to address all these issues in the same programme to deliver a better transition service.

This was emphatically confirmed by Meleis (2000), who highlighted the multiple and complex patterns of the transition phenomena, in the sense that the individual undergoing the transition usually experiences more than one type of transition at a time, and that multiple transitions may occur simultaneously. According to the same author, these multiple transitions cannot be understood if they are isolated from each other. If a patient is not prepared or ready, when they experience these multiple transitions they will deal with the one they rate as the most important while ignoring all the others. This could potentially lead to negative psychological consequences, delayed social functions, or health problems, depending on the type of transitions ignored.

Nurses and other healthcare providers need to consider and target their interventions towards the patterns of all significant transitions in an individual's life, rather than focusing only on a single transitional aspect. Those involved with transition services should be equipped with therapeutic interventions derived from an understanding of the properties and the conditions inherent in the transition process, and the experiences and needs of clients and their families in order to promote healthy responses to transition (Meleis, 2000). However the literature lacks clear guidance for healthcare professionals about the most appropriate interventions, the way these interventions should be implemented, and the timing for interventions among other important practical considerations (While, 2004; Reiss, 2005; Lotstein *et al*., 2008; Steinbeck *et al*., 2008; Rapley and Davidson, 2009; Rutishauser *et al*., 2010; Tuchman *et al*., 2010; Towns and Bell 2011).

This study seeks to address these gaps in the literature, and therefore this work and others like it are necessary for the field to develop. In addition to exploring the transition experience in relation to life limiting and chronic illnesses, such studies should draw up comprehensive guidelines or interventions for the transition service that can guide healthcare professionals during their actual practice in the clinical setting. Such studies, which have direct practical implications in the clinical setting, could contribute in bridging the gap between the research studies and the clinical practise in the transition area.

1.7.3 Aims of the study

The aims of this study were as follows.

1. To investigate the subjective experience of transition of adolescents and young adults with CF to understand their needs during the transition from a paediatric to an adult healthcare setting, and explore factors that facilitate or hinder this process.

2. To explore relevant professionals attitudes and consider practices to conceptualize healthcare interventions that address the transition process for adolescents and young adults with CF

3. To recommend relevant and feasible transition service guidelines for best practice for adolescents/young adults with CF, which are based on the perspectives of professional healthcare providers and are informed by the experiences of adolescents and their parents/guardians.

1.7.4 Study questions

This study addressed the following questions.

1. What are the needs and experiences of adolescents/young adults with CF and their parents/guardians during the transition from a paediatric to an adult healthcare setting?

2. What are the key components of best practice service transition guidelines from the perspective of both healthcare professionals and service users?

1.7.5 Approaches to the study

This study used a sequential exploratory mixed method design, which was used to recommend a set of relevant transition guidelines that can be implemented within the clinical setting in Ireland. This work was done in two phases.

In the first qualitative phase, the needs of adolescents with CF during transition and factors that facilitated or hindered this transition were explored through in-depth interviews. Also in the first phase, transition service healthcare professionals were consulted to give their opinions about the best interventions to address the CF adolescents' reported needs. This was achieved through focus group interviews.

In the second quantitative phase, a transition service survey questionnaire was formulated based on the results of the first phase. This survey was then administered to a large number of the transition service stakeholders in Ireland in order to determine the relevancy and the feasibility of the suggested guidelines. The aim was to identify the guidelines that were considered to be relevant and feasible by the majority of healthcare professionals.

1.8 Chapter summary

This chapter provided the context of the study by presenting essential background information on CF, the developmental stage of adolescence, and the practical necessity for adolescents with CF to transition between two different healthcare settings. The chapter presented the purpose of the study, and detailed the specific aims to be achieved, as well as covering the questions that will be answered through the study's research. Finally the importance of carrying out the current research study was presented. The next chapter provides a critical review of salient literature in which the context of the study is set.

Chapter 2: Literature review

2.1 Introduction

This chapter provides a review of the current literature and research that covers the transition process of adolescents with CF from the child healthcare setting to the adult one. The review covers four main areas: the meaning of transition; adolescence and the transition to adulthood; the effect of chronic and life limiting disease on adolescents and the transition to adulthood; and finally, transition for adolescents with chronic and life limiting illness from a child healthcare service to an adult healthcare setting. Before addressing these areas in detail, the literature search strategy will be presented.

2.2 Search strategy

The literature for this study was identified through an electronic search using the EBSCO search engine, and the following electronic databases were searched: Cumulative Index to Nursing and Allied health Literature (CINAHL); Health Source: Nursing/Academic Edition; Psychology and Behavioural Sciences Collection; SocINDEX; and the Medical literature analysis and retrieval on-line (MEDLINE) database.

The search used the following key words individually and in combination to identify the literature: “Transition”; “Transition Theory”; “Adolescence”; “Young adult”, “Transition and adolescents / adolescence”; “Transition for adolescents with cystic fibrosis / CF”; “Transition and young adult”; ”Young adult and CF”; “Transition for adolescents with chronic illness”; “Adolescence and chronic illness”; and “Adolescents or adolescence and cystic fibrosis / CF”.

The review included literature that met the following criteria:

- Published in the years between 1990 and 2012.
- discussed issues related to one of the key words identified;
- written in or translated to English;
- journal articles with abstracts and cited references;

- Published in peer reviewed journals, conference proceedings, publication or recommendation of specialised body or organisation or relevant governmental report.

After conducting the initial electronic search, a classification of retrieved articles for relevancy to be included in the literature review was conducted. In this process, the titles of the retrieved articles were scanned for relevancy to the research topic. The abstracts of those thought to be relevant (n=521) were retrieved and read. The article was then classified as either not relevant and then discarded, or relevant and the full text was retrieved and reviewed (n=109).

To maximise the literature review process, the electronic search was further augmented by a manual search. During the manual search, the reference list of the retrieved articles was further scanned for other relevant articles. Searches of the library catalogue (OPAC) and the Google Books website were also carried out to identify some relevant texts. These websites were searched using the keywords "transition in healthcare", and "transition in adolescents with chronic illnesses OR life limiting illnesses". Through these searches, a number of relevant books were identified. The final number of articles reviewed was 159 articles.

Finally, the evaluation process included critically reading through the article looking for the purpose of the study, methodology used, study setting, study findings, limitations, and recommendations. All these data were extracted and organised in a coding table that was used for reporting and presenting the literature that was reviewed.

Four key areas emerged from the literature review: (1) the meaning of "transition"; (2) adolescence and the transition to adulthood; (3) the effect of chronic and life limiting illnesses on adolescents and their transition to adulthood; and finally, (4) transition for adolescents with chronic and life limiting illness from the child service to the adult healthcare setting. The following review of literature will address these areas in detail.

2.3 The meaning of transition

This section focuses on the meaning of transition, it starts by reviewing different definitions for transition in the literature, the process of transition as described by some scholars in the literature, meaning of transition in the context of healthcare, the factors that affect transition, and finally some frameworks to address this phenomena as suggested by key authors in this area.

2.3.1 Etymological references

The word transition is defined in the Oxford English Dictionary (OED) (2010) as "passing or passage from one condition, action, or place, to another" or as "change". According to the same source, the word is used in different contexts, such as in physics to express the change of an atomic nucleus or an orbital electron from one quantised state to another. In chemistry, it describes a set of "transitional elements", while in music it means the passage from one note or key to another. The term has also been used in geography to indicate the passage from one stage of development or formation to another, and in linguistics to describe the historical passage of language from one well-defined stage to another.

Webster's Dictionary (1993) also defines transition as "development or evolution from one stage, form or style to another". From an anthropological point of view, Van Gennep (1960) highlights that the life of an individual in any society is a series of passages or transitions from one age to another and from one occupation to another. Van Gennep's seminal work on transition (1960) is among the most distinguished in this field, and he further proposed that the idea of transition is implicit in the fact of existence so that a person's life comes to be made up of successive stages with beginnings and endings.

Despite the plethora of specific meanings for the term "transition", the concept almost always implies a change or movement in a particular direction. This change and movement can occur in different contexts and at all levels, but the most relevant context for nursing and the social sciences is when this transition occurs among humans at the level of the individual, family, group, and organisation (Van Gennep, 1960; Parkes, 1971; Bridges, 1980; Silverman 1982).

2.3.2 The transition process

The literature identified multiple descriptions that address the transition process (Van Gennep, 1960; Parkes, 1971; Bridges, 1980; Schumacher and Meleis, 1994). However, this literature emphasised the universal features of transition, and in addition to the idea of change, these also include features of direction and process. This indicates that transition usually occurs as a process with different stages and with distinctive characteristics for each of the stages (Van Gennep, 1960; Parkes, 1971; Bridges, 1980; Schumacher and Meleis, 1994).

Van Gennep described three phases for the transition process. In the first phase ("the separation") the individual or group withdraws from the first role or place and begins moving to the new role or place. The second phase ("the liminality") occurs when the individual or group has left one place or state but has not yet entered the next. During this stage, the person dissociates from their current status and usually accepted norms and routines are often ignored (Turner, 1995). At this point, the person or group undergoes transformations that enable the entrance into the next and last stage ("incorporation"). In this phase, the individual has the ability to enter a new and important role, place or stage in their life and return to a state of balance. Van Gennep (1960) described rites or ceremonies that mark each transitional stage in different cultures. However, he emphasised that while these rites mark the beginning or the end of a transitional stage of a person's or group's life, they can fail to help him/her or the group to incorporate into the new role or stage.

Similarly, Bridges (1980; 1986) in the context of organizational psychology defined transition as a process that has three distinct phases. The first one is the "ending phase", which means disengagement or disenchantment from the current situation. The second phase –the "neutral phase" - is marked by disorientation, disintegration and discovery. Finally, the "new beginning phase" occurs, which involves the person finding meaning and a new future.

Silverman (1982) also described three stages for the transition process in relation to bereavement. The first stage is defined as the "impact stage", where the individual rejects the new reality and the past role is still dominant. The individual's ability to make progress in the transition is dependent on their capacity to pass this stage,

which can be helped by introducing them to someone else that has lived through the same experience and is now enjoying a new stable life. The acceptance of the individual to talk with this helper indicates a readiness to consider making the transition. In the second stage – or the "recoil/presence stage" - help is focused on providing specific information about the current role or condition and how to deal with it. Finally in the third "accommodation/self-generation stage", the individual tries to incorporate all the new information or ideas that he/she receives into new identities, and then starts to practise the new behavioural patterns and new ways of dealing with themselves and others. From these seminal theories therefore, it would seem that transition evokes a sense of movement towards some degree of resolution or integration following a period of instability or change which may change or transform the outcome for the individual.

2.3.3 Transition in the context of healthcare

Within the literature, health researchers usually define the concept of transition as a change that is taking place, which arises as a result of a developmental situation in addition to another events, as well as the efforts of the individuals undergoing the transition to adapt and regain normality (Chick and Meleis, 1986; Meleis, 1991; Blum *et al*., 1993; McDonagh, 2005; Kralik, 2006; Meleis, 2010).

Kralik *et al*. (2006), Chick and Meleis (1986; 2010) and Meleis (2010) all published seminal works about transition within the healthcare context. These will now be discussed.

According to Kralik *et al*. (2006), the concept of transition involves people's responses and adaptation to a change that occurs over time. For these researchers, this concept has emerged in nursing and health science. Over the last three decades there has been a significant contribution from nurses in the understanding of this concept, which was highlighted in their literature in their exploration of how the concept of transition was used in the healthcare field. In this meta-analysis of the literature, the researchers reviewed all articles on transition published in the health sciences databases over ten years (1994-2004). They indicated a wide spread use of the word "transition" that differed according to the context of use and the focus of

the study. The authors concluded that the wide use of the word indicated its importance and relevance to the healthcare field

The work carried out by Kralik *et al*. (2006) is reinforced by recent work carried out by Chick and Meleis (1986; 2010) and Meleis (2010). These studies put the concept of transition into the context of health and healthcare services, and highlight the transitions that people with health problems like CF or other chronic and life limiting illnesses experience during the course of the illness and their personal development.

Meleis (2010,p.25) defines transition as "passage from one life phase, condition, or status to another". This period of transition is characterised by disconnectedness from the individual's own social context, a transient loss of familiarity to their surrounding environment, the emergence of new needs that must be met, and the replacement of an old set of expectations with new, non-matching ones (Chick and Meleis, 1986; 2010; Meleis, 2010).

2.3.4 Types of transitions and factors that affect it

The literature covering the transition process revealed four main types of transitions. These include: developmental transitions; situational transitions; health-illness transitions; and organisational transitions. These transitions may occur at all levels: societal groups, organisational, family and finally at the individual level (Schumacher and Meleis, 1994; 2010; Meleis, 2010). The family and individual level is the main concern of this study, and the existing literature reveals that at this level transitions may occur in identities, role, relationships, abilities and pattern of behaviour (Silverman, 1982; Schumacher and Meleis, 1994; 2010; Meleis, 2010)

The literature reviewed reported many factors that can affect transition, regardless of the level that the transition occurs in, and the specific nature of the transition. The factors reported in the literature include: the preparation for the transition; the individual's knowledge about it; and the attitudes, values and rituals of the individual or the society within which the individual is living (Silverman, 1982). Schumacher and Meleis (1994; 2010) and Meleis (2010) reported further factors that may influence the transition process, which include: meaning; expectations; knowledge and skill; environment; level of planning; and emotional and physical well being.

In relation to the idea that "meaning" is a factor that affects the transition process, Schumacher and Meleis (1994) argued that the patient's interpretation of what the transition means for them has an impact on their ability to carry it out, their experience of it, and its potential consequences on their health. Adlersberg and Thorne (1990) supported this notion, and reported that the meaning that a patient attaches to their transition is important, as it may change or determine the person's behaviour and responses toward that transition. Adlersberg and Thorne (1990) wrote a paper reflecting on their experiences of interacting with widows over the loss of their partners. The authors noted that while some participants described it as a negative experience, others attached positive meanings to it, like new opportunities for self-development.

In relation to the level of a patient's knowledge about the transition process, researchers in the literature who have written about transition in different health and social situations have emphasised the importance of acquiring good knowledge and skills to help the individual during the transition experience (Kenner and Lott, 1990; Ladden, 1990; Wong, 1991; Howard-Glenn, 1992). According to Schumacher and Meleis (1994), lack of knowledge during the transition will cause a feeling of uncertainty, which might disrupt the transition process.

Imle (1990) reported environment is another factor that can affect transition. Environment includes physical buildings and facilities as well as social networks that surround the person undergoing the transition. These networks can include family, friends, healthcare professionals, and support groups. Imle examined the transition to parenthood for 23 expectant parents, and emphasised the importance of the environment as an external facilitative factor to the transition process. The study used a two-phase qualitative ethnographic design, and carried out in-depth interviews with participants. Silverman (1982) argued that the existence of support systems can have a buffering effect and contribute positively to a sense of wellbeing and therefore enhance the transition for those who are experiencing it. These findings were supported by a number of other researchers who have warned that the absence or lack of such support during transition may leave the person lost in

negative feelings like powerlessness, confusion, frustration and conflict (Kenner and Lott, 1990; Johnson *et al*. 1992).

The level of planning is another important factor that determines how easy and smooth the transition process can be. Evidence in the literature comes from Kertoof (1988) who suggested that better planning can contribute to a non-eventful and less stressful transition. Transition planning should include identifying all the key personnel involved and any potential problems or issues that might arise in the context of initiating an effective communication network between them in order to co-ordinate transition efforts (Howard-Glenn, 1992; Wong, 1991).

Kertoof's (1988) study about the transition effect of the resignation of a manager in an organisation highlighted potentially serious negative effects of a transition that is undertaken quickly and abruptly. This emphasised the importance of a well-planned transition. The importance of planning the transition process was further supported by Howard-Glenn's (1992) theoretical paper suggesting a framework for the transition of an oxygen-dependent neonate to the home setting. The researcher equally highlighted the importance of well-planned, early initiation and comprehensive transition for the achievement of the desired outcomes.

Schumacher and Meleis (1994) also state that the emotional and physical well being of the individual is an important factor during the transition. If these aspects of the individual are ignored or negated, they can interrupt the assimilation of new information during the transition process (Kenner and Lott, 1990). Imle (1990) confirmed these findings and reported that an unpredictable transition may cause stress and affect the transition negatively, while a well-planned transition will help the individual maintain normal body functioning and emotional well-being, and consequently carry out a more managed transition process.

2.3.5 Frameworks to address transition phenomena

The literature review identified two main suggested frameworks to deal with the transition process (Silverman 1982; Meleis *et al*. 2000). These frameworks shared the view that transition phenomena are usually complex, with multiple transitions that can take place simultaneously, with a different number of factors that can affect

the transition, in addition to the multiple stages of the transition process itself. All these factors necessitate the use of a comprehensive framework that guides the care given during this process, and that ensures best management of the transition process.

Silverman's (1982) proposed framework supports individuals during transition, whether they happen due to a role change or due to life events. The framework incorporates the social and individual factors that might affect the transition process (e.g. personal resources, social support and factors associated with individual social status). It also incorporates the meaning of change for the individual undergoing the transition. Finally, it covers an assessment for the baseline state of the individual before the transition, covering physical and mental health, self-concept, and life satisfaction. It then compares this to the individual's state after carrying out the transition process to evaluate the transition outcomes.

The essence of Silverman's (1982) framework is that socialisation is a useful mechanism for teaching individuals undergoing transition effective and efficient behaviour to help them cope with their transitions. This suggests that socialising with individuals who have gone through the transition process can help individuals who are preparing to go through the same experience. Therefore, support during the transition process would be more efficient if provided by those who had passed through the same experience and navigated through its different aspects. This role model support system has the potential to provide valuable information and problem-solving techniques that are more relevant and possibly more acceptable to those undergoing the transition.

Meleis *et al*. (2000) provide a more comprehensive and more healthcare-relevant framework. This framework is composed of four components, which are: the nature of transition; the transition conditions; the patterns of responses; and finally, the healthcare or nursing interventions.

The nature of transition is further divided into types of transition (developmental, situational, health/illness or organisational transition), patterns of transition (single, multiple, sequential, simultaneous, related or unrelated) and properties of transition

(transition time, critical events, etc). The transition conditions are further divided into facilitators and inhibitors that can be caused by the person undergoing transition. Finally, the patterns of response to transition can be measured or monitored by process indicators and/or outcome indicators.

The four main components of this transition framework affect - and can be affected by - each other. For example, the nature of transition can affect and being affected by the conditions of transition, which in turn can affect the transition outcomes. However, all these elements will and should have an impact on the healthcare interventions, which should be modified based on the nature of transition, the conditions of transition, and the outcomes of the transition.

As evidenced from this framework (Meleis *et al*., 2000), the management of the whole transition process should be carried out in a comprehensive manner that considers all these elements and creates a balance between them. In their framework on transition, the previous researchers stressed that the person undergoing the transition tends to arrange the transitions (if multiple transitions are occurring) according to their own personal priorities. The individual then gives attention and directs most of their effort to what they consider to be the most important one. This might leave the person at risk of ignoring a particular type of transition that might have a detrimental effect on their life.

The transition "outcome indicators" are an important component of this framework. These indicators will help health professionals working with patients during a transition process, such as working with adolescents with CF (Meleis *et al*., 1994 pp.24-26). Based on previous predictors, a transition would be smooth and successful if the adolescent were able to feel connected to the past while making new contacts in the new setting and interact with the staff and other patients in the new setting. This would lead to the patient developing a sense of self-confidence in relation to the multiple illness and developmental tasks and activities they were required to carry out, helping them demonstrate competence and mastery in managing the new setting, roles and activities. This result in a "dynamic" identity, which emerges from the experience of the old and the new setting, and can be

modified, reformulated with elements added and others dropped at any time to suit new circumstances.

Informed by these factors and the personal plans for the person undergoing the transition, healthcare professionals in the clinical setting can develop interventions that nurture and facilitate the multiple transitions that are taking place. This would make adolescents' experiences during these transitions more favourable, and less stressful and less risky, hopefully nurturing the mechanisms that improve their abilities to deal with transitions in the future (Meleis *et al*., 1994; Silverman, 1982).

The next section will discuss transition in the context of the adolescent developmental stage and the multiple transitions that take place during an adolescent's journey to adulthood. It will review the literature that highlights some issues during this journey, such as variation among adolescents in the achievement of main developmental milestones, needs of adolescents during these transitions, the mechanisms that adolescents use to cope with all transitions during this period, and the potential effects of chronic and life limiting illness on an adolescent's development.

2.4 Adolescence and the transition to adulthood

Evidence suggests that adolescence is a critical transition period in which adolescents face many developmental challenges related to personal autonomy, sexual development, cognitive functioning, intimacy, identity and achievement (Adam, 1996; Spear and Kulbok, 2001). After adolescence, the adolescent moves into a new unfamiliar period of life, taking on new responsibilities and independence and striving to become an autonomous adult (Adam, 1996; Spear and Kulbok, 2001). The success of progress through the adolescence developmental stage varies in normal adolescents (Taanila *et al*., 2005; Maggs *et al*., 2008)

The variance in child development progress during adolescence and into adulthood was highlighted by the Taanila *et al*. (2005) study that was carried out in Northern Finland. The aim of this large scale quantitative longitudinal study was to examine the development of 12,058 children between infancy to the age of 31. The study gathered developmental information about participants at aged one, then aged 14, 16

and 31. The information was collected using health records, interviews with parents and questionnaires. The gathered information included items such as age of standing, walking and talking, bladder and bowel control at the age of one year, cognitive and physical development and achievement in school at ages 14 and 16, and finally, the participants' highest achieved educational level at age 31. The results of the study show a variance in the achievement of the developmental milestones among the participants in the various developmental stages (e.g. during childhood, adolescence, and during adulthood). Those participants who achieved the childhood developmental tasks earlier were more likely to be better in achieving the other developmental milestones during adolescence and adulthood, and achieved higher educational levels later in their lives.

Similar findings were also reported by another study carried out by Maggs *et al.* (2008) in the UK. In their quantitative longitudinal study, the researchers examined childhood and adolescent predictors of alcohol use and harmful drinking in adolescence and adulthood. They collected predictors of alcohol use at age seven, and then again at ages 11 and 16. The predicators were collected from the British National Child Development Study from data that covered 7,883 females and 8,126 males. The study concluded that social background during childhood and adolescence can predict and affect adolescent behaviours and development during adulthood.

2.5 Effect of chronic and life limiting illness on adolescence and the transition to adulthood

The effect that a chronic and life limiting illness has on adolescent development and the transition to adulthood was evident in the literature, which highlighted that developmental progress and the engagement of the adolescent in the appropriate developmental tasks might be significantly delayed if they have a chronic or life limiting illness. This is mainly due to illness-related limitations that adolescents with chronic and life limiting illnesses can suffer from (Pless *et al.*, 1993; Atkin and Ahmad 2001; Hokkanen *et al.*, 2004; Grootenhuis *et al.*, 2006; Stam *et al.*, 2006; Maggs *et al.*, 2008). The latter studies highlight the fact that young people with

chronic and life limiting illnesses have the same developmental issues as healthy young people. However, due to all the extra tasks and challenges they face as a result of their illness, these adolescents may not be able to achieve the expected developmental and social milestones required from them, or may achieve them but at an older age than their counterparts. Adolescent development could be disrupted due to repeated hospitalisation, poor health status, decreased physical strength and skills or changes in appearance (Pless *et al*., 1993; Atkin and Ahmad, 2001; Madden *et al*., 2002; Hokkanen, *et al*., 2004; McEwan *et al*., 2004; Yeo and Sawyer, 2005; Stam *et al*., 2006; Rhee, *et al*., 2007).

Pless *et al*. (1993) also argued to this same end, in a study that examined the psychosocial consequences of chronic disease that began in childhood. The study analysed data from the UK national birth cohort, and 12,537 children were followed from birth until age 23. The study found that chronic conditions in childhood might have an effect on the severity of behavioural and psychosocial problems in adulthood. The results of the same study found that males with chronic illnesses were significantly more debilitated, had poorer educational qualifications and longer periods of unemployment than their peers from similar backgrounds. The study presented possible reasons for such consequences but supported the explanation that these psychosocial consequences are adverse effects that might have been provoked by the chronic disease.

In their qualitative study, Atkin and Ahmad (2001) showed another example of how chronic and life limiting illness might affect an adolescent's development and quality of life. The researchers used in-depth interviews to explore the strategies and resources that young people use to cope with sickle cell disorder or thalassaemia major. The study involved 25 participants (aged between 10 and 19 years) who participated in two interviews six months apart to detect differences in experience, as a result, show the variability in the disease condition. Respondents found their illness difficult to cope with, but they endeavoured to maintain a normal life despite their illness. They suffered a sense of uncertainty about their future, and felt limitations as a result of their chronic illness, as well as reporting disruptions in their social life and a sense of isolation as a result of frequent hospitalisation. They employed strategies

to minimise differences between them and their peers, and these strategies were aimed mainly at maintaining a sense of normalcy. They included forgetting about the illness, confronting their limitations, enhancing their knowledge about the chronic illnesses and thus having more of a sense of control over the illness. These were in addition to religious beliefs and social support (considered a main source of support for most of the participants).

According to the Hokkanen *et al*. (2004) study, chronic conditions in adolescence can affect physical, cognitive, social and emotional development for adolescents. This qualitative descriptive study was carried out in Finland. The study conducted three focus group discussions with a total of 20 adolescents with cancer, who were aged between 13 to 18 years old. The researcher found that the Finnish adolescents with cancer experienced many health problems, suffered from changes in their physical appearance, and had anxiety and a sense of inferiority as a result of their illness. The chronic illness also affected the adolescents' social relationships with people around them and with their parents, as well as affecting their independence.

Yeo and Sawyer (2005) reported similar effects of chronic and life limiting illnesses on adolescents. Their clinical review addressed different aspects of adolescents, and their review covered the effects of chronic illness and disability on adolescence. They noted physical effects (short stature, pubertal delay, low weight and obesity) and emotional effects (a sense of alienation from peers, frustration with the requirements of managing their condition and negotiating the healthcare system). They also noted that the cognitive and social effect of chronic illness would make them prone to social isolation and stop them from participating in recreational and sporting activities.

The affect of chronic and life limiting illness on adolescent development was again highlighted by more recent studies such as Stam *et al*. (2006) and Grootenhuis *et al*. (2006). Both studies argue that adolescents with chronic and life limiting illness achieve developmental milestones in their adolescence later as a result of their illness. Stam *et al*. (2006) compared the achievement of developmental milestones between adolescents with (n=650) and without (n=508) chronic illness. The researchers administered a questionnaire to 1,158 young adults, aged between 18 to

30 years old. The study found that a significantly lower number of young adults with chronic illnesses had paid jobs at age 18 or younger, had been on a holiday for the first time without an adult, had had a girl/boy friend at age 17 or younger, had had sexual intercourse for the first time at age 18 or younger, and had had a membership with a sport club while in secondary school. These results showed that the group with chronic illness had achieved fewer milestones than their peers without chronic conditions, especially in domains such as autonomy development, paid jobs, secondary school, psychosexual development and sexuality.

Similarly, the Grootenhuis *et al*. (2006) study assessed the achievement of developmental milestones in adolescents and young adults with renal disease. This study examined whether having this illness affected the young adults' quality of life later on. The study used a cross sectional survey to assess the quality of life of the participants, and a retrospective part of the study used the course of life questionnaire to assess the achievement of adolescent developmental tasks and milestones. A total of 75 young adult patients participated in the study, aged between 20 and 30 years old. They were recruited from the database of the National Dutch Registry of Patients on Renal Replacement Therapy and the database of all paediatric nephrology centres. After the statistical analysis of the study, it was found that patients with renal disease achieved fewer milestones than their peers with respect to autonomy, social and psychosexual development, and displayed less risky behaviour. The patients who achieved fewer social milestones while growing up experienced more emotional problems and less vitality, and they had a lesser overall quality of life in terms of their mental health.

Reflecting on all the results shown in the previously reviewed studies, it seems important that all healthcare professionals should endeavour to enhance and develop the care provided for children with CF and other chronic and life limiting illnesses during transitions to adolescence, adulthood, and during any other type of transition. Further, it is important to allow these adolescents to manage these tasks successfully, avoid any potential negative consequences as a result of risky behaviours common in this developmental stage, and achieve the required developmental milestones on time.

2.6 Adolescents coping with the effects of chronic and life limiting illness on their health and development

Adolescents use different coping mechanisms to control the effects of the chronic and life limiting illness on their development and on their lives, as has been described in the literature (Gil *et al*., 1997; Schmidt *et al.,* 2003). These coping mechanisms are usually flexible and positive in children and young adolescents, but later on individuals can become less flexible and less amenable to change (Gil *et al*., 1997; Schmidt *et al.,* 2003) and their mechanisms can be prone to evolving into negative health behaviours, such as tobacco use and risky sexual behaviours (Britto *et al*., 1998; Spear and Kulbok, 2001; Suris and Parera, 2005; Ginsburg and Jablow, 2006; Taylor *et al*., 2007). The evidence suggests that such risk-taking behaviours are as prevalent among adolescents with chronic illnesses as their peers, despite the increased potential for adverse affects on their health.

Gil *et al*. (1997) investigated the flexibility of adolescents' coping mechanisms in a longitudinal quantitative survey study, which assessed change of pain-coping strategies in young children, adolescents, and adults with sickle cell disease. The study included 141 patients with sickle cell disease, and it was carried out over an 18-month period. The researcher used the Coping Strategy Questionnaire subscales and measured coping skills at baseline, then nine months and again at 18 months. To analyse the direction of change in coping mechanisms between young children and adolescents, the researchers used repeated ANOVA measuring techniques. The test indicated that older adolescents had significantly higher negative thinking and had developed illness-focused coping strategies when compared to younger children and young adolescents. The researcher concluded that for children and adolescents with sickle cell disease, their coping mechanisms change over time, and are more flexible and prone to change than those of adults.

Research in the nineties (Britto *et al*., 1998) explored the prevalence and age of onset of risky behaviours such as smoking and sexual activity in adolescents with cystic fibrosis and sickle cell disease. The researchers compared the data of 321 participants aged between 12 to 19 years old in the intervention group with another

demographically similar comparison group without any chronic conditions. The intervention group participants were recruited from five main major paediatric care centres, while the control group participants were recruited from public schools. Both the health centres and the public schools are located in North Carolina in the USA. The study found that 21% of adolescents with cystic fibrosis and 30% of those with sickle cell disease had smoked, and 28% and 51% respectively had had sexual intercourse; however, the majority were older than their peers in the comparison group at the time when they engaged in these behaviours. The researcher concluded that adolescents with cystic fibrosis and sickle cell disease had engaged in more health risky behaviours than expected, although the prevalence of such behaviours were lower among their group compared to their peers.

Another more contemporary study by Suris and Parera (2005) reported similar results. This study assessed whether adolescents in Catalonia with several chronic conditions differed from their healthy peers in risk-taking behaviour. The sample was drawn from the Catalonia Adolescent Health database by a cross-sectional study of students aged between 14 and 19 years old. The study was carried out in early 2001, when a representative sample was selected. This sample included 7,057 male and female adolescents who participated by completing a questionnaire survey. At the end of data collection, 6,952 valid questionnaires were further analysed. Among the participants, 665 reported a history of chronic illness limiting their daily activities, and were used as an "index" group, while the remaining composed the comparison group. The study results showed higher rates of sexual intercourse and risky sexual behaviour among participants, especially among girls with chronic illnesses. Furthermore, the study found that chronically ill youth were as likely or more likely to smoke, drink or use illegal drugs than their healthy peers. Based on these results, the study researchers recommended that these adolescents receive the same anticipatory guidance in relation to these health risky behaviours as their healthy counterparts.

Both studies mentioned above (Britto *et al*., 1998; Suris and Parera, 2005) agree that such prevalence for health-risking behaviours among adolescents with chronic illness can threaten or have negative impacts on health. It is necessary, therefore, that

this matter be given more attention by healthcare professionals, who should target adolescent patients with specific and developmentally appropriate interventions. These interventions should take advantage of flexibility features of children and adolescents coping to enable them to promote their own control over all aspects of their lives and health and, consequently, enhance the quality of their lives (Schmidt *et al*., 2003; Skinner and Zimmer-Gembeck, 2007; Washington, 2009).

2.7 Transition for children with chronic and life limiting illnesses from the child healthcare service to an adult healthcare setting

The next section will present the literature on different aspects of the transition process, with particular reference to healthcare transitions between child and adult care settings. This will include definitions, characteristics, elements of transition, negative impacts of the absence of comprehensive transition service, the importance of a successful transition, and finally, the currently available healthcare practices that address transition in the literature which may have relevance to the needs of adolescents with CF.

2.7.1 Characteristics of the transition from the child service to an adult healthcare setting

Reviewing the literature revealed two main characteristics for the transition from the child to the adult healthcare setting. These were the move in care between two different healthcare settings, and the multifaceted nature of the change process. Ignoring these two main features or not considering them might compromise the transition process and imply some side effects on the patients' health during and post transfer (Sommerville, 1997; Watson, 2000; McDonagh, 2005; Shaw *et al*., 2004; Kipps *et al*., 2002).

McDonagh (2005) presented a theoretical paper that discussed the meaning of transition for adolescents with chronic and life limiting illnesses, which covered the transition process as it involved a move between two different healthcare settings. McDonagh is a key author in the field of transition of children with chronic and life

limiting illnesses in the UK, and has undertaken many studies about the transition of children with juvenile idiopathic arthritis (JIA). This paper explored the differences between the two settings, stating that in the children's hospital, adolescents with chronic illness have known their paediatrician and paediatric nurse for a long time, and the service and the education sessions there are focused on the parents. But in the adult healthcare system, individuals are surrounded by much older adults, and the service is directed more towards the adolescent themselves, and consultation without the presence of any family member is common (McDonagh, 2005).

These findings were supported by Shaw *et al*. (2004) who reported in their study that adolescents described the clinic consultation style in the new adult setting as shocking and uncomfortable, in addition to be reported as anxious to the parents. This is despite the fact that being seen for treatment alone in the clinic (without parents) is generally seen as a developmental requirement, and might in some cases be requested by the adolescents themselves. The study by Shaw *et al*. (2004) aimed to identify the transitional needs of adolescents with juvenile idiopathic arthritis (JIA), and the researchers carried out focus group discussions with 55 adolescents with JIA aged 12 to 18 years old, young adults with JIA aged 19 to 30 years old, and the parents of both groups. Study participants called for a more co-ordinated service that focused on their needs, and prepared them to carry out the transfer competently. The study demonstrated how the difference between the child and the adult setting could negatively affect young adults after transfer, especially if they were not fully prepared to cope with such a change, as was reported by the participants in the same study.

The transition process for adolescents with a chronic and life limiting illnesses has another main characteristic, which is described by Blum *et al*. (1993, pp.571) is as "a multifaceted active process." This is a theoretical description of the meaning of transition, where transition should be seen as "a multidimensional process with the transfer to adult care is only a single event in the much longer process of transition" (McDonagh2005, pp.364). Based on this view, the transition process is a series of other steps that are preceded by and proceed other steps in a bigger comprehensive process to achieve the desired transition. McDonagh (2005) also highlighted the

importance of the participation of both the paediatric and adult care providers and the institutions in the provision of the transition service, as the success of the whole process could be threatened if one side or part of the transition process is ignored.

2.8 Elements of the service during transition

Research in the literature has reported many elements that should be included in any transition programme, based on an assessment of adolescent and young adult needs in different countries and across different chronic and life limiting illnesses (Ghosh *et al*., 1998; Scal, 2002; Brumfield and Lansbury, 2003; Shaw *et al*., 2004b; McDonagh, 2005; Reiss *et al*., 2005). Among these elements are the information elements (Scal, 2002; Nixon *et al*., 2003; Suris *et al*., 2004; Suris and Parera, 2005), the need for comprehensive care in the transition process (Madge and Bryon 2002; Shaw *et al*., 2004b; McDonagh, 2005; Reiss *et al*., 2005), the need to acknowledge the role of family during the process of transition (Scal, 2002; Shaw *et al*., 2004a; Reiss *et al*., 2005), and finally, the need to provide training for healthcare professionals on issues related to adolescent developmental stages, communication, and the transition process (Scal, 2002; McDonagh *et al*., 2004; McDonagh *et al*., 2006).

2.8.1 Information as an element in the transition service

Some researchers have reported that the information needed during the transition period for adolescents with chronic and life limiting illness is broad, and extends beyond the medical aspects of the chronic condition (Scal, 2002; Nixon *et al*., 2003; Zack *et al.*, 2003; Suris *et al*., 2005). There is a gap in healthcare professional practices when it comes to meeting these needs, and one of the most serious information gaps reported by the previous researchers is in the area of sexual health (Nixon *et al*., 2003; Suris and Parera, 2005). It was evident from the literature that addressing the information needs of CF adolescents as part of any transition service is a priority, and finding out what information they need should be a priority during the preparation for transition and during the actual transition process. The literature reports that adolescent sexual health and development is a key informational gap that is not well addressed in the clinical setting, despite studies showing that adolescents with chronic and life limiting illness are as sexually active as their peers (Suris *et al*.,

2005). This is especially worrying as adolescents with chronic and life limiting illnesses are more prone to health complications, as illustrated by the Stam *et al*. (2006) study that was presented earlier.

In the Suris and Parera (2005) study that was previously discussed, the researchers conducted a large scale study to assess sexual behaviour, sexual orientation, pregnancy and abuse history among adolescents from Catalonia with or without a chronic condition, drawn from a sample of about 36,284 between 7th to 12th grades. The results indicated that there was no difference reported between adolescents with or without a chronic illness in the proportion having intercourse, the incidence of pregnancy, contraceptive use or sexual orientation.

Despite this, healthcare professionals failed to provide adequate information to their adolescents' patients and their families about this issue. This was highlighted in the Nixon *et al.* (2003) study that assessed the ability of cystic fibrosis doctors to meet the sexual information needs of adolescents and their parents. The study was carried out in Australia and included 55 girls and 52 sets of parents. Participants completed a questionnaire that included questions about the provision of information on female sexual health issues (menstruation, thrush, fertility, contraception, safe sex, sexually transmitted diseases, and osteoporosis). The results of the study showed that 87% of adolescents and 78% of parents reported that their CF doctor had never discussed any of these issues with them. Furthermore, 54% of adolescents reported that they needed more information from their provider, but they stated that they would prefer the healthcare professionals to initiate the discussion (34%) as they might feel embarrassed to do so themselves. A high percentage (96%) of parents stated that more information should be provided, especially before puberty.

In relation to the exchange of information, especially during the transition period, Zack *et al*.'s (2003) study in the USA investigated the benefits of preventive counselling on the experiences of adolescents and adults with cystic fibrosis (CF) during transition to adult-centered care. During the study 32 CF patients (19 female, 13 male), who were aged 16-43 at the time of the study, participated in a face to face interview. During the interview participants were asked 27 structured questions and completed a 30-item self-administered questionnaire. The questions focused on

healthcare professionals' practices of preventive counselling on different issues related to the adolescent's health, illness and transition. The findings revealed that among the participants only one CF adolescent had a transition plan developed to guide the transition process; moreover, more than half of the adolescents reported receiving counselling on a spectrum of preventive healthcare issues, and, more importantly, those who received such counselling reported that they would like to discuss more issues than had actually been discussed during the counselling sessions.

2.8.2 The need for comprehensive care as an element of the transition service

The literature highlights the need to provide transition care that considers the different aspects of the transition process as well as the developmental changes that are taking place while caring for adolescents with chronic and life limiting illness (Shaw *et al*., 2004b; McDonagh, 2005; Reiss *et al*., 2005). Shaw *et al*. (2004b) undertook a study to examine the transitional needs of adolescents with JIA. The researchers carried out focus group discussions with 55 adolescents with JIA aged 12 to 18 years, young adults with JIA aged 19–30 years, and their parents. Participants confirmed the importance of looking at the hospital transfer as just one component of the transition process, and encouraged the use of an approach that acknowledges the unique developmental needs of the adolescent population. This includes having special facilities and staff who are sensitive to adolescent needs and trained to discuss adolescent issues, and foster their participation in their care and in decision making in relation to treatment options.

Similar findings were also reported in Madge and Bryon's (2002) study in the UK. The study reported the process of development of a transition care model for CF services, the goal of which was to encourage its implementation in practice and evaluate its outcomes. The programme was designed based on information about the current issues regarding transition to adult care as derived from CF patients who are currently using the service. The study used a quantitative approach and utilised a survey questionnaire designed by the researchers based on a review of the current literature about transition. Twenty one CF adolescents with an age range from 14 to 17 years attending the Cystic Fibrosis Centre in a large educational hospital

completed the questionnaires (14 boys, 7 girls). Participants were asked about the appropriate transfer age to the adult setting, and were asked to rate a number of statements regarding the planning and process of transition to adult care.

At the end of the study the researcher proposed a model of transition that included various elements of transition care. The transition elements included coordination of care elements, and preparation elements for transition, including psychosocial, encouraging independence in health management, provision of information about adult CF centres and adult health care services. The process elements, which commonly occur at 16 to 17 years of age, include visits to the adult centres and agreeing the transfer date. Finally, the outcome elements evaluate the process after the first visit to the adult centre is completed. The study concluded that although most participants were reluctant to leave the security and safety of their paediatric setting, the transfer was still perceived by the majority of them as inevitable. Most participants confirmed that with adequate preparation, coordinated and a comprehensive transition service, the whole process can be made more achievable and less stressful.

The comprehensive nature of the transition service was explained by McDonagh (2005) and McLaughlin *et al.'s* study (2008). McDonagh (2005) indicated that the structure of a transition programme should always foster personal and medical independence and critical problem-solving techniques for each adolescent patient. The research went on to state that transition programmes should contain a preparation period and an educational programme for patients and their families to addresses the medical, psychosocial and vocational aspects of care, and that the programme should be future-focused and follow a proactive approach in contrast to the reactive approach more familiar in adult health.

Similarly, McLaughlin *et al.'s* (2008) carried out a quantitative study in the USA to explore the transition practices in multiple cystic fibrosis programmes. Health care teams from 195 cystic fibrosis programmes were invited to participate; among them teams from 170 programmes actually participated, with a response rate of 84%. 448 surveys were completed by participants. The survey contained 105 questions that gathered data about the different aspects of the recommended transition practices,

and was developed by the researcher during the course of the study based on recommendations in the literature. The survey measured the health care teams' adherence to the recommended transition practices. The study results showed that initial discussion and preparation for transition occurs at around age 17, providing inadequate time to prepare adolescents for transition and foster self-management skills. The study also showed that 50% of the programmes do not have transition readiness assessment procedures, less than a third (28%) offer dedicated time that focuses on transition, more than a third had no routine evaluation of the transition process, and only 10% have a written list of self-management skills necessary for adolescents. Another significant finding was the presence of considerable variability in transition support provided to young adults with cystic fibrosis. The study concluded that the current transition service needs to be more comprehensive and organised; such improvement should include an earlier start for the preparation for transition, greater focus on development of self-management skills for adolescents, and, finally, the development of a nationally agreed and accepted list of skills which need to be acquired by adolescents to accomplish more successful transition.

These latter points were reinforced by the Reiss *et al*. (2005) study, which argued the need to focus on providing future planning for care with the adolescents themselves soon after diagnosis. It also argued for adequate training to be given to adolescents with chronic illness on the skills required to manage their condition, and finally, it stated the need to allow adolescents to use skills independently in the clinical setting. Reiss *et al*. (2005) argued that it was necessary to carry out these tasks in distinct stages and in a planned manner. The latter study conducted 34 focus groups and individual interviews with 143 young disabled adults with special healthcare needs, and with their family members and healthcare providers. The study aimed to examine the adolescents experience during the transition of care between the paediatric oriented setting and the adult oriented setting. The researchers reported three stages for the transition process: "Envisioning a future", "Age of responsibility", and "Age of transition" (Reiss *et al*., 2005,pp 115).

The first stage ("Envisioning a future") starts as soon as the disability is identified, and help is offered to the adolescent to promote future planning. According to the

study, the focus during this planning is on the future rather than the details of the plans, so the aim is to encourage future independence. However, future education, employment options, independent living and required healthcare were reported to be among the main elements of the planning process.

In stage two ("Age of Responsibility"), family members encouraged adolescent independence by teaching and giving responsibility to the young person to carry out tasks of daily living and medical self-care.

In stage three ("Age of Transition"), the adolescent is expected to carry out their health related activities independently, with maturity rather than actual age as the main criterion of their assessment, especially in very serious conditions, such as some cases of heart disease (Reiss *et al*., 2005, pp 115).

2.8.3 The need to acknowledge the role of family as an element of the transition service

Family support is an important factor for adolescents with chronic and life limiting illness. It is an important backup for adolescents going through a transition in healthcare setting, especially for those who have seriously disabling conditions, where the family role of supporting their child is vital for the success of the service (Scal, 2002; Shaw *et al*. 2004a; Reiss *et al*., 2005). Acknowledging this supportive role is important to provide the desired good quality in the transition service. However, Shaw *et al*. (2004a) reported that some parents may tend to be overprotective, which can disturb any transition plans to enhance the adolescent's knowledge and decision making about their condition, thus the family role should be well balanced and managed by healthcare professionals.

The Reiss *et al*. (2005) study that was discussed earlier reinforces the important role for the family in supporting and helping their child during the transition process. The study also showed that the family role in this situation changed significantly over time. Initially, the family participated in care, while later on, their role changed to cover teaching and helping the child carry out tasks of self and medical care. Finally, when the adolescent approached young adulthood and the age of independence, the

family continued to support the child while giving him/her the chance to carry out activities related to their own healthcare.

Healthcare professionals should create balance and negotiate this role to ensure parents do not hinder the transition process (Shaw *et al*., 2004a). This is usually done by giving adolescents the option of being seen by professionals without their parents in some of the clinics in the paediatric setting, in order to improve their independence and facilitate confidentiality (Reiss, 2005). This must be done while still bearing in mind that ignoring parents' role might deprive adolescents of an important support network, that could even diminish over time if not managed properly (Scal, 2002). Scal (2002) indicates the need to start early intervention in the transition service to educate the adolescent and their parents about maintaining and balancing their support.

2.8.4 Training and development for healthcare professionals as an element of the transition service

Many studies in the literature reported that healthcare professionals had unmet training needs, especially on issues related to adolescence health and development as well as in transitional care (Scal, 2002; McDonagh *et al*., 2004; McDonagh *et al*., 2006). These unmet training needs contributed to some of the reported shortcomings in healthcare practices during the transition process that were reported earlier in this literature review.

Increased training for healthcare professionals was reported in Scal's (2002) study, where the researcher examined approaches undertaken by primary care physicians to addresses the issues that adolescents encounter during transition. The study reported the responses of 13 healthcare professionals in a survey that included 53 items about transition services, barriers, and the training and background of the professionals. Despite the small sample size that might limit the generalisability of the results, all participants in the study indicated the need for additional training for primary care physicians working in transition over issues of behaviour and behavioural change, as well as sexuality and reproduction during adolescence. These were identified as

areas in which the respondents felt least effective in addressing the needs of adolescents and their families.

The need for further training was again highlighted by the McDonagh *et al*. (2004) study discussed previously. The study gathered information from 263 healthcare professionals who provided transitional care and 22 clinical personnel who were involved in the implementation of the transition service. The data was gathered through two questionnaires. The first was designed to identify the transitional needs of adolescents with JIA from the perspectives of professionals involved in their care. The second questionnaire measured the following: perceived barriers to implementing an appropriate level of care for adolescents; the healthcare professionals' perceived skill and comfort in addressing adolescence issues, concerns and needs; the perceived knowledge of information and resources available to healthcare professionals; the perceived importance of addressing adolescence-related issues; and finally, the perceived confidence in addressing these adolescence-based needs and issues. The study showed that 43% of the participants reported a need for more education and training in multiple areas that included the following: how to plan and co-ordinate the transition process; issues related to available resources for adolescents (e.g. relevant leaflets, websites, organisations, etc.); issues related to future job and career choice and the impact of JIA on a chosen career; legal and illness related benefits; adolescents' developments, needs, mental health and peer issues; generic and sexual health issues (e.g. alcohol, drugs, healthy eating, contraception); the impact of JIA upon education and the presence of any educational supports; independent living issues; and finally, interpersonal skills (e.g. communication with adolescents and parents).

The results of the same study (McDonagh *et al*., 2004) showed that over 50% of respondents reported low or very low perceived skill or comfort levels in addressing specific issues like suicide risk, sexually transmitted infections/HIV/hepatitis and gay/lesbian sexuality. They showed similarly low knowledge of information and or available resource covering issues like suicide risk, sexuality, drug use, eating disorders, dating/vulnerability, body image, parental conflict and peer relations. Finally in terms of perceived confidence, more than 25% of respondents lacked

confidence in key areas of transitional care, such as fertility, peer support, benefits and available adolescent programmes/agencies/services.

Another study was carried out by the same authors two years later (McDonagh *et al*., 2006), which showed that the educational needs for these same healthcare professionals had not been addressed or met. The more recent study by McDonagh *et al*. (2006) was carried out to determine the education and training needs of healthcare professionals in adolescent health, and the cross-sectional study included 159 doctors, nurses and other allied healthcare professionals working in British children's hospitals. Participants rated 'lack of training', 'lack of teaching materials' and 'lack of community resources' as the main barriers to providing appropriate transition care. The majority of participants (60%) had not received any specific training in adolescent health before, and the majority scored low scores in perceived knowledge, confidence and/or skill in key subject areas of adolescence such as growth and puberty during adolescence, adolescent mental health, peer relations, health education and promotion, education/vocation, and communication.

2.8.5 Negative impact for lack of transition service

Ignoring the characteristics of the transition process and some or all of the elements that were reported as being essential to the process might have a negative effect on the patient undergoing transition and their health (Sommerville,1997;Watson, 2000; Kipps *et al*. 2002).

Kipps *et al*. (2002) examined the efficacy of different transfer procedures from paediatric to adult centres. The researcher followed the attendance rate of young people at four different diabetes services centres before and after the transition process. The study found that the average attendance rate for diabetic adolescents generally fell from 94% in the children's setting to 57% two years after transfer to the adult clinic. The attendance rate was significantly lower in centres that offered no transition preparation (attendance rate in these centres fell to as low as 29%). Attendance was shown to be much higher in those centres where young people had the opportunity to meet the adult diabetes consultants prior to transfer, and the attendance rate in these settings was as high as 71%. According to the researchers, the decrease in attendance was attributed to multiple factors, such as the adolescents'

developmental stage itself (where compliance to treatment and diabetes control usually deteriorate). Another factor was the difference in care approach between the child and the adult centres. One of the main factors was shown to be the mode of transfer of the adolescents to the adult clinic. The study showed that those who were directly transferred from the child setting to the adult clinic (or to the care of their GP) had subsequently lower attendance rates. The indirect transfer mode (where adolescents had the chance to meet the other staff, interact with them, and familiarise themselves with the new setting) attributed to an improved level of clinic attendance and diabetes control post-transfer.

Sommerville's (1997) study looked at the importance of adolescent preparation on the outcome of the transition. In this study, researchers examined the treatment outcomes and how they were related to the early provision of multi-disciplinary, organised and co-ordinated care for adolescents and young adults with congenital heart disease. The author reviewed 341 death cases of patients with congenital heart disease, and although the method used for conducting this preview was not reported by the author, the author indicated that the deaths of 20% of patients with congenital heart disease were premature and avoidable, and 50% occurred in those who were well, or had only mild disability but had received healthcare that was not properly organised and did not involve key care providers.

Finally, Watson (2000) explored the effect of transition of adolescents with renal transplant on their compliance with their treatment and incidence of graft loss. The researchers reviewed the progress of 20 young adults who had been transferred from the paediatrics unit to three different adult centres at a mean age of 14.3 years. The researchers reviewed records from the opening of the adult clinic and focused on all patients transferred there with a functioning transplanted kidney. During their review, the researchers looked at plasma creatinine levels before and after the transition, in addition to looking at cyclosporine levels tests at the time of creatinine measurement. The study showed that eight transplants failed within 36 months of transfer, and in seven out of 20 (35%), the transplant failure was unexpected. The researchers attributed the failure rate to be mainly due to non-compliance with treatment that resulted most probably from lack of follow-up after the transfer. The

researchers recommended more preparation for adolescents prior to transfer through education and all other possible support before and after transfer, in addition to a continuous dialogue between the staff in the paediatric and adult settings in order to avoid these life threatening incidents.

In conclusion, the results of the previous studies (Sommerville, 1997; Watson, 2000; Kipps *et al*., 2002) highlight the importance of transition preparation and co-ordinated care on the transition outcome. They further highlight the importance of carrying out more studies that establish the need for co-ordinated and uninterrupted healthcare during transition, to avoid negative consequences ranging from psychological distress and anxiety to medical catastrophe or premature death.

2.8.6 Impact of a successful transition

Changes in morbidity and mortality following an improved transition process can only be measured with large numbers of patients and over a long period of time. However, there is emerging evidence that well-organised transition programmes do have measurable benefits for young people and their parents/guardians, such as those described in the studies of Nasr *et al*. (1992), Cowlard (2003), Coleman *et al*. (2004), LaBrie *et al*. (2008), and Van Walleghem *et al*. (2008). Notably, evidence identified in this area has reflected the needs of the CF population.

An example of such potential benefits are reported in the Nasr *et al*. (1992) study that evaluates a transition programme as a means of transferring care from a paediatric to an adult setting. The study involved surveying young adults with CF attending an adult CF centre, where the young adult had been transferred through a special transition arrangement. This arrangement involved the adult CF team providing their care for the adolescent patients in the children's hospital before they made the transition to the adult service. Of the 40 adolescent CF patients who completed a self-administered questionnaire, most thought that the transition programme made the change from paediatric to adult care easier. All patients were more prepared leaving the paediatric clinic and recommended that all adolescents should go through the same transition program. The authors of the study concluded that the transition process can be more effective through a well-structured and well-organised transition programme with committed paediatric and adult healthcare staff.

Similar conclusions were reported by Cowlard's (2003) study, which presented the results of implementing a new system for the transition of CF adolescents from the child to the adult healthcare setting. The system included a handover appointment in the paediatric clinic that involved both the paediatric and the adult teams. During the handover, the patients were able to meet with the medical staff, the adult CF nurse, dietician and physiotherapist. The main goal of the joint meeting was to introduce the patients to the new team in an environment where they already felt comfortable. The process was facilitated by one of the paediatric CF nurses, who also facilitated a similar visit to the inpatient ward and day care unit, and a meeting with the adult CF team. This system of transfer was audited, and the perspectives of adolescents with CF and healthcare professionals about the transition from paediatric to adult care were collected using an audit form developed for the purpose. Overall, the results of the audit showed the move to the adult clinic remained a stressful event for the participants, but the participants acknowledged the significant improvement in the transition process and that the preparation given to them did help them prepare for the future; however, they stated that the process still needed more improvement. The researcher indicated that the auditing process revealed the need to further improve the transition service through establishing a separate transition clinic.

These results were further supported by LaBrie *et al*. (2008, pp.148), where the researchers reviewed the young adults with rheumatoid arthritis (YARD) program in Canada, a programme that included setting up a transition clinic to provide continuity of care for adolescents during their transition to the adult clinic. The programme helped adolescents to manage their condition, provided counselling about education and career, and designed a personalised fitness programs. The study retrospectively reviewed the charts of 136 adolescents who had been transferred to the clinic, and the review collected data about the diagnosis, vocational status, number of clinic visits and non-attendance rate for the period from February 2006 to May 2008. In this time, 128 out of the 136 patients in the clinic attended either university or post-secondary education (48), high school (56), or worked full time (24). There was only a 6% (29/455) non-attendance rate, and finally, all patients were seen on their own after their first visit to the clinic.

Another related recent study is the one authored by Van Walleghem *et al*. (2008). During this study the author explored whether introducing "the system navigator service" (2008, pp.1529) could improve the transition of adolescents with type 1 diabetes to the adult service. The system navigator service included a central medical database and a support individual to help adolescents and young adults navigate through the adult service. The research involved two groups. The first group participants were 82 individuals aged 18 years old who used the new system navigator service while they were undergoing transition. The second group had already recently made the transfer to the adult service without using the navigator system, and they were aged between 19 to 25 years old (n=62). Data from the adolescents and young adults in the two groups were collected by telephone every six months. This data covered their medical visits, the presence of chronic complications, diabetes-related hospitalisations or severe hypoglycaemia, and barriers to accessing care in the adult diabetes care system. The authors reported that this service helped the young adults in the second group who dropped out from the adult service to rejoin again, and helped the newcomers to the adult service reduce their fall-out rate from 40% (as reported in the second group) to 11%. Participants in the first group also reported no long-term complications compared to the second group, who reported long term complications like miscarriage, blindness, and amputations.

Finally, two studies were carried out in Australia (Craig *et al.* 2007) and the USA (Chaudhry *et al.* 2012) to evaluate the effectiveness of a programme developed to help adolescents with cystic fibrosis during their transition. The first study in Australia, evaluated a two-phase programme. The first phase was for preparation, it starts in early adolescence, encourages clinic attendance, provides education for adolescents in various topics relevant to their illness, and promotes self-management skills. The second phase (active phase) starts at age 16 and includes interventions to foster self-management skills, an orientation to adult setting and adult healthcare professionals, agreeing the date of the first adult clinic and close coordination of the process between the two settings with the primary health care general practitioner. The study used quantitative survey methodology in which 137 adolescents and their parents, from both the pre-transition and post-transition groups, completed the

survey questionnaire. The survey collected data over a six-year period, and the data included patient and parent concerns about adult health care, their participation in steps of the transition process, their satisfaction with transition and health-related quality of life, and, finally, measures of the severity of the adolescent's condition (lung function tests and body mass index) were also included.

The results of the study revealed that most participants were satisfied with the transition programme, especially those who received more intervention. The result highlighted the importance of the presence of a structured and planned transition service: such a service would positively impact on the outcome of transition and the patient's experience while carrying out this process.

The second study was carried out in the USA (Chaudhry *et al.,* 2012). This quantitative study used a questionnaire which was completed by participants during their clinic appointments. The questionnaire compared the experiences and opinions of patients in the post-transition period for those who were transferred through the structured programme and those who were not. A total of 91 patients completed the questionnaire. Forty four of them were transferred through the transition programme. These patients showed higher levels of satisfaction, more positive perceptions about their health status, and more independence. The study concluded that establishing a transition programme could be important in optimising patient health, continuity of care and improving patients' adherence to treatment. However, it is worth noting that the survey included only those who attended the CF clinic. It consequently might have ignored some of the CF population who might be unsatisfied and have dropped from attending clinics.

In conclusion, previous studies have established that structured transition service has potential to improve the care outcomes during transition for adolescents with CF and other chronic and life limiting illnesses. However, there is still a lack of details on what are the key elements and components of this transition service. The need to identify and agree on these elements still exists.

2.8.7 Existing practices to address transition

None of the literature identified made mention of a comprehensive model or framework that deals with the whole process of adolescents transitioning from a child to an adult hospital (Flume *et al.*, 2004; Soanes and Timmons, 2004; While *et al*., 2004; Crowley *et al.*, 2011; Doug *et al*. 2011). There was some evidence of implemented healthcare professional practices that were described that had contributed to the enhancement of particular aspects of this process (While *et al*. 2004; Crowly *et al.,* 2011; Doug *et al*., 2011). This was evident in key studies in the literature that examined the current international practices that address the transition process.

In relation to the absence of a comprehensive or systematic transition service, Flume *et al.*'s (2004) study in the USA explored CF transition team members' perspectives on the current transition services. This quantitative study used a transition care survey which was distributed to all CF centres across the country. Healthcare professionals working in these centres were asked to complete and submit the survey electronically. Survey participants were asked about the organisation of CF care and team structure in their centre, their role during transition, and their perceptions about current transition care service and the already established transition programmes. Two hundred ninety one surveys were completed and submitted, with respondents coming from different healthcare specialities such as nurses (46.4%), social workers (16.8%), nutritionists (15.8%), respiratory therapists (11.7%), and others (e.g., physical therapists, psychologists, or genetic counsellors) (9.3%). The study findings suggest underdeveloped transition programmes across the CF network and the presence of great variability in the criteria used for transferring the child to the adult setting (for example, age, pregnancy of the CF patient, marriage), and indeed in transition care in general. The latter was highlighted by the various models of care provided for patients after transfer such as the young CF adults being treated by an internist working within a separate adult programme or an internist attending the paediatric CF clinic, or in some centres the continuation of care for young adults by a paediatric CF physician in the paediatric setting.

In terms of current practices that address the transition period, While *et al*.'s (2004) study aimed to identify current healthcare professional practices that improve the management of transition and enhance the continuity of care during this process. The researchers used a systematic process to examine the practices reported in the literature, and the process started by identifying published reports about transition practices. They examined the quality of the methodology used to evaluate the practice, and finally they identified the key components of successful practices. The study reviewed 5,319 items, but of these, only 369 were relevant to the study aim and passed to the second stage. Of the 369 items, only 126 items were considered for further examination as practices that contributed to "good" transition care. Following the examination of the literature reports, the researcher concluded four models that underlie current transition practices. These are listed as follows.

1. Direct transition models focused on communication between those involved in the transition service. This model is primarily focused on relationships between services and addresses the continuity of information and cross-setting team continuity.

2. Sequential transition models focus on the longitudinal continuity of care by restructuring the service to consider the change of adolescents' needs as they move to the adult setting. This model aims to prepare adolescents for such a change by building an extension to the service within the paediatric setting, or as a conjunction between the paediatric and the adult settings.

3. Developmental transition models focus on personal growth and development, with the transition starting from the premise that the young person will need some help in acquiring the skills and support systems necessary to use or experience adult care effectively.

4. Professional transition models focus on the complex professional skills needed to help the adolescent make the transfer smoothly.

Further evidence of the lack of a desired comprehensive transition service was the review study carried out by Crowley *et al.* (2011). The review aimed to identify programmes and components of transition care that contribute to the development of

transition care for young people (11–25 years) with chronic illness or disability. The review included those studies which evaluate the health outcomes following the implementation of one or more new interventions. The search included MEDLINE, HMIC, PsycINFO, CINAHL and IBSS and Embase databases, and identified 1998 literature. Abstracts of the articles were screened initially and irrelevant articles were excluded. Ten studies were included in the final review, among them only six reported improvements in care outcomes following implementation of new transition interventions. The identified interventions in these studies included those directed at either the patient (educational programmes, skills training); health care professionals (named transition co-ordinators, joint clinics run by paediatric and adult physicians); or health services (separate young adult clinics, out-of-hours phone support, follow-up interventions). All the significant interventions identified through this review were related to the diabetes mellitus transition service; among these identified interventions patient education interventions and transition clinics were the most effective and most reported transition intervention.

Finally, Doug *et al.* (2009) undertook a systematic review of the literature to evaluate the evidence on the transition process from child to adult services for young people with palliative care needs. The study searched five databases (Medline, CINAHL, PsycINFO, British Education Index and the International Bibliography of the Social Sciences) from January 1995 to February 2008. The search also included the reference lists of included studies and contacting experts in palliative care to identify relevant studies. All included articles were assessed for quality through a predefined scoring system with scores ranging from 1 (very poor) to 4 (good) for the different components of the study. In total, 92 studies were included in the final review; these studies were of variable quality. The results of the review highlighted an absence of standardised transition programmes; moreover, the majority of the guidelines and interventions located were not developed based on sound evidence, and, finally, there was evidence of poor continuity between child and adult providers mostly due to flaws in the practices in the child settings. However, it was noted during this study that CF is emerging among the most promising fields in terms of efforts to develop this practice area.

In summary, the reported practices try to address an important aspect of the transition service (e.g. communication between healthcare professionals, or the growth and development of the adolescent). However, concentrating on one aspect only might inhibit understanding of the complex nature of the transition, and so there becomes a danger of ignoring or missing other important aspects of this phenomenon. Adolescents in receipt of transition care that was supported by one of these listed practices would be deprived of the positive points of other practices that focus on other equally important aspects of transition care.

Therefore, there is a need for a comprehensive framework for a good understanding of the transition phenomena, which is complex and multi-dimensional in nature (Meleis, 2000). Such a framework is expected to overcome the shortcomings of the previously mentioned practices, by combining all their benefits, and providing a comprehensive service that covers the spectrum of issues implied in the transition process. This issue will be further discussed in the next section.

2.8.8 The need for more comprehensive service

The transition programmes and practices reported in the previous sections indicate considerable benefits of the transition service (Nasr *et al*., 1992; Cowlard, 2003; LaBrie *et al*., 2008; Van Walleghem *et al*., 2008). However, the literature still reports a gap between the patient's needs and the actual care provided by healthcare professionals during transition. The reviewed literature indicated that the current transition service does not meet the needs of patients with chronic and life limiting illnesses during this transitional period, and therefore needs to be further investigated and developed (Veit *et al*., 1995; Westwood *et al*., 1999; Farrant and Watson, 2004; Coleman *et al*., 2004; While, 2004; Reiss, 2005; Lotstein *et al*., 2008; Steinbeck *et al*., 2008; Tuchman *et al*., 2010; Towns and Bell, 2011). It is evident from the literature that the current service needs further and considerable improvement in terms of organisation and co-ordination in order to meet all the needs of adolescents during this process. Only then will the service provided deliver its potential benefits.

Some contemporary studies in the literature illustrated the inadequacies of the current transition service. Among these were the studies of Westwood *et al*. (1999) and Farrant and Watson (2004). Westwood *et al*.'s (1999) study included 47

adolescents from a total population of 61 adolescents and adults who attended the CF clinic in Cape Town in South Africa. Using a semi-structured survey questionnaire, the study explored the perspectives of these participants on different aspects of the transition from child to adult-oriented service. This was achieved by gathering data about participants' perceptions about growing up and being independent, and their attitudes and feelings about the transfer process, especially those related to the timing aspect of the process. The study reported that the majority of adolescents and young adults with chronic illness who had undergone transition or were about to do so were significantly concerned about the process, and lacked the knowledge to identify who their healthcare provider would be after transfer. They did not know what to expect from the adult centre, or whether the adult centre knew about their disease or not. Although the study population and sample size are small, it laid the foundation for the need to establish a more smoother and comprehensive transition service.

Similarly, Farrant and Watson (2004) study included 53 adolescents with different chronic illnesses and 45 sets of parents, all of whom answered a self-report survey. The majority of participants expressed significant dissatisfaction with the transition service they had received, especially in the area of provision of information. The authors reported that such dissatisfaction has a potential impact on the use of healthcare services and health outcomes.

Another study that explored the current transition service and reported the lack of a comprehensive approach was Soanes and Timmons' (2004) study. The study examined the needs of young people with chronic illnesses and their perspectives about ways to improve the current service. This qualitative study purposefully selected seven adolescents (aged 14–17) who attended the youth club of a large teaching hospital in London in the UK. During the interview most participants reported that they had never been told about the transfer to adult care before. Their experiences revealed significant inconsistencies in healthcare professional practices, indicating the lack of a systematic approach for the provision of a transition service in that hospital. Most participants reported feeling anxious, concerned as a result of

the lack of adequate support, about feeling alone, and about the added responsibilities and the need for independence.

Similarly, recent study by Kirk (2008) reported similar results. This study explored the experiences and perspectives of disabled adolescents and young adults about their transition. The researcher used in-depth interviews with 28 participants aged eight to 19 years old, who were recruited through community children nursing teams. The study reported that adolescents experienced this transitional period as a time of uncertainty mainly due to the lack of information. The participants were concerned about the availability of appropriate expertise and support in the new setting, the loss of relationships with familiar staff in their current setting, and the need to adjust to the new culture and setting. The participants also reported that they suddenly had to develop skills of responsibility, decision-making, and liaising with the new service providers soon after the transfer because of the lack of appropriate training in the child setting. Therefore, the importance of any transition programme would originate from its ability to enhance the knowledge of both adolescents/young adults with chronic and life limiting illness and their healthcare professionals, as the current literature reported a gap in this regard.

Finally, the continuous need for a comprehensive transition service was highlighted in the study by Steinbeck *et al*. (2008). The study examined the current transition service provided for adolescents with different chronic conditions in New South Wales in Australia. The study collected data over a one-year period from 200 clinicians who were working in 68 tertiary paediatric hospitals. The data was collected using an individual interview, and information collected included data about numbers of adolescents, who were in the transition phase at the time of study, the current transition practices that were carried out in the clinical setting, and the follow-up mechanisms to ensure that the young people had actually accessed adult services after the transfer process. The results of the study found that the transition process was inconsistent, had poor quality databases that did not contain some basic information about the adolescents who were undergoing transition, there were few clear policies and procedures for the transition service, and finally, there was a lack of co-ordination and communication with the adult services.

2.9 Summary of the literature review

The literature review has covered four broad areas related to the transition of children with CF from the child healthcare setting to adult setting. These areas include: the meaning of transition; the transition of adolescence to adulthood; the effect of chronic and life limiting illneses on adolescents and the transition to adulthood; and finally, the transition of adolescents with CF and other chronic and life limiting illness from paediatric to adult services. The review revealed that adolescence is a stage of significant change and development, and that the presence of CF or any other chronic or life limiting illness adds to the burden on adolescents when it comes to achieving required developmental tasks and milestones.

The review further indicated that the transition process is a multidimensional phenomenon that requires similarly multidimensional care to competently manage the amount of change that might be taking place at the same time. There was evidence in the literature of the potential harm that may occur as a result of stressful or unplanned transitions. This could be problematic for the healthcare system itself, and also harmful for the adolescent's health and wellbeing.

The literature review showed shortcomings and gaps in the practices of healthcare professionals during this important stage of life for adolescents with CF or any other chronic and life limiting illness. These include shortcomings in communication and providing information, which leave the adolescents lacking in essential support, knowledge and skills to achieve the required transition between the different healthcare settings.

The literature reported important components of the transition care, along with some current practices that address these elements. It was noticed during this review that while these practices contribute to a better quality transition service, the service itself still appears to be incoherent, not addressing the different aspects of the process, and therefore it was difficult to see how they could be used to guide the transition process in question. It was evident there was a need for a study that proposes a comprehensive framework for the transition service; a framework to address the different aspects of the multiple and complex transition phenomena, and to cover all the adolescents' needs while they are going through the transition process.

It was noted that the majority of studies reviewed in the literature are not about CF, but related areas of chronic and life limiting illnesses. The themes arising from these studies have resonance with the topic of CF but the fact that there are so few in the area of CF enforced the need for this study. The importance of this study was further underlined due to the absence of any such study in Ireland that addresses transitional care services or explores the needs of patients and their families during this sensitive period of their lives. This is especially important in the context of the Irish healthcare system, where CF is such a prevalent health concern. The lack of evidence in regard to the Irish context - in addition to the general lack of knowledge in this field illustrated by the literature review - further highlights the need for this study.

Chapter 3: Research Framework

This chapter examines the research paradigm, the research strategy, and the data collection methods used to provide a rationale for the chosen research framework. Issues related to validity and reliability will be addressed.

3.1 Research paradigms

Research processes are usually guided by a set of assumptions and beliefs that the researcher adopts while conducting their studies; assumptions and beliefs that determine how the world around the researcher should be studied and understood (Creswell, 2009; Denzin and Lincoln, 2005). Clark (1998) described this as 'research philosophy', which is the most basic level of research methodology, and refers to assumptions on general features of the world, such as reality, truth, nature and proofs of knowledge. According to Morgan (2007, p.53) the word 'paradigm' may also be used to describe a particular philosophy, referring to the "consensual set of beliefs and practices that guide a particular field".

Morgan (2007), suggests that 'paradigm' can be used in other ways. These include:

1. World views. These are ways of thinking about and experiencing the world. As the most general definition of the word, this may not be useful in assisting researchers in the practical conduct of a research project.
2. An epistemological stance. This represents the researcher's belief system and world-views on philosophical issues of knowledge, such as the nature of knowledge and ways to knowing.
3. Shared beliefs among members of speciality research areas. This represents the views of scholars in this area as to the most meaningful questions and the most appropriate procedures to address these questions.
4. A model example. For example, how research is carried out in a specific field.

The paradigm adopted by the researcher (or the philosophy that underpins any research process) may affect or shape the research method used (Denzin and

Lincoln, 1998). In addition, some other factors might determine the method used. These include: the research goal; the nature of the phenomena of interest; the nature of the research question; and practical considerations (Shih, 1998).

Understanding research paradigms and making a particular choice is important (Easterby-Smith *et al*, 2002). It helps the researcher to specify research methods and a strategy that will be used during the course of the study, and it assists the researcher in evaluating different methodological weaknesses, limitations and strengths, and consequently avoids using inappropriate methods.

The following sections address the positivist, constructivist and pragmatist paradigms as they represent the three philosophies that relate to this research project, focusing on the pragmatic approach.

3.1.2 Positivist paradigm

The positivist paradigm is based on a realist ontology that believes in an independent reality driven by natural laws. It contends that things can be studied as hard facts and that the relationship between these facts can be established as scientific laws (Smith, 1998; Guba, 1990).

The epistemological assumption of positivism is that an objective reality exists independently of human behaviour and the mind, and thus requires the researcher to be objective while using their senses to gather measurable, objective and discernible data (Guba, 1990; Holton, 1993; Crossan, 2003).

According to Clark (1998, p.1244), positivism adopts a "correspondence view of truth, with true statements taken to correspond with the knowable facts of reality". Therefore, true statements are those that can be verified against external reality by means of examination and observation.

Accordingly, the main concepts identified in the positivist paradigm are:

- *Value freedom;* this means that research elements are separated from researcher's beliefs and preferences.

- *Causality;* this implies that casual relationships can be established between study variables.
- *Operationalisation;* of the study variables to be measured quantitatively.
- *Independence;* This means that the role of the researcher should be independent of the subject under examination.
- *Reductionism;* this reduces the study problem to smaller measurable variables (Crossan, 2003, p.51).

Advancements in scientific technology and the continuous challenge to positivist ideas led to the development of instrumentalism and post-positivism, which forced the positivist paradigm to revise its original ideas, such as the denial of unobservable facts and the role of the researcher (Clark, 1998).

Post-positivism suggested that knowledge is also reality-based, and that the role of the researcher is to describe and interpret this reality in an objective manner using different data collection techniques, such as observation and interviews (Bailey, 1997). Post-positivism supports a belief in rigour, precision and logical reasoning, but without being strict as to what can be physically observed or measured from it (Guba and Lincoln, 1998; Letourneau and Allen, 1999).

3.1.2.1 Criticism of the positivist paradigm

One of the main arguments against the positivist approach is that it does not provide the means to examine human behaviour, because humans are subject to many influences on their behaviour, feelings, perceptions and attitudes. The data that the positivism paradigm provides is useful but limited, as it only provides superficial data on phenomena (Crossan, 2003; Parahoo, 1997).

Another criticism is the requirement for non-biased involvement of the researcher in the research process. According to this view, a study can only be bias-free or objective if the researcher can achieve full detachment from the research process, and act as a neutral observer who reports their observations free from experience or social context (Holton, 1993).

3.1.3 Constructivist paradigm

Natural inquiry, interpretive research, critical theory and constructivism are all descriptions for qualitative research (Guba and Lincoln, 1994). These terms are most commonly used to refer to specific perspectives within the paradigm. For example, the term 'naturalistic inquiry' refers to the type of research that interprets meanings within their natural context, while terms like 'critical theory' and 'constructivism' were used later to reflect more specific positions of this philosophy (e.g., relationships between the researcher and informants, and so on) (Bailey, 1997).

Constructivism is based on assumptions that knowledge is not static, and that people (and their goals and psychological processes) can be influenced by the contexts or the environment where they exist. Therefore, from the constructivist worldview, multiple perspectives do exist, and reality is subjective in nature, constructed by individual mentalities as they interact with the environment around (Bailey, 1997; Creswell, 1998).

Multiple mental constructions exist regarding reality (relativism) with the knower subjectively and interactively linked in a relationship to what can be known (Guba and Lincoln, 1994). During the research process, the researcher relies on communication and on their collection of stories, narratives, observations and descriptions of experiences to create knowledge (Annells, 1996; Morse, 2005; Lincoln and Guba, 2000).

The main assumption within this paradigm is that the social world does not exist independently, pending discovery, but is rather a contextual, mental world that is constructed by the researcher and the research participants (Rather and Greene, 2000).

3.1.3.1 Criticism for the constructivist paradigm

The most commonly discussed controversial issues around qualitative research are concerns in relation to validity or trustworthiness (Sandelowski, 1993); dependence on the interaction between the researcher and the elements of the research (Parahoo,

1997); dependence on personal impressions and lack of generalizability (Mays and Pope, 1995).

However, such criticism - originating from a quantitatively oriented philosophy - is refuted by qualitative researchers, who minimised the importance of using these terms and criteria within the qualitative inquiry, and argued for the need to change it to suit this philosophy. These researchers favoured the adoption of validity methods, which are accepted by the research community as legitimate ways of collecting and analysing data; hence, the goal in this paradigm is to understand meanings, and not reach the 'truth' (Bailey, 1997; Morse, 2005; Collingridge and Gantt, 2008; Reitmanova, 2008).

3.1.4 Pragmatist paradigm

The philosophical movement termed "pragmatism" began in the late 19th century and is attributed to the American philosopher Pierce. It was subsequently developed, refined and elaborated on by numerous scholars (Maxcy, 2003).

Pragmatism is a practical and outcome-oriented method of inquiry that is based on action, and its consequences and benefits. This method states that the success of a theory depends on its effectiveness in practice. However, this notion of success might be reconsidered once the theory stops working (Johnson and Onwuegbuzie, 2004; McCready, 2010).

This paradigm focuses on the research problem as being more important than the research method, and encourages the researcher to use all approaches to understand the problem. Pragmatism is based on the belief that action, situation, and consequences generate knowledge (Creswell, 2003). Meaningful research begins not with a single method or set of methods, but rather with a single experiment and the desire for a better world (Wolfe, 1999).

The goal of pragmatism as outlined by Johnson and Onwuegbuzie has been to:

> *"find a middle ground between philosophical views, to find a workable solution and 'reject many longstanding philosophical dualisms like (e.g., rationalism vs. empiricism, facts vs. values, subjectivism vs.*

> *objectivism)' and finding instead a more moderate versions of philosophical dualisms based on how well they work in solving problems".*(Johnson and Onwuegbuzie, 2004, p.18)

Proponents of the pragmatic paradigm advocate a needs-based approach to research methods, where researchers can put together procedures from different approaches to produce higher quality results. The argument is that both the constructivist and positivist paradigms have points of strength, and if these are used together, they can produce higher-quality knowledge and evidence (Johnson and Onwuegbuzie, 2004; Garrett, 2007; Greene and Gracelli, 2003; Creswell, 2003).

The philosophy of pragmatism offers researchers a way to select methodological mixes that allow better answers to many of their research questions. According to Tashakkori and Teddlie (2003, p.52): "It generally challenges the idea that social science inquiry is able to access the real world by solely the virtue of a single scientific method."

3.1.5 Rational for Choice of Research Paradigm

To choose the appropriate research paradigm method to guide a research study, a researcher must consider the primary goals that their study was setup to achieve.

The primary goal of this study was to establish guidelines of service to guide the care provided for adolescents with CF during their transition from a children's hospital to an adult setting. The literature reviewed indicated limited exploration of the experiences and opinions of transition service stakeholders about the transition service in Ireland; therefore, the inclusion of adolescents with CF as service users and health care professionals as service providers would make the suggested guidelines more relevant.

The experiences of these participants would be explored first in the study and then would be used to formulate the proposed service guidelines. These guidelines then need to be verified by the wider CF service stakeholder community to ensure they represent the views and opinions of the whole group.

The positivist paradigm was considered unsuitable for this study, as it has limited ability to achieve the first aim of the study, which is exploring the experiences of transition service stakeholders in using the transition service. This phase is especially important, as it would be expected that future transition service guidelines should be drawn from the results of this inquiry.

The constructivist paradigm has a great deal to offer in exploring and understanding the experiences of CF transition service stakeholders; however, it has limited ability to achieve the second aim of the study, which aims to verify the relevance and feasibility of these proposed guidelines with the wider CF service in Ireland, and across the different children and adult settings. Therefore, this paradigm was rejected.

It became evident that no single method could provide the necessary information to complete the two parts of the study. Both qualitative and quantitative methods have important roles to play in the achievement of the goals of this study. Therefore, a decision was made to adopt the pragmatist paradigm, which was considered the most appropriate for the needs of the study.

3.2 Research strategies

The differences between different paradigmatic positions are constantly debated by academics. The compatibility between different philosophical positions has received much attention, and researchers have divided into different positions in regard to this issue (Tashakkori and Teddlie, 1998).

Some have written on the absolute incompatibility between the different philosophical positions due to core differences in the basic assumptions (Smith and Heshusius, 1986). Others have discussed similarities and refuted claims for total separation (Dzurec and Abraham, 1993; Clark, 1998). Dzurec and Abraham (1993) are among the researchers who defend the similarity of both the positivist and constructivist paradigms, arguing that both paradigms employ techniques to enhance the quality of study results, and use text to analyse their data and present their findings.

Clark (1998) states that, despite the established distinction between methods, these two paradigms are not as diverse or mutually incompatible as usually described. Clark goes on to state that strict classification of methods under particular paradigms is neither correct nor useful. A detailed discussion regarding claims for similarities and even possible combinations between the components of different paradigms will be presented in the later sections of this study, covering pragmatism and mixed methods. This section provides an overview about research strategies and includes a review of qualitative, quantitative and mixed method research strategies.

3.2.1 Qualitative research approaches

In general terms, qualitative research approaches focus on studying social phenomena that cannot be studied by means of measurement or experiment. These approaches seek to answer questions about how social experience is created and given meaning (Denzin and Lincoln, 2005). Qualitative research utilises mainly interviews and observation as the main data collection methods, and this approach is especially appropriate for exploring new phenomena about which little information is known (Munhall 2001; Denzin and Lincoln, 2005; Creswell, 2009)

Within qualitative research design, some researchers have advocated use of specific approaches, like ethnography, grounded theory, and phenomenology (Hollway and Wheeler, 2002; Lobiondo-Wood and Harper 2002; Creswell, 2009). According to Creswell (2009, p.177) researchers within these approaches study “individuals”, as in phenomenology, or explore “process, activities and event”, as in grounded theory and case study, or, finally, study the “culture” among a particular group or society, as in ethnography.

Within all these approaches the researcher is searching for an intimate relationship with the participants to understand their experience in the context of the research phenomena. Munhall (2001) and Creswell (2009) focus on both the participant experience and the context in which these experiences happen, and in doing so gain a comprehensive understanding of the phenomenon using narrative data derived from the participants’ descriptions (Munhall, 2001).

Qualitative research employs different strategies for collecting and analysing data. The data collection techniques used include the following: observation, interviews, reviewing documents (e.g. diaries, letters, newspapers), or reviewing audio-visual materials (e.g. photographs, videotapes etc.). In relation to data analysis, the goal of the researcher is to make sense of this data through reflecting on the data, asking analytical questions, gathering more data, and making interpretations (Coffey and Atkinson, 1996; Silverman, 2005; Creswell, 2009)

A brief over view of main qualitative approaches will be presented next; these approaches will include ethnography, grounded theory and phenomenology.

3.2.1.1 Ethnography

Ethnography is a qualitative research approach that seeks to understand people's ways of living, believing, and responding to changes in their environment and life circumstances (Burns and Grove, 2009).

Historically, ethnography emerged as a result of unsuccessful attempts by early scholars to use questionnaires to undertake their own field-work. These researchers consequently warned against these rapid data collection methods and stressed the importance that researchers take time to thoroughly understand the deep connections and meaning of particular phenomena. It was in 1980's that ethnography grew theoretically and guided research studies (Tedlock, 2000).

The underlying assumption of ethnography is that by direct participant observation and relatively prolonged interaction with participants in their everyday life, ethnographers learn to see, think, feel, and sometimes behave as an insider or native person in a particular group or culture. Through this process, ethnographers can reach an understanding of beliefs, motivations and behaviours of their subjects (Hammersley, 1992; Tedlock, 2000, Creswell, 2007). This assumption is based on the belief that the realm of meaning emerges from the material and organic strata that surrounds the human being, rather than emerging from the human being themselves (Tedlock, 2000).

Ethnographers typically start the process of ethnographic study or inquiry about a particular culture, sub-culture, or cultural group by reading relevant anthropological literature. They gain access to site of the study, and then start to build a network of relationships with the key informants in this setting. Ethnographers start to identify patterns among the subjects, and then they interpret how these subjects are connected to their larger social network. Through this engagement with participants, ethnographers can learn the meanings or details of particular phenomena (Creswell, 2007).

Within the sphere of healthcare, one of the major contributions of ethnography may be to promote culturally-specific care (Baillie, 1995).

3.2.1.2 Grounded theory

Historically, grounded theory was developed and described in the 1960s by Glaser (1965) and Glaser and Strauss (1967). According to Strauss and Corbin (1998, p.1), grounded theory is an "effective method of discovery", and refers to the process of generating a theory through systematic data collection and analysis within the research process.

The essence of grounded theory is that people's behaviours and experiences within a particular social world tend to have some patterns, similarities and commonalities; although these relationships may not be perceived easily by outsiders (McCann and Clarice, 2003; Creswell, 2007). Researchers using this approach pursue their work to uncover these unarticulated psychological problems or phenomena that are experienced by particular social groups (Hutchinson and Wilson, 2001). Their main role during this process is to capture the essence of this social phenomenon, and present it in a theory to introduce an entirely new way of understanding the observations or the data from which it was generated (McCann and Clarice, 2003).

According to Hutchinson and Wilson (2001), data gathering in grounded theory research generally follows the pattern of field-work. During this process, the researcher chooses their research setting and becomes immersed in that social environment. Hutchinson and Wilson (2001) go on to discuss how important elements in this process are the researcher's reflection on their own experiences and

feelings during the research process, in addition to careful observations of the participants, and informal interviews which augments observations and serve to clarify meanings attributed by the participants themselves to a given situation.

The key principle of grounded theory is its generation of data from participants in the field who have experienced the process from acting or interacting with other social group members (Strauss and Corbin, 1998). These actions, interactions, or social processes through the process of data collection, analysis and verification allow formation of categories that are the main components of a grounded theory (Creswell, 2007). This process was further explained by Creswell (2007), who highlighted that the systematic approach followed in grounded theory typically depends on observations, and the conduct of around 20-30 field interviews, where the aim is to collect and analyse data until all details of categories are examined, elaborated on and discussed.

This process of continuously comparing new data with the emerging categories is called the constant comparison method of data analysis, and is central to the grounded theory methodology (Cooney, 2010). During the process of theory generation; a researcher uses open coding and then axial coding to identify one major category that is the core of the phenomena. Around this main core, other items are all drawn in one axial coding model. These include other causal conditions (what caused this phenomena), strategies to respond to the core phenomena, intervening conditions, and consequences of actions (Creswell, 2007).

3.2.1.3 Phenomenology

Phenomenology was developed through the work of German philosophers, such as Husserl and Heidigger, and was further influenced by other European philosophers like Merleau-Ponty (Patton, 2004; Creswell, 2007; Parahoo, 2006). This tradition was further refined and developed by contemporary scholars like Gadamer (1976) and Van Manen (Parahoo, 2006; Dowling 2007). But according to Mickunas and Stewart (1990), the development of the phenomenological inquiry was partially a reaction to the strict scientific principles of empiricism, which were deemed unsuitable for exploring human phenomena.

The term phenomenology has been widely used in recent literature. Patton (2004, p.104) argues that authors have indicated that phenomenology can refer to a philosophy, a paradigm of inquiry, an interpretive theory, or a social science perspective or orientation. This lack of clarity was further noted by other researchers who reported the absence of one set of thoughts that can be referred to as phenomenology. Phenomenology was therefore split into three schools: transcendental (Husserl, 1970), hermeneutics (Heidigger, 1962), and philosophical hermeneutics (Gadamer, 1976).

These different forms of phenomenology share a similar focus on exploring how individuals make sense of their experiences, and transform those to their consciousness. As Patton (2004, p.104) puts it: "how this individual perceive these experiences, describe it, feel about it, judge it, remember it, understand it, and describe it to others."

The goal of phenomenology is to explore ways in which people experience and understand their world, their relationships with others and to their environment (Van Manen, 1996). There is a fundamental assumption within phenomenology that focusing on the perceptions and the meanings attached to particular experiences will awaken consciousness and allow us to better understand that experience (Parahoo, 2006; Creswell, 2007). Patton (2004) further explains that our understanding is initiated by sensory experiences, which must then be described, explicated, and interpreted to complete this understanding.

Phenomenology is an approach that considers life experiences from the perspectives of those who have experienced them. Therefore, this approach is especially useful when a study goal is to explore and understand newly identified, explored or defined phenomena, or when the intent is to understand phenomena from those who have lived it and experienced it.

3.2.2 Qualitative approach used in this study

After reviewing different potential qualitative approaches, it was clear that the goals of the first exploratory qualitative phase of this study of understanding CF adolescents and healthcare professionals working with their CF patients resonated

with the goals of the phenomenology tradition of understanding participant's experiences. Therefore this approach was selected. Other qualitative research approaches were not selected, as their goals were not consistent with goals of this study.

While this study used the principles and tools of the phenomenological approach, the study is not considered a 'pure' phenomenological study. The goal of the study was not to understand the lived experience of CF adolescents and explore how they make sense of it, and transform it to their consciousness, nor to explore ways in which adolescents experience and understand the transition experience, which is the typical purpose of phenomenological studies (Van Manen, 1996; Patton 2004). However, this study borrowed from the phenomenology tradition in exploring and understanding the experiences of study participants going through the transition process, with a goal of identifying elements of this experience, including their needs during this experience, as well as factors that influence it.

Furthermore, the study adopted elements of the phenomenology tradition during the sample selection, data collection, and data analysis processes. In sample selection and data collection, participants who had experienced the transition experience were selected to participate in the interview process, and finally, data analysis then took place, using phenomenological data analysis techniques as detailed by Van Manen (1990).

As the phenomenology tradition has been used to guide the qualitative phase of this study, it will be further explored in the following section.

3.2.3 Further elaboration on phenomenology

Phenomenological study describes an individual's interpretation of their experiences, the meanings they attribute to these experiences, and how they express them. Most importantly, this approach stresses the notion that those individuals who experience phenomena are then best-placed to discuss the experience with other individuals who did not, after such discussion take place the experience can be constructed (Parahoo, 2006; Creswell, 2007).

During a phenomenological study, researchers look for the essential, consistent, and central underlying meaning of the experience. The researcher may use common phenomenological tools like phenomenological reduction to analyse specific statements and themes and search for all possible meanings. They may use bracketing of researcher experience to avoid preconceptions and judgments (Creswell, 2007; Parahoo, 2006), and they use intuition to formulate a full picture of the participants' experiences (Creswell, 2007).

Within the phenomenological tradition there are different methodological approaches to phenomenology. The differences between these approaches depend mainly on the role of the researcher's prior knowledge and experience, and how that can be managed during the research process. The initial phenomenological movement developed by Husserl was descriptive in nature, and required the researcher to utilise 'bracketing' to stop their previous knowledge and conceptions from interfering with the research process. In this way, the researcher will be able to approach the phenomena with an open mind and fresh eyes, free from prior bias and judgments (Boyd, 2001).

Other phenomenological scholars like Heidegger (the developer of the hermeneutical phenomenology approach) and Gadamer disagreed with this concept of bracketing, arguing that it was an impossible process. These scholars instead called researchers to draw on their previous knowledge to be able to understand the phenomena (Hedigger, 1962; Gadamer, 1976). They also considered the researcher's experience and previous knowledge as an important component, crucial to understanding the research phenomena, and the scholars further stressed the importance of knowing how the individuals come to experience the phenomena in the way they do, rather than just describing these experiences (Parahoo, 2006).

A more contemporary perspective in phenomenology and utilized in this study is Van Manen's phenomenological perspective. According to Dowling (2007), Van Manen's writings combine the descriptive and the interpretive views of phenomenology, and they agree with the phenomenology of Husserl by indicating that facts can be described. However, Van Manen argues that these facts must be

understood as interpretations rather than descriptions, since the facts are described linguistically, which is by virtue an interpretive process (Dowling, 2007).

Van Manen does not embrace Husserl's view of bracketing, though, he instead acknowledges the necessity of studying the world before reflection upon it (Van Manen, 1990).

To analyse the phenomenological descriptions of experiences given by research participants, many strategies have been described. The guidelines developed by Van Manen (1990) are the most explicit and clear, especially for novice researchers. This approach is composed of the following steps:

- Familiarisation,
- Coding,
- Preliminary naming of categories,
- Comparison of categories,
- Identification of themes.

3.2.4 Quantitative approaches

One of the main characteristics of quantitative research is its focus on reducing a problem into smaller variables that can be studied and examined (reductionism). Another focus is on objectivity, where researchers try to remain detached from the study so as not to affect results by introducing bias (Burns and Grove, 2005). Quantitative research approaches, as opposed to qualitative ones, focus on the collection of objective measurable data where the goals are to describe a phenomenon (descriptive), measure relationships (correlation, none experimental), or determine cause-effect relationships (experimental, quasi-experimental studies) (Thomas, 2003; Polit and Beck, 2006; Creswell, 2009; Gliner, 2009).

Survey designs or basic descriptive studies usually focus on one variable at a time by providing a quantitative numeric-dominated description of the variable under study (e.g. attitudes, opinions) (Creswell, 2009; Gliner, 2009). Drawing on the sample data and characteristics, the researcher usually makes descriptions, generalisations, and claims about the whole population of the study (Creswell, 2009). In these descriptive survey studies, the same study might include more than one variable at a time

(Gliner, 2009); however, these variables will be explored using descriptive statistics only (e.g. averages, percentages, mean, and frequency distribution) without establishing any relationships between the variables (Burns and Grove, 2005; Polit and Beck, 2006; Creswell, 2009; Gliner, 2009).

In relation to comparative or correlational studies, a comparisons between the multiple variables within a study are carried out, sometimes with an aim to find out possible hypothesised correlations between some or all of these variables (Burns and Grove 2005; Polit and Beck, 2006; Creswell, 2009; Gliner, 2009). In these studies it is difficult to establish or attribute causalities, due to inability to control the many extraneous variables that also affect the study variables (Gliner, 2009).

Quantitative studies may also be experimental in design. For any quantitative study to be considered as experimental, it should have two main criteria. The first is the presence of an "active" variable that can be manipulated by the researcher during the course of the study. The second is the random assignment of participants to study groups. The second criterion is what differentiates the randomised or true experimental study from a quasi-experimental study. The latter design allows for the examination of relationships or causality between variables in a situation where full control could not be achieved, or with already-established groups that could not be changed (Gliner, 2009, p.47; Burns and Grove, 2005).

According to Creswell (2009) experimental designs intend to test the impact of particular treatment or an intervention on the study outcome, this is typically done while controlling for all other factors that might influence that outcome. Random assignment of research individuals to control and treatment groups as one form of control, by doing so the researcher can then isolate whether it is the treatment and not other factors that influence the outcome. However, according to Black (1999), in real experimental situations, the implementation of some aspects of an experiment might not be possible, so the design might require modification to allow its application. This consequently results in variable experimental designs, such as pre- and post- test designs, and post-test only with controlled group designs, among others.

3.2.5 Quantitative approaches used

The purpose of this study was to develop guidelines for best practice to guide the care provided for adolescents with CF during their transition from children's health care to adult health care. The goals of the second phase of the study were to investigate the opinions of a large number of health care professionals working with CF patients about the relevancy and feasibility of the guidelines developed in the first phase of the study. A quantitative survey approach was considered the most appropriate for this. The approach allowed drawing a large representative sample from the health care professionals to explore their opinions on the suggested guidelines, and this was achieved based on their ratings for the different items within a survey that contained variable proposed guidelines for the transition service. The goals of this phase of the study were neither to compare nor correlate between different variables, nor to establish causal relationships; therefore other types of quantitative approach (correlational and experimental) were excluded.

The Delphi method was considered as an alternative to the survey method used in the context of this study; however, it was later excluded. The purpose of the study was for participants to identify and consider the relevancy and feasibility of the proposed transition interventions rather than seek consensus on which transition interventions were more or less important. Therefore iterative rounds of data collection as required in Delphi methods to achieve consensus would not develop the information further (Bruce *et al.,* 2008; Keeny *et al.,* 2001).

The following section will elaborate on the survey approach, as this was the quantitative method adopted during the course of this study.

3.2.6 Surveys

Surveys are the most common type of descriptive study, and are mainly used to obtain information about practices, opinions, attitudes, and other characteristics of participants. In addition to these data, survey studies tend to gather demographic data as well, assuming that this information will help in interpreting and understanding the study (Knapp, 1998; Houser, 2008). Data gathered in this way helps provide

information about prevalence, distribution of particular variables within the population, as well as highlighting any relationships between these variables.

Survey designs allow researchers to study characteristics of different variables by providing mainly a quantitative numeric data of the variable under study (Creswell, 2009; Gliner, 2009). These data can be obtained by different means, such as interviews, questionnaires, interrogation of previous records, as well as from observation over single point of time (cross-sectional) or over an extended time span (longitudinal) (Houser, 2008).

By interpreting the gathered sample data, researchers can formulate explanations, comparisons, predictions, and generalisations about the general population. However, key to achieving this is following a systematic robust research process. Adequate or large sample sizes are included to reduce errors resulting from sampling and to allow for possible percentages of non-responses. Appropriate sampling strategies must be followed, and the validity and the reliability of the study instrument must be insured (Knapp, 1998; Burns and Grove, 2005; Polit and Beck 2006; Creswell, 2009)

The typical survey process usually consists of four main steps: calculating and selecting the survey sample, selecting or developing appropriate survey instruments, administering the survey instrument to collect data, and analysing the data to extract results (Houser, 2008). This research process can be an efficient way of gathering data from a large number of subjects (Knapp, 1998; Houser, 2008) especially with the aid of the internet, which has provided additional possibilities for accessing studies in a convenient way for both participants and researchers (Houser, 2008).

However there are drawbacks to survey studies. Information gathered may be superficial, and researchers may be unable to further explore the responses to identify unclear answers, contradictions, or emerging patterns in the data. Also, questions might be misinterpreted by subjects, resulting in unreliable data and difficulty in interpreting results later on (Knapp, 1998; Burns and Grove, 2005; Polit and Beck, 2006; Houser, 2008; Creswell, 2009).

3.3 Mixed methods research approaches

This section provides an overview of mixed method research strategies, and highlights some issues related to carrying out this type of research. The section starts by presenting arguments about the suitability of mixing research methods, followed by a presentation of the types of mixed methods reported in the literature. The section concludes by discussing some criticism of the use of mixed methods.

3.3.1 Overview of mixed methods research

The mixed methods approach involves collecting and analysing quantitative and qualitative data in a single study (Creswell, 2003), with the aim of confirmation and/or completeness of data, where data from each method confirms or completes data from the other approach.

Researchers have increasingly used mixed methods techniques to expand the scope of and deepen insight from their studies (Adami and Kiger, 2005), based on the assumption that both quantitative and qualitative methods have limitations which can be neutralised if both methods were used together. (Johnstone, 2004, p.259)

The suitability of mixing quantitative and qualitative methods (especially in the social sciences) was also confirmed by researchers who argued that the world is not naturally qualitative or quantitative place, but rather can be expressed and presented in a better way through both numbers and words, which should be given equal importance (Yoshikawa *et al*,2005).

For Ford-Gilboe *et al*. (1995), Yoshikawa *et al*. (2005), and Morgan (2007), mixing methods brings the researcher closer to understanding the phenomena by providing variable data, and enables the answering of the research question by letting the question guide the selection of appropriate methods, and not vice versa.

Creswell (2003) supported this view, saying that the underlying logic of mixing methods is that neither quantitative nor qualitative methods are sufficient in themselves to capture the trends and details of some situations. When used in combination, both quantitative and qualitative data yield a more complete analysis and complement each other.

In health care research, there are arguments that support the use of mixed methods. The most basic is the complexity of health services, which requires an epistemology for nursing that acknowledges this reality. The ontological position that considers reality as complex and multidimensional implies the need to use different methods to illuminate the issue under investigation (Foss and Ellefsen, 2002).

Drawing on that, it seems that despite the contradictory viewpoints of different paradigms, the use of mixed methods is still feasible (Ford-Gilboe *et al*, 1995; Sandelowski, 2000). The two paradigms of inquiry should not be seen as dichotomies, but as different positions on each side of a continuum where many different positions are possible in between (Foss and Ellefsen, 2002).

Within this, the combination of two approaches is possible or even necessary, to develop health research (Dzurec and Abraham, 1993; Sandelowski, 2000). Researchers use different types of questions and different data collection techniques that emerge from different paradigms to elicit two or more dimensions of the phenomena, while keeping the basic assumptions or positions for each paradigm intact.

According to Sandelowski (2000), the technical level of research is the place where the combination actually occurs. Combination at this level involves the use of sampling, data collection and data analysis techniques, which are commonly referred to as qualitative and quantitative. This process takes the benefits of data collection techniques from different methodological traditions, allowing for an innovative use of a wide range of techniques to achieve a variety of purposes (Sandelowski, 2000; Kelle, 2001).

However, the successful combination of quantitative and qualitative research within the same project depends on priority decisions taken by the researcher when deciding on the principal and complementary methods of inquiry, and the sequence decision regarding which method will precede the other (Morse, 1991; Morgan, 1998).

3.3.1.1 Classification of mixed methods

Morse (1991) and later, Morse and Niehaus (2009) classified mixed methods as either primarily qualitative with an added component of quantitative design, or vice versa. The authors reported two different types of method triangulation, depending on the relationship between the methods used and the sequence of use. These are as follows:

1. Sequential triangulation, when the results of one method are essential for planning the next method;

2. Simultaneous triangulation, when the interaction between the two methods is limited and both are used at the same time; however, the data still complements each other at the end of the inquiry.

Creswell (2009) has further described six strategies for mixed methods designs:

1. Sequential explanatory strategy, where the qualitative phase is carried out after the quantitative phase to explain and clarify the results of the quantitative phase.

2. Sequential exploratory strategy, where the qualitative phase precedes to explore and inform the second quantitative design.

3. Sequential transformative strategy, where the methods are carried out sequentially, but the study has a theoretical guiding perspective that is "more important than the use of methods alone".

4. Concurrent triangulation strategy, where both phases are done concurrently and have similar weight in the study.

5. Concurrent embedded strategy, where both phases are done concurrently but with a primary method guiding the whole study, and a secondary supporting method.

6. Concurrent transformative strategy, where the methods are carried out concurrently, but the study has a theoretical guiding perspective that is "more important than the use of methods alone". (Creswell, 2009, p.212)

Any of these designs could be chosen, depending on which best achieves the goals of this research study.

3.3.1.2 Criticism of mixed methods

Criticisms of mixed methods have focused mainly on two issues. The first is the extra resources, time and expertise needed for the researcher to carry out this type of research. Proponents of this critique have warned that the unavailability of this expertise may hinder method combination and the research process (Moccia, 1988). It might also further contribute to the accumulation of the weaknesses of the methods used, and instead of correcting and strengthening the other method, the combination may invalidate the entire research project (Morse, 1991).

The second critique has focused on the importance of the selection of research philosophy as a fundamental activity that should reflect researcher philosophies. Within this argument, ignoring this significant step in the case of mixed method research converts the research process to a neutral technical process that relies only on the question asked (Moccia, 1988).

3.3.2 Rational for choice of research strategy

Addressing the current study research problem and achieving the study goals could not be achieved without using mixed method design.

First, there is a scarcity of literature about the needs of CF adolescents during the transition from children hospitals to adult hospitals within the Irish context. Second, there is an absence of information about the factors that affect this process within the Irish context. Third is the need to make the suggested transition care guidelines as relevant and feasible as possible to the whole CF population within this demographic, to enhance adherence and implementation later on.

All these factors necessitate the need for an initial phase that explores transition service stakeholders in this matter, and a second phase that builds on the findings of the first phase, and subsequently recommends transition service guidelines. Furthermore, a sequential exploratory mixed methods design was selected, as

exploration of the transition service stakeholders should be qualitatively achieved and should precede the second phase (of establishing transition care guidelines).

The decision to use mixed methods research was also reinforced by the need to employ criteria and rigour measures suitable for both approaches in addition to following a robust methodological decision-making process that is documented explicitly throughout the research process.

3.4 Rational for data collection methods

Data collected during the research process can be classified into self-reports, observation, and bio-physiological measures. Self-reports consist of participants' answers to questions posed by researchers, whether given as part of an interview, written narratives, or answers on particular survey questionnaire. Observation data is collected by directly observing participants' actions, behaviours, and characteristics. Finally, bio-physiological measures are used during medical investigations, which are based on collecting physiological or physical data or specimens from the participants (Polit and Beck, 2006).

In the context of this study, observation and bio-physiological measures were rejected, as they are less appropriate in gathering data about the transition service stakeholder experiences in and perspectives about the transition service. Self-report methods (including interviews and surveys) were considered the most appropriate, as this way encourages participants to talk about their transition experiences. This includes asking them to express and articulate their opinions about possible ways to improve the service, and provide feedback on any proposed service guidelines.

3.4.1 In-depth interview

Depending on the purpose of the study, researchers could use a semi-structured or unstructured type of interview. According to Donalek (2005), the semi-structured interview uses pre-planned, open-ended questions focusing on different aspects of the research phenomenon. In contrast, an unstructured interview may start with an opening question and then consist of the researcher guiding the participant during the interview to fully describe his/her experience.

Price (2001) has stated that in-depth interviews give nurses the opportunity to understand participant's stories and then interpret what this means for conceptualising nursing care. However, Price also identified two main issues in the literature regarding interviews, especially the power of the researcher to lead and shape the interview, and the issue of how to get the most possible information from the interviewee, without them feeling they have been interrogated.

There are seven techniques reported by Russell Bernard (2000) for maintaining conversation in an interview and probing into the participant's stories. These include: remaining silent and allowing the participant to complete the story, repeating the participant's own words to encourage him/her to continue, using words like 'yes' or 'OK', using long questions to encourage a detailed answer, and asking leading questions if there is a need to encourage the participant to take a stance and argue.

According to Corbin and Morse (2003), the interview process is divided into four phases: the pre-interview, the tentative phase, the immersion phase and the emergence phase. The interview advances gradually through these phases, moving from introducing the goals of the interview and making small talk to establishing trust, to becoming immersed in the aspects of the experience, and finally progressing to when the interview becomes less informative and both parties emerge from the experience.

3.4.2 Focus group interview

Focus group interviews are defined by Kitzinger and Barbour (1999) as group discussions exploring a set of issues, or centred on a specific topic and co-ordinated by a moderator or facilitator (Sim, 1998). According to Webb and Kevern (2001), the focus group interview method is based on interaction between participants that generates a rich data set through interaction and discussion that could not be obtained using other data collection methods (Webb and Kevern, 2001).

This interactive element of the focus group interview affords it high face validity according to Kreuger (1994), as a point raised by one participant is validated or disagreed with by another participant in the group. Kreuger (1994) further reported

that eight to 12 participants is a suitable number for a focus group, even though smaller sized groups have been used in the literature (Sim, 1998).

The interview is usually co-ordinated by a moderator, who acts to stimulate the discussion around a particular interest point while avoid directing the discussion or enforcing a particular view (Sim, 1998). The role of the moderator needs to be balanced and not prominent during the interview, and should only form between 5% - 10% of the resulting transcripts as suggested by Hague (1996).

Krueger and Casey (2000) suggest that five categories of questions should be used in conducting the focus group interview: opening, introductory, transition, key and ending questions. These are explored as follows:

- *Opening questions* are easy and brief questions to establish rapport and encourage interaction between group members.
- *Introductory questions* introduce the discussion topic.
- *Transition questions* move the discussion from the introduction to the key questions on the topic.
- *Key questions* serve as the main focus of the study.
- *Ending questions* help conclude thoughts and allow participants to reflect on what has occurred.

The discussion and interaction between the group participants can generate a large amount of data, which can be used in formulating questionnaire items using the interviewee's words and vocabulary, which is common within these interviewees' common areas of interest. This was confirmed by Morgan (1997), who highlighted the fact that focus groups are a widely used source of information for questionnaire formulation.

However, the literature reports several factors that can affect group dynamics and thus the quality of data gathered during these interviews. Among these reported factors are the age of the participants, their gender, income, occupation, education, race, religion and socioeconomic status, and finally, power relationships. The literature advises that groups be as homogenous as possible to enhance interaction

and decrease barriers to communication between group members. Finally, power relationships are a main factor that can affect group interaction, especially if some participants in a group are perceived as they hold more power over other participants (Kreuger, 1994; Morgan, 1997; Krueger and Casey, 2000; Webb and Kevern, 2001).

3.4.3 Survey questionnaires

In quantitative research, data collection or measurement is carried out to produce trustworthy data that can be used in statistical analysis (Burns and Grove 2005). Among the commonly used data collection methods in quantitative studies are questionnaires or surveys (Gliner, 2009).

The survey technique is a self-reporting type of data collection, in which participants provide information about themselves, their attitudes, their knowledge, their opinions and so on through written or verbal responses to a pre-prepared question list (Burns and Grove, 2005).There are some limitations inherent in the use of questionnaires that must be considered. For example, it is possible that participants might not respond to questions, might misinterpret items, or provide only superficial information, and there is no further opportunity for participants to clarify this information (Burns and Grove, 2005; Gliner, 2009). However, the majority of these limitations could be avoided by careful design of the questionnaire (DeVaus, 1996) and by follow-up with study participants to enhance the response rate.

3.5 Method design considerations

During the planning of the different phases of the study, some consideration was given to achieving the best possible outcomes from the various methods employed. During planning for the in-depth interview and the focus group interview processes, a flexible interview guide was considered to be the most appropriate for this study. It was also identified that two pilot interviews needed to be carried out: a pilot individual interview and a pilot focus group interview. This was in order to test and develop the research skills in carrying out the interview process.

In relation to the survey questionnaire, some issues were identified and considered during the implementation of this process. These included the need to develop clearly formulated questions, as well as clearly worded instructions for filling out the questionnaire, so a user-friendly questionnaire could be developed. Finally, a pilot test was also considered. A problem of response rate and tight sample size were anticipated, so strategies to improve the response rate were undertaken, which included a reminder letter to be sent to the participants, and mailing a second questionnaire to the participants.

3.6 Approaches to analysing quantitative and qualitative data analysis

This section presents an overview of the data analysis techniques used in this study to analyse data collected during the in-depth interview, the focus group interview, and the survey questionnaire.

3.6.1 Data analysis of the in-depth interview

The analysis of the qualitative data is the process of moving from raw interview data to an evidence-based interpretation, which can be published to inform the clinical practice. This process usually starts with the process of coding data, which according to Rubin and Rubin (2005) results in the identification of key themes and patterns. These authors go on to state that the process of coding is considered an important part of the analysis process, during which data are condensed into analysable units by creating similar segments from the data. Different segments then are linked to each other and lead to the formulation of categories of data that have some common properties and elements.

Different strategies have been described for analysing the phenomenological descriptions of experience given by research participants. However, Van Manen's (1990) methodological concepts fit well with the goals of this study, and are written more explicitly and in clearer terms than some others, especially for novice researchers. Therefore, the principles of Van Manen's data analysis procedure were chosen to guide the analysis of the in-depth interview data.

The Van Manen (1990) phenomenological thematic analysis technique was used to extract themes and analyse data during the course of this study, According to Van Manen:

> *"The theme is the experience of the meaning, the focus or, the point, as I read over an anecdote; I ask, what is its meaning, its point? … Theme is the form of capturing a phenomenon one tries to understand, themes describe an aspect of the structure of lived experience"*. (Van Manen, 1990, p.87)

To extract these themes from narrative texts, three approaches have been described by Van Manen:

1. The holistic approach or sententious approach
2. The selective or highlighting approach
3. The detailed or line-by-line approach.

Using any of these approaches, the procedure is composed of the following steps: familiarisation, coding, preliminary naming of categories, comparison of categories, and identification of themes.

This process consists of the researcher familiarising him/herself with the data during the data collection process, and afterwards through continuously reading through interview transcripts. During this process, recurrent themes or common texts will be noted and then transformed and reduced into "singular statements" that capture the "main thrust" of the meaning of the statements (Van Manen, 1990, p.92). Van Manen indicates that no single statement can reflect the "fullness of the life phenomenon" but rather can help "point at, allude to, or hint at" an aspect of the phenomena (1990, p.92). These singular statements are then clustered together and compared with each other, and similar statements are merged to form the study themes. The final themes collectively reflect the knowledge gained during the study about the phenomena of interest.

3.6.2 Data analysis of focus group interview

Morgan (1997) demonstrated that focus group interviews could be a self-contained research method, or used in conjunction with other methods. The analysis of data from either type of interview is dependent on the time invested in the process and the rigour of the analysis. For example, if focus group interviews are used as a preliminary phase to assist in the planning of another subsequent phase, then the data analysis would not be as extensive and rigorous as if the process was used as a self-contained focus group (Morgan, 1997).

The methods for analysis of focus group interview data are similar to those methods of data analysis used in individual interviews, but some considerations are unique to group setting, like considering areas of agreement or controversy, how views are reinforced and modified during the discussion, and finally, areas that are considered as priority to the group participants and discussed thoroughly or discussed before others. These issues can be observed and recorded during the course of the interview and may help add context to the analysis and during the interpretation process (Krueger, 1998; Krueger and Casey, 2000).

According to Krueger (1998) the analysis of the focus group data should include:

- *First,* a discussion between the group moderator and the assistant immediately after the interview takes place, to capture the first impression from the data. The discussion usually includes the important ideas discussed within the interview, how did they differ from what were expected, any important quotes that need highlighting, any possible changes for the next focus group interview.
- *Second,* carefully listening to the tape recorder and reading the transcription for the relevant parts. The researcher then will read the transcripts and attach a label to relevant ideas as he/she comes across them.
- *Finally,* repeatedly occurring ideas are gathered and then combined under one heading which represent an emerging theme.

3.6.3 Survey questionnaire data analysis

This section will provide an overview of the principles of quantitative data analysis, focusing on descriptive frequency statistics as the main technique used for survey data analysis in this study. The section will also briefly present the analysis of the variance (ANOVA) test, as it was used to compare different participant groups scores for the subsections and the overall survey.

Data gathered during any quantitative research project are classified into nominal (data which can be categorised and named), ordinal (data which can be ranked or ordered), interval (data which shows the order and degree of magnitude), or ratio (data which has a natural zero) (Jakobsson, 2004; Botti and Endacott, 2005; Polit and Beck, 2006).

Determining the type of data collected is central to selecting the appropriate inferential or descriptive statistics, and when choosing between parametric or non-parametric tests (Botti and Endacott, 2005). Parametric data is based on the assumption that the data has come from a population with a normal distribution curve, and allows for a greater variety of tests. However, this is only true when applied to interval and ratio data, and not to ordinal data (Jakobsson, 2004). On the other hand, non-parametric tests have 95% sensitivity when compared to parametric tests (Botti and Endacott, 2005). This makes them a better choice for ordinal data, especially if a larger sample size can be achieved to enhance the ability for detecting statistically significant differences (Jakobsson, 2004).

The analysis of numerical data gathered during survey studies usually begins with descriptive statistics; however, it is not uncommon to find some descriptive studies, in which the whole analysis procedure will be limited to descriptive statistics only. The main goal of this type of statistics is primarily to describe the characteristics of the sample, and the degree to which a particular group shares attitudes, beliefs or opinions on particular variable (Parahoo, 2006; Polit and Beck, 2006; Burns and Grove, 2009).

Measures of central tendency are the most popular types of descriptive statistics, and these consist of the mode, the median, the mean, and the percentage (Parahoo, 2006;

Polit and Beck, 2006; Atkinson, 2008; Burns and Grove, 2009). Theoretically, for data that has a normal distribution, the mode, the median and mean are equal; however, in data obtained from real samples, these are usually different (Burns and Grove, 2009).

Percentage indicates how large or small particular sub-group is when compared to the whole group. This measure is calculated by dividing the number of the sub-group by the total number within the group, and then multiplying by 100. The mean is the sum of the scores divided by the number of the scores being summed, so the mean is the most commonly used measure for central tendency and is the appropriate measure to use with intervals and ratio data (Atkinson, 2008; Burns and Grove, 2009).

The mode is the score that more frequently occurs within the group scores, and is the appropriate measure of central tendency to use in nominal data, while the median is the score that represent the centre of the total scores. The mode and the median is more appropriate measure for central tendency for ordinal data (Burns and Grove, 2009).

In the context of this study, the Percentage and the mean scores were the main measures used. The percentage score represented the majority of the participants' positions from the relevancy and the feasibility of every individual's suggested guidelines, while the mean scores reflected the general trend among participants about the importance and feasibility of the proposed guidelines in general, and in regard to the different care guideline domains.

If the numerical data being analysed contains inputs from different sub-groups within the sample, then detecting differences between these sub-groups could provide valuable data for some researchers. To that end, analysis of variance (ANOVA) tests are usually carried out. Within these tests, an analysis for the presence of difference between the means of more than two groups is performed. Within this test, a0.05 significance level is usually used, and indicates if significant that at least two pairs of the different groups' mean scores are different. In such a case, further tests (such as Tukey's test) are required to examine different groups'

mean scores and determine which pair of groups are significantly different from each other (Atkinson, 2008; Burns and Grove, 2009).

The ANOVA test is a parametric test, which means it is carried out for interval and ratio data where assumptions of normal distribution for the study population can be made. However, in cases of ordinal data, it is inappropriate to make these assumptions, and therefore non-parametric tests- such as Pearson's Chi-Squared test are more appropriate.

Within this study, to compare groups in relation to their responses on particular items, the Pearson's Chi-Squared test was used. The ANOVA test was used to compare scores for the subsections and the overall survey on averages scores of the appropriate items (Parahoo, 2006; Polit and Beck, 2006; Burns and Grove, 2009).

3.7 Validity and reliability

This section presents issues of validity and reliability in relation to quantitative and qualitative research. The debate about differences between the quantitative and qualitative approaches in regard to validity and reliability will be highlighted, before describing the different strategies employed in both approaches.

The development of reliability and validity measures was prompted by fears of inaccurate measurement of variables, and consequently possibilities of errors during data collection procedures. The development of these measures reflects the concerns of researchers about the acuity and the quality of research findings (LoBiondo-Wood and Harber, 2002). Validity is defined as acuity of the instrument in measuring what it was developed to measure; while reliability is defined as how consistent the instrument is in measuring the attribute it is supposed to measure.

While these measures are generally accepted within the quantitative domain as criteria to judge the quality of research studies, qualitative researchers have questioned the suitability of these measures to be used within the qualitative domain (Sandelowski, 1993; Ryan-Nicholls, 2009). These researchers argue that since the type and the goals of both inquiries are different, then different measures should be used. However they acknowledge the necessity of using alternative rigour measures,

and reported that the qualitative domain has been always undermined due to the absence of such mechanisms (Morse and Field, 1996; Morse, 2006).

3.7.1 Use of validity and reliability terms in qualitative research

Qualitative health research continues to be described by some researchers as subjective and opinion-based, rather than a method that can lead to valid and reliable scientific evidence (Morse, 2006). However, Morse argued that this is mainly due to the differences between researchers about definitions of health, and the importance of addressing the different aspects of this phenomenon rather than focusing only on curing aspects, such wider view of health require the use of qualitative research approaches in addition to the quantitative methods adopted mainly in the medical profession (Morse, 2006).

Such differences in the definitions of basic concepts will affect the research techniques used in different paradigms. It further provokes differences in the methods used to assess the results of these different techniques. In other words, it affects the way that different groups of researchers measure the validity and reliability of their study results (Tobin and Begley, 2003; Ryan-Nicholls, 2009).

Researchers, especially from the qualitative domain, have always opposed connecting the application of strict validity measures with the value or the truth of the study results (Sandelowski, 1993; Ryan-Nicholls, 2009). The previous researchers argue that studies that might use stringent validity and reliability measures might not always produce valuable or true results. Therefore, any general rules on judging validity in particular studies or domains of inquiry are rejected (Sandelowski, 1993; Ryan-Nicholls, 2009).

According to Sandelowski (1993), the differing nature of qualitative research necessitates the use of compatible assessment techniques that consider the specific nature of this type of research. Similarly, Morse (1999) highlighted that these rigour measures can be used after being modified to fit the qualitative context, and warned against ignoring the use of similar measures, as this will damage qualitative research and decrease its value.

3.7.2 Criteria for rigour for both research traditions

To address the difference between the quantitative and qualitative approaches in relation to the rigour criteria, Guba and Lincoln (1994) suggested four criteria to judge the quality of both research approaches. These criteria are presented in the table (Table 1) below. The first column in the table represents those suggested by the two authors, while the second and third columns represent the equivalent measures used in both quantitative and qualitative approaches.

Table 1- Rigour criteria in quantitative and qualitative studies

Study Quality Criteria	Measure in Quant. Studies.	Measure in Qual. Studies.
Truth value	Internal validity	Credibility
Applicability	External validity	Transferability
Consistency	Reliability	Auditability
Neutrality	Objectivity	Confirmability

3.7.3 Criteria for rigour in qualitative research

Guba and Lincoln (1994) suggested credibility, applicability, auditability and conformability as alternative measures that are more appropriate for use in qualitative research. These different strategies will be presented and followed by a description of different procedures for achieving them.

Credibility in qualitative inquiry refers to the understanding of study phenomena as they are lived and perceived by study participants (Guba and Lincoln, 1994), and it reflects researcher accuracy in analysing study data. Credibility is enhanced when researchers reflect on their experiences during the study (Koch, 2006) by reporting

clearly the participants' perspectives in the study, and by verifying study findings with participants and other researchers (Morse and Field, 1996).

Applicability is concerned with ensuring the findings of the study can fit into similar contexts outside the study situation (Ryan-Nicholls, 2009; Koch, 2006). This can be enhanced by detailed reporting of the context in which the study was carried out, in addition to reporting the patients' perspectives (Morse and Field, 1996).

Auditability applies to the ability of other researchers to follow the decision trail used by the investigator to ensure that it falls within acceptable professional and ethical limits (Koch, 2006). According to Morse and Field (1996) audibility implies that a study carried out in a similar context would have results that were consistent with original study findings.

Confirmability requires the researcher to show the way in which interpretations have been arrived at via the inquiry and the extent to which these findings were free from bias (Guba and Lincoln, 1994; Koch, 2006).

3.7.4 Strategies for ensuring rigour in qualitative research

To enhance the audibility, credibility and applicability of studies, Ryan-Nicholls and Will (2009, p.80) suggested some practical techniques. These are listed as follows.

Auditability can be enhanced by:

- Describing the study's purpose.
- Justifying participant selection criteria, and how these participants were accessed.
- Describing and justifying data collection, data analysis and the interpretation process.
- Describing any "participant-researcher influences on one another" if they exist.

- Keeping all personal memos, data-display charts showing coding instructions, categorical data assignments and particular data component linkages.

Applicability can be accomplished through:

- The use of examples and data that is representative of the study phenomenon.
- Using triangulation in data sources and using data collection procedures to confirm findings.
- Seeking validation of findings from study participants.

Additionally, Creswell (2003) suggested some strategies to ensure rigour in qualitative studies. These include: triangulation, rich descriptions of study procedures, reporting and possible sources of bias, prolonged engagement with study participants, and the use of peer debriefing, member-checking and external auditors.

Finally, Guba and Lincoln (1994) recommend that data analysis by another researcher and extended contact with subjects can provide measures of validation of research findings.

3.7.5 Criteria of rigour in quantitative research

In quantitative studies, validity, reliability and objectivity are the appropriate measures for ensuring rigour (Guba and Lincoln, 1989). These measures will be described in this section, followed by a presentation of strategies that can be used to ensure rigour in quantitative studies.

Validity ensures that the research instrument measures what it was designed to measure, by ensuring that each item or group of items measures the essence of the intended domain (content validity), or the extent to which results can be generalised to other groups or contexts (external validity) (Polit and Hungler, 2000).

Another measurement of validity can come from a correlation of one study's results with other well-identified or well-established criteria, surveys or instruments. This

validity measure is called criterion-related validity (Eldridge, 2010; Powers and Knapp, 2006).

Reliability refers to the extent to which findings can be replicated in another study or setting (Denzin and Lincoln, 1994), and it can be measured through the test-retest technique, split-halves technique, coefficient alpha or parallel form technique (LoBiondo-Wood and Haber, 2002).

Objectivity refers to the extent to which research processes and findings are free from bias, and the ability of the researcher to study subjects without influencing them (Denzin and Lincoln, 1994).

3.7.6 Strategies for ensuring rigour in quantitative research

The need to ensure rigour in quantitative studies is a matter of consensus within the quantitative research literature (Polit and Hungler, 2000; LoBiondo-Wood and Haber, 2002; Powers and Knapp, 2006; Macnee and McCabee 2008; Burns and Grove, 2009). Within this literature, many strategies are reported that can help researchers establish validity and reliability in their studies. These strategies will now be described.

3.7.6.1 Validity

To establish validity in quantitative studies, literature about quantitative research identified many different approaches (Burns and Grove, 2003; Parahoo, 2006; Macnee and McCabee, 2008). Among them are the content validity, criterion related validity and construct validity.

Content validity is the extent to which the questions in the questionnaire collectively are adequate to represent the phenomenon, and include all the major elements relevant to that phenomenon. In addition to identifying key domains to be included and key questions to be asked, content validity helps identify questions that are irrelevant and should not be included (Parahoo, 2006).

To enhance the content validity of the study, the researcher might consult key sources in the literature that identify main components of the study phenomena (Burns and Grove, 2003), or consult individuals who are considered experts in the

study field (Burns and Grove, 2003; Parahoo, 2006; Macnee and McCabee, 2008). The latter approach was reported by Frank-Stromborg and Olsen (2004) as the best way to establish content validity, provided an explicit and structured expert-selection process was followed.

The second validity testing approach is criterion-related validity, where results of a newly developed measuring tool are compared with another one that measures the same concept. The second measure in this case acts as a criteria to evaluate the validity of the new measure (Burns and Grove, 2003; Parahoo, 2006; Macnee and McCabee, 2008). Burns and Grove (2003) highlighted many sources that can be used as the criterion to assess the validity of a measure or an instrument. These sources include:

- Comparing with groups known to have particular concepts.
- Comparing with other established and already tested tools that measure the same or closely related concepts.
- Comparing the measure results with a predicted, concurrent, or future event or set of behaviours, etc.

Based on the last source of comparison, criterion-related validity was classified as concurrent, where the predicted event can be measured at the same time, or in the future, where the predicted event can be measured in the future (Burns and Grove, 2003;Parahoo, 2006)

According to Parahoo (2006), construct validity is the most difficult validity measure to achieve. The difficulty arises as some concepts are so abstract that it is difficult to describe or define them, thus making it more difficult to empirically test them. However, according to LoBiondo-Wood and Haber (2002), it is possible to test for construct validity. Methods for this include:

- Hypothesis testing, by hypothesising study results based on an empirical robust evidence base. If the hypothesis was supported, then validity can be claimed for the measure.

- Comparing the results obtained from the measure with other tools that measure similar concepts and constructs, or with groups known to have particular concepts or trait.

- Using the factor analysis approach to examine relationships between particular concept variables, variables of the same concept are related and support one or more aspects of that concept.

3.7.6.2 Reliability

Several approaches are proposed to assess the reliability of the study measure or instrument. These include test re-test reliability, internal consistency (coefficient alpha), split-halves test, parallel or alternate form reliability, and inter-rater reliability if the study is using human observers as the study tool (Burns and Grove, 2003; Frank-Stromborg and Olsen 2004; Parahoo, 2006; Macnee and McCabee, 2008).

Inter-rater reliability is used when a study is using human observers to collect data. This test measures the agreement between observations, so high inter-rater reliability denotes agreement between the observers on what they had observed for the majority of the study (Burns and Grove, 2003; Frank-Stromborg and Olsen, 2004; Parahoo, 2006; Macnee and McCabee, 2008).

The test re-test control is carried out by administering the measure on two separate occasions, and then comparing the results. Close results with minimum deference denote a reliable instrument. Internal consistency reliability is found by calculating the coefficient alpha. This coefficient reflects how a respondent's answers to the different questions within the measure are related to each other. This is represented with a value that ranges from zero (denoting an unreliable test) to a value of one (denoting a reliable instrument) (Burns and Grove, 2003; Frank-Stromborg and Olsen, 2004; Parahoo, 2006; Macnee and McCabee, 2008).

Split-halves tests are carried out by splitting the study group in half. The answers of the participants in one half of the group are then compared with the other half. As these questions are measuring similar concepts, the results of the answers in the two

halves should produce similar results. Similarly, parallel or alternate form tests are carried out by administering two forms that measure the same concept. Similar results for both questionnaires will indicate reliable measures are being used (Burns and Grove, 2003; Frank-Stromborg and Olsen, 2004; Parahoo, 2006; Macnee and McCabee, 2008).

3.7.7 Ensuring rigour within this study

The four rigour criteria identified by Guba and Lincoln (1994) were adopted in this study to address rigour issues. This was to address the issue of the research being a mixed methods sequential exploratory study, where quantitative and qualitative methodological approaches were employed.

In the first qualitative phase of this study, credibility, applicability, auditability and confirmability were used. In the second quantitative phase, content validity will be used to ensure rigour in the study. Construct validity and criterion-related validity were not possible because tools for comparison are not available.

Content validity testing was considered the most appropriate test in supporting the goals of the second phase of the study. This testing is important, as it ensures that the questions and the questionnaire in general convey the intended idea exactly to the participants. Content validity testing also ensures that all domains of the transition service are covered within the questionnaire, and that the questions are phrased correctly and clearly. Finally, this testing will ensure that all relevant questions are included and irrelevant ones excluded, and that the questions are clustered appropriately within the subscales.

The reliability measure was not considered relevant in this study, due to the fact that the intent of reliability is to assess the ability of the survey instrument to measure the construct or variable of interest to the study consistently every time, and in different settings. However, the goal of the survey in this study was not to measure a particular construct or concept (such as stress, coping satisfaction), but rather to measure the level of agreement between the study participants regarding the relevancy and feasibility of particular items in the survey. Furthermore, it was acknowledged that the application of this survey in a different context or setting

might yield a different result, due to other physical locations having different available resources, a different health system or different geographical needs. This survey was designed to cover the specific experiences and needs of a sample of Irish adolescents within the Irish health care system, based on the available resources within this system.

3.8 Chapter summary

Different inquiry paradigms were presented in this chapter, along with the rational for the choice of the pragmatic paradigm to guide the study. This paradigm would provide a flexible approach that improved the study's understanding of the research problem, and consequently helped achieve the study's goals. The chapter then included a review of the research strategies, with a description of the influence of the phenomenology approach on this study and the reasons for the presence of this influence. Within this section, the rational for using mixed methods research was presented, in addition to a discussion of various data collection methods. The chapter concluded by presenting issues related to validity and reliability and the description of rigour measures that can be used within mixed methods research.

Chapter 4: Research methods and procedures

This chapter describes the research methods used in the research. It presents a detailed description of all the research procedures, including ethical approval, instrument development, pilot studies, sampling and sample size, data analysis, process and procedures undertaken to ensure rigour.

This study used a sequential mixed method design, which involved a qualitative phases and a subsequent quantitative phase. Within this chapter, the methods used within each phase will be described separately. Initially, the chapter will describe ethical issues as addressed in the context of this study. This will be followed by a description of the study research phases. Next, the chapter will divide into two sections; each section will describe the methods used in each phase of the study.

4.1 Ethical considerations

To conform to the ethical procedures that guide the conduct of research studies, three key areas were addressed in this study. These include:

- The need to obtain ethical approval to cover all the participating hospitals and healthcare settings.
- The need to adhere to issues of informed consent as required by the participating hospitals and healthcare settings, and as recommended by the Department of Health and the relevant scientific organisations (e.g. Medical Research Council, British Psychological Society, National Children Bureau).
- Adopting appropriate strategies to protect and maintain the privacy and anonymity of study participants, including issues of unequal power, and preventing harm.

4.1.1 Ethical committee approvals

Ethical approval to conduct the study was sought from all the hospitals and healthcare settings, where this study took place. Initially in the course of the study, ethical approval were obtained from the two largest referral teaching hospitals in Ireland where services for children and adults with CF are offered (see details in

section **4.3.6.1.2**) to carry out the qualitative phase, However as the second quantitative phase required a total population sampling (see section **4.4.4.1**), further ethical approvals were sought and gained from other CF centres in Ireland.

Ethical approval application forms were completed, and the forms included those designed locally for use in particular settings, or proposed by Health Service Executives (HSE) and adopted by some hospitals. The application forms were accompanied by the study proposal, and in some cases the relevant ethical approval committees asked the researcher to attend committee meetings to present the study.

Finally, ethical approval to carry out the whole (n=2) or the second phase (n=7) of the research study was obtained from the participating settings (Appendix 19).

4.1.2 Issues of informed consent

Informed participation was considered key to the ethical conduct of this study, therefore the local guidelines for the hospital and health care settings along with the national and international recommendations in this regard were followed and adhered to.

In relation to the consent form (Appendices 4, 5, and 6), all participants were required to give consent for their own involvement in the research process. This was based on the recommendations of ethical committees (Medical Research Council, 1991; National Children Bureau, 1993; British Psychological Society, 1991), and in conformity with Irish law, which allows a 'minor' to give consent for any medical or surgical procedure if he/she is above 16 years of old (Non-Fatal Offences Against the Person Act, 1997). It was not considered necessary to obtain parental consent for participation, as all participants were adolescents and young adults, aged 16-20. However, parents were given a full explanation of the research process, and about their children and their own participation (where relevant) in the study.

The consent form was prepared in a way that conveyed as much data as possible in clear and accessible language. The consent form was designed to include the following information:

- Information about the proposed research presented in accessible language.
- Information about the optional nature of participation in the study.
- Adolescents and young adults were encouraged to question the researcher on the aims and methods of the research.
- Information about confidentiality and privacy within all the research activities.

Consent forms were posted to the participants, along with information leaflets about the study two weeks before the date of the interview. Those that agreed to participate were asked to sign the consent form and bring it with them to their interviews.

Survey questionnaire respondents were also given an introductory letter (appendix 1, 2 and 3) inviting them to participate, which explained the aims of the study, and explained how participants could fill out the questionnaire. Participants were informed about the time they needed to spend filling out the questionnaire and told how their data would be used. Finally, the letter explained that when participants filled out the questionnaire, they were giving their own informed consent for participation.

4.1.3 Maintaining privacy and anonymity of participants

Various measures were considered to maintain the privacy and anonymity of study participants in the individual interviews, the focus group interviews, and finally in the survey questionnaire phase.

During the individual interviews and the focus group interviews, participants were given the chance to raise and discuss any issues about the study or the interview schedule with the researcher. This was particularly important during the individual interview to overcome issues of unequal power between the participant and the researcher. Following this, participants were informed that voice recording would be used in the interviews, and permission was sought and obtained from all participants for use of voice recording during the interview.

Following interview, all participants were allocated a number, so that no individual was identified by name. All names of participants, individuals or institutions that

were mentioned during the interview were removed during the transcription process. Interview recordings were stored in a secure location, to be destroyed at the end of the study.

Privacy and anonymity was also ensured for survey participants. Each participant was allocated a number which was used to code the survey questionnaire. Questionnaires were entered into the computer using this study number, which make the identification of the participants from stored data not possible. Study numbers were stored separately from the questionnaires and securely, with access restricted to the researcher only. All data will be destroyed at the end of the study.

4.1.4 Issues to overcome unequal power

As this study includes adolescent participants, younger than the researcher, procedures to overcome the issue of unequal power were considered. Such procedures include consulting with adolescents regarding their ideas on the best ways to conduct the interview, checking regularly throughout the interview that they were happy to continue with the interview, and reminding them that they could withdraw temporarily or permanently at any stage without any consequences on their course of treatment (Mahon *et al*, 1996; Mauthner, 1997; Morrow and Richards, 1996; Thomas and O'Kane, 1998).

4.1.5 Prevention of harm

During the course of this study, there was no evident harm caused to the study participants. However, initially in the study minimal psychological discomfort or distress was anticipated as a result of recalling memories, which in some cases might be unpleasant to the participants. To deal with such incidents, should they arise, an ethical protocol was prepared (Appendix 7). The protocol describes the procedure to be followed in such a situation, the possible intervention, and lists the available support.

Where participants distress was apparent, participants were offered a break and reminded that they could cease the interview, either temporarily or permanently,

with no adverse consequences for their care or management. Psychological support was made available by the social workers' department and by the adolescent support unit if needed, but this was not called upon by any of the participants.

There was no anticipated physical harm to participants, as this study did not involve any treatments or other invasive procedures.

4.2 Overview of research phases

Based on Creswell's (2009) classification of mixed method studies, this research used a sequential exploratory design, where the first qualitative phase of the study was carried out to inform the second quantitative phase of the study. This design is particularly useful where the research question seeks to first understand the desired phenomena prior to conducting a quantitative study. This applies to the objectives of this study, where understanding the experiences and needs of CF adolescents and young adults during the transition process was an important initial factor to guiding the process of designing relevant health care intervention guidelines. Figure 3 presents the study phases.

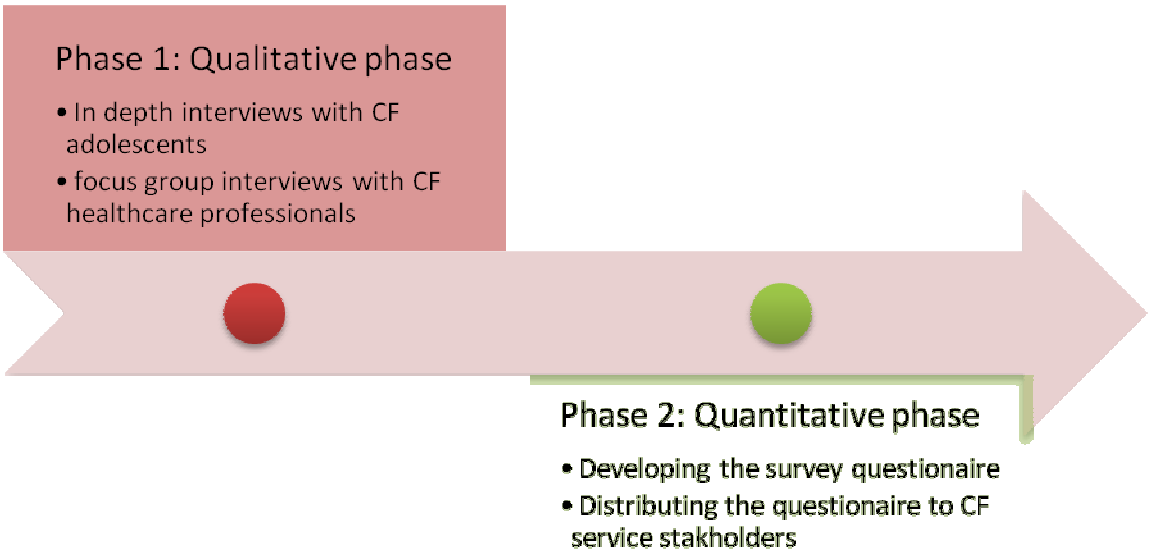


Figure 3- Study Phases

The first phase of this study formed the qualitative component, and utilised both in-depth semi-structured interviews and focus group interview techniques. The aim of the in-depth interview was to explore the needs of the adolescents/young adults and their parents/guardians during the transition period. The focus group interviews allowed health care professionals to discuss the reported needs of adolescents/young adults, and then allowed them to suggest guidelines for interventions to achieve these needs. Figure 4 details the sequence of the first phase of the study.

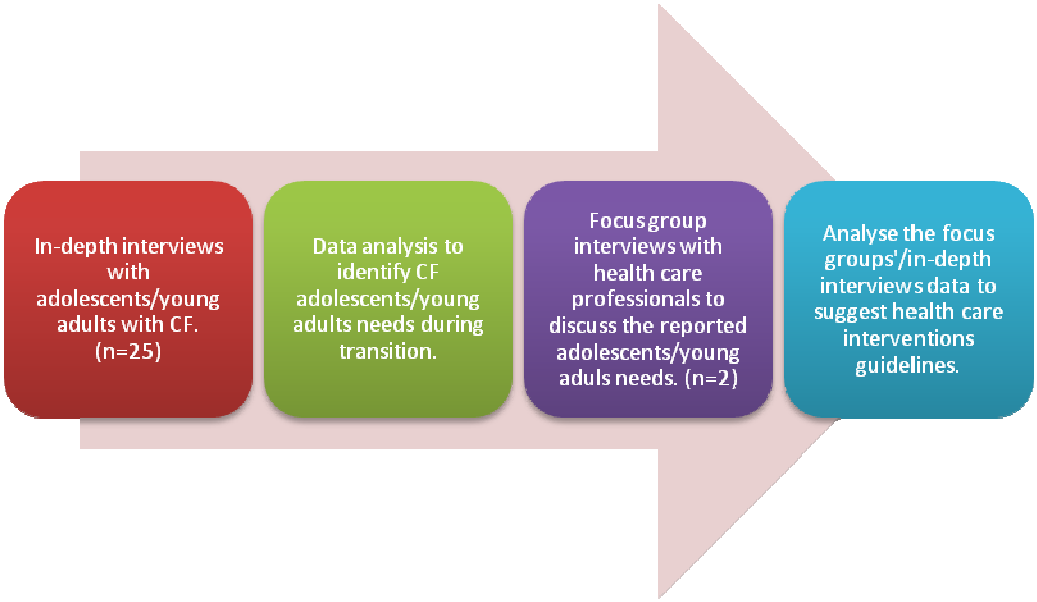


Figure 4- First qualitative phase of the study

The second phase incorporated the distribution of the recommended intervention guidelines to a larger number of health care professionals, where the guidelines were rated for relevance and importance. This enhanced the transferability of the results. Figure 5 shows the second phase of the study.

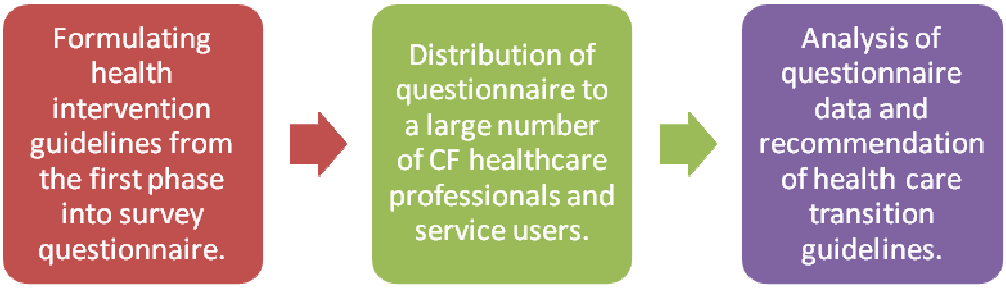


Figure 5- Second quantitative phase of the study

4.3 Phase one: in-depth and focus groups interviews

The first phase of the study consisted of 25 in-depth interviews with adolescents and young adults with CF, who had experienced the transition from the children's healthcare setting to the adult healthcare setting. The processes undertaken in this phase will be described in the following sections, and will include: description of the process of conducting pilot interviews, the process of sample identification, access to the sample and recruiting participants, the interview and the focus group process, data analysis, and the procedures undertaken to maintain rigour.

The goal of this phase of the study was to answer the following questions:

1. What are the needs of adolescents/young adults with CF during the transition from a paediatric to an adult healthcare setting?
2. What are the factors that facilitate or hinder the transition process for adolescents/young adults with CF when transitioning from a paediatric to an adult healthcare setting?
3. How do/did CF adolescents and young adults perceive the care provided for them in the course of their preparation to make the transition from the paediatric to adult healthcare setting?

4. What are healthcare professionals' suggested interventions to address the multiple issues reported by CF adolescents and young adults in their transition phase?

4.3.1 Pilot interviews

Prior to conducting the pilot interviews, an interview guide was developed for both the in-depth individual interviews with CF adolescents and for the focus group interviews with CF healthcare professionals.

The goals of the pilot interviews were: to examine the extent to which the interview guide elicited the information sought; to identify any other relevant issues; and to examine if modification was needed – either of the interview guide or the interviewing techniques - to improve effectiveness of the interview process, during both the individual and the focus group interviews.

4.3.2 Interview guide for in-depth interviews

An interview guide was developed to guide the data collection procedure during the in-depth interviews (Appendix 8 and 9). The guide was constructed based on existing studies into transition experience from the literature, and also from the goals and objectives of this study. This is to make sure that all the potentially relevant dimensions of the transition experience were covered. The pre-prepared questions helped participants focus on specific events and situations, but in keeping with phenomenology tradition, the questions were open enough to allow participants to develop the conversation to remain relevant to their experience and situation. For example:

"Can you talk to me about your care at X hospital?" (For adolescents before the transition).

Questions in the interview guide were formulated in a non-directive manner using an open-ended format, which allowed respondents to answer openly and to elicit the maximum response from all participants. For example:

"Can you describe the experience of moving to the adult hospital?" (For young adults after the transition).

4.3.3 Interview guide for focus group interviews

In relation to the guide for the focus group interviews (Appendix 11), it was developed based on the results of the in-depth interviews with CF adolescents and young adults. During these focus group interviews, all issues reported by CF adolescents and young adults needed to be discussed, and relevant interventions to address these issues needed to be suggested by group participants.

4.3.4 Pilot individual interview

One pilot in-depth interview was carried out. The participant for the interview was the first CF adolescent that accepted participation in the study. The procedures for obtaining consent followed the agreed procedure designed as part of the study. The interview lasted for 45 minutes, and was transcribed and analysed to identify potential issues. The analysis identified the need to amend interviewing techniques to be more appropriate to the participant's developmental stage, and the need for some technical changes (e.g. interview setting, recording instrument) to improve the outcomes of the study. However, the data collected from this interview was included in the study data.

4.3.4.1 Amending the interviewer techniques

During the interview process, it emerged that participants appeared unclear about some words that were used during the interview process; for example, terms like 'transition' and 'health care interventions'.

This alerted the researcher to use more appropriate language during the interview process, using vocabulary that avoided the use of medical terms and used general language that could be understood by adolescents and young adults. This was important, since the way questions are phrased can affect the substance of the answer (Kortesluoma *et al*., 2003).

An example of this language was:

"Can you tell me about any experiences about the transfer that did not go so well?"

"Was there any event, or action from anybody that did not help you during the transfer?"

4.3.4.2 Technical issues

The fact the participants were reporting information in relation to their current health care providers practices, might affect the amount of data they might have disclosed during the interview. This might be further exacerbated by the presence of tape recorder, which might have made participants hesitant about sharing aspects of their experiences, especially negative experiences, as they may have feared some kind of retribution following their feedback.

To try and mitigate this, various techniques were introduced to develop an interactive, less formal, and more trusting researcher-participant relationship such as a less obtrusive audio recording process. This included arriving earlier to arrange the setting, to fit and check the recording instrument before the participant arrived, and to fix the recording instrument out of the participant's view. Participants were also given a choice of where the interview took place, and they were asked if they wanted to do the interview with or without the presence of their parents. An informal exchange of dialogue also took place prior to the interview to make them feel more at ease with the process (Al-Yateem, 2012).

4.3.5 Pilot focus group interview

The pilot focus group interview was arranged in one of the settings with the largest number of healthcare professionals working in the CF unit. This was arranged to leave adequate numbers to participate in the actual focus group interview that would be held later. The pilot focus group interview consisted of four healthcare professionals currently involved with CF adolescents during their transition from paediatric hospitals to adult hospitals. Participants had different specialities and different roles during the transition process. They all worked with each other in the CF unit, and were interviewed in a conference room booked for that purpose in the same unit.

The interview lasted for 60 minutes, and was then transcribed and analysed to identify potential issues. The analysis showed that all participants contributed meaningfully to the discussion process; however, encouraging healthcare professionals to openly discuss their views about the current service appeared to be a challenge to the moderator. This was especially true when the healthcare professionals were expressing views relating directly to current practices in their department or the practices of colleagues. To overcome this issue, when moving to discuss a new topic, the moderator asked group participants to write their initial impressions and thoughts about the topic on a piece of paper. The moderator then collected the paper, and started to read these thoughts to prompt discussion around each subject. This procedure allowed a degree of anonymity that helped participants to present their suggestions and thoughts more easily. They could then discuss and elaborate on these suggested ideas openly in the focus group interview, without challenging each other's views and practices. This technique contributed to a better group discussion, and to potentially better quality data.

4.3.6 Interviews and focus groups

In the first phase of this study, the focus was on gathering data about the perceptions of CF transition service stakeholders about the currents transition service, and then to gather some suggested interventions to guide the service in the future. It was anticipated the following volume of interviews would be enough to achieve the goals of this phase, and provide the qualitative data required: 25 in-depth interviews with adolescents and young adults with CF, and two focus group interviews with CF healthcare professionals.

4.3.6.1 Determining the sample for the interviews

In this section the inclusion and exclusion criteria for the interview participants will be initially described. Then a detailed description of the sampling, data collection and data analysis procedures will be given, first for the in-depth interviews and then for the focus group interviews.

4.3.6.1.1 Inclusion and exclusion criteria

Inclusion criteria

The inclusion criteria for participants in the in-depth interview were as follows:

- Being diagnosed with CF
- In the paediatric setting, the participant had been listed by healthcare professionals for transfer to the adult setting.
- In the adult setting, the participant had been transferred to the adult hospital within the last two years (in order to be able to accurately recall events).

For healthcare professionals:

1. Working with adolescents/young adults with CF during this transitional period for a period of more than two year.

Exclusion criteria

CF adolescents/young adults were excluded if they:

- Were cognitively impaired.
- Could not communicate effectively in English.
- Were critically ill and unable to participate in the interview.

Health care professional were excluded if he/she had less than two years of experience working with CF patients, because he/she might not have enough experience to suggest practice guidelines during the focus group interview.

4.3.6.1.2 Sampling for the in-depth interviews

The selection of the sample was based on purposeful selection. This is in keeping with the tenets of the phenomenological tradition, where only those adolescents and young adults who had experienced the transition or preparation for the transition were considered for participation (Munhall, 2001).

In order to identify the study sample, CF centres that provide services for children and adults with CF were identified. Figure 6 presents all CF centres in Ireland along with the number of CF patients in each centre.

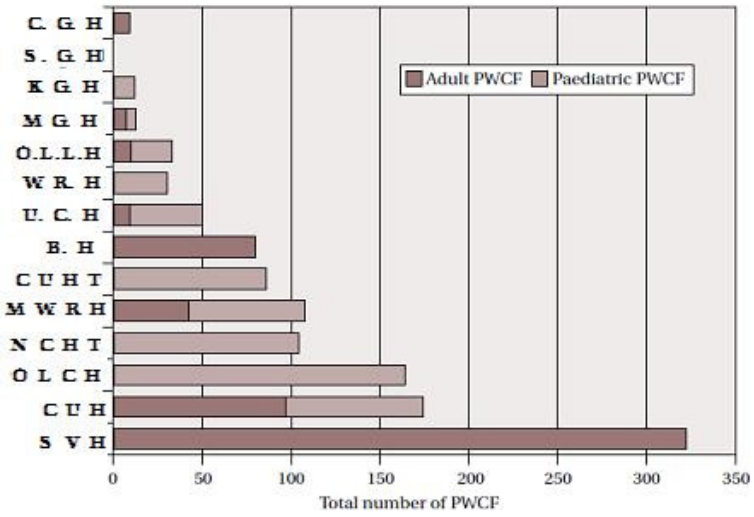


Figure 6- CF centres in Ireland, with CF population in each centre, used with permission from CFRI (CFRI Annual Report, 2006)

Based on the data about these centres, it was decided that the sample for the in-depth interviews and focus group interviews of this study would be drawn from the two largest academic hospitals in Dublin. One of these two hospitals is the main CF centre that provides CF services for children, while the other provides the same service for adults. These hospitals are referral CF centres, which oversee the care of the majority of CF adolescents from all over Ireland. Moreover, due to size and service provision, a larger number of healthcare professionals are working there, which enabled greater participation in the healthcare professionals' focus group interviews. After selecting the hospitals, healthcare professionals working in the CF clinic in these hospitals were accessed. These professionals have records of all CF patients in their departments. Participants who met the inclusion criteria were identified from the records, and their details were retrieved and they were invited to participate in the interview.

A total of 35 adolescents and young adults who met the inclusion and exclusion criteria from the paediatric and adult hospitals were identified. These participants were invited to participate, among them 25 participants agreed to participate, while 10 participants declined participation in this study for lack of time to participate or lack of interest in participation. It was anticipated that 20 to 25 in-depth interviews would be sufficient to gain full understanding of the transition experience for adolescents with CF; however, the researcher stayed open to the possible need to recruit more participants from other CF centres. Data collection continued until saturation was reached, which is the criteria indicating adequate sample size and data collection process in qualitative research, rather than sample size calculation, which guides sampling in quantitative studies. It was clear after conducting the last (25^{th}) interview that saturation had been reached, as there was no new information emerging from the data analysed, therefore the decision to stop carrying out further interviews was taken.

Participants who agreed to participate were consulted about the time and venue of the interview, and those who expressed difficulties with current arrangements were offered alternatives; either more convenient places or times to suit them in order to encourage participation.

4.3.6.1.3 Sampling for the focus groups

For the healthcare professional focus group interviews, all those who were involved directly in the care of adolescents/young adults during the transition in both the paediatric and adult hospitals were invited to participate (n=25).

4.3.6.2 The conduct of the individual interviews

Potential participants who met the inclusion criteria were invited with their parents to participate in the study by letter (see Appendices 1, 2, and 3). Letters for adolescents, young adults, and their parents were formulated to address the information needs of each different age group. The letters provided a full description of the purposes of the study and procedures of the interview. Participants who agreed to participate were informed that the interview would take place at the end of their next

appointment or visit to the clinic, and would be carried out for both the adolescent/young adult and the parent or guardian separately, unless they desired otherwise.

In-depth interviews took place in the hospital where the care for adolescents and young adults took place. A dedicated interview room was used for this purpose, and was identified in the two hospitals. Where this was not possible due to participant factors such as late arrival to the clinic or time restrictions, arrangements were made with the participants to carry out the interview in a convenient place near or at home (n=10).

Where applicable, the layout of the interview room was prepared beforehand by the interviewer to promote informal discussion and decrease the intrusion of the recording device on the conduct of the interview. The interview guided by the interview guide; however, this guide was used in a flexible manner, to ensure coverage of all the transition areas. Furthermore, the questions were phrased in an openway, allowing participants to respond in detail, describing their perceptions and experiences. An example of these questions is as follows:

> *What was most important to you when moving from X to Y hospital?*
>
> *Can you tell me any experiences about the transfer that did not go so well?*
>
> *Was there any action or event that did not help you during the transfer?*

Another consideration was the use of developmentally-appropriate language, which avoided the use of medical terms, and replaced them with general language that could be easily understood by adolescents and young adults.

4.3.6.3 The conduct of the focus group interviews

A letter was sent to all potential participants (n=25). Two focus group interviews took place in the paediatric and adult hospitals participating in the study, with eight healthcare professionals in each group. A multidisciplinary group of healthcare professionals was convened (n=16 in both focus group interviews), including CF

clinical nurse specialists, dieticians, physiotherapists, social workers and paediatricians. The aim of the focus group was to present the findings of the in-depth interviews that represented the reported needs of adolescents/young adults during the transition phase, and then ask the healthcare professionals about any suggested interventions that addressed these needs.

To assist in conducting the focus group interview, a research assistant who was familiar with focus group interviews was employed. The assistant is a healthcare professional who was trained at master's level and used the focus group interview method during her postgraduate research study. The assistant was assigned the task of writing down field notes, not only to protect against the possibility of machine failure, but also to record the non-verbal interactions and communications between the participants; she also participated in the debriefing session with the researcher to highlight important data arising at the end of each interview (Webb and Kevern, 2001; Sim, 1998).

The meeting took place in a venue in each setting to facilitate attendance, and the discussions were audio-recorded. However, strategies were employed to protect against the potentially adverse effect of recording on the ease of communication and free exchange of data between participants (Al-Yateem, 2012). These included using a highly sensitive recorder that was as small as possible to be unobtrusive during the interview, as well as minimising the visual prompts that indicated that the participants were being recorded.

Before the interview, the interviewer arrived early to arrange the setting and to fit and check all instruments before participants arrived. This allowed the participants and the researcher to focus on the interview and speak in an informal way (Al-Yateem, 2012).

The focus group interview started with the researcher introducing himself and his assistant to the participants, and thanking them for taking part in the study. This was followed by a 10 minute presentation about the results of the in-depth interviews with the adolescents/young adults. During this, the assistant assigned number codes to the participants and started recording the interactions.

The discussion among the group was triggered by an exploratory question such as:

"May I ask your views on the issues raised by this presentation?"

"… how relevant is this need to the practice in your hospital?"

The discussion was moderated by the researcher. The researcher encouraged maximum participation from the healthcare professionals through probing and questioning assumptions whilst attempting to maintain the least possible involvement and direction. The moderator intervened mainly to encourage discussion around a particular point, or when the discussion around a particular need was saturated to prompt movement to the next need. For example:

"… ah ... that was interesting … now what about …."

When moving to a new area of discussion, group participants were asked to spend some time writing down their initial impressions and thoughts about the topic on a piece of paper. The moderator then collected the papers and started to read these thoughts, prompting discussion around each one. This allowed open discussion for most of the issues, without participants feeling personally threatened, and without them having to challenge each other's views and practices publicly.

4.3.6.4 Interviews' data analysis

Figure 7 presents the data analysis procedure used for both in-depth interviews and focus group interviews. The figure is followed by a detailed description of both procedures.

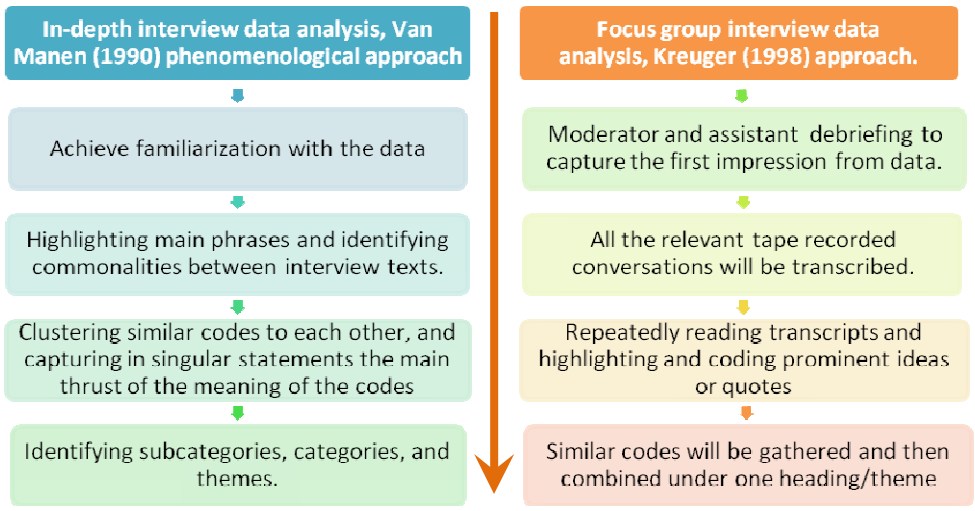


Figure 7- Data analysis procedures used in the qualitative phase

4.3.6.4.1 In-depth interview data analysis

Van Manen's selective or highlighting approach was used to analyse data collected in the in-depth interviews (Appendix 10). This included first transcribing the audio verbatim. These transcriptions represented the participants' descriptions of their experiences, and they were then read several times to achieve familiarisation with these experiences; to get sense of the data as a whole, and to record initial notes on the data. Throughout the reading, the researcher asked what statements or phrases seemed "particularly essential or revealing" about the transition experience (Van Manen, 1990, p.93).

These statements, phrases, or words were highlighted and considered in more detail. This was followed by a phase of initial descriptive coding, in which the highlighted sentences, phrases or words were coded using participants' own words. Similar codes were clustered together to create initial categories and subcategories. Finally, all categories and subcategories were compared to each other to identify main themes that represented the experiences of the participants.

4.3.6.4.2 Focus group interview data analysis

The analysis of transcribed focus group interview data followed Krueger's (1998) systematic approach for analysing and reporting focus group results.

During the focus group interviews, the data was captured and handled by voice recording in addition to the notes taken. A session for debriefing and discussion was carried out immediately after each focus group between the moderator and the assistant to capture first impressions from the data. This discussion included the most important themes or ideas discussed during the interview. Finally, it was determined which data were considered to be important and should therefore be highlighted, along with a discussion about any potential changes on the interview schedule.

The exchange of data and the communication patterns between participants were assessed carefully during the discussion and were noted to inform the analysis process. An example of such a communication pattern was a lengthy discussion around a particular point, or the greater contribution of a particular healthcare professional group (e.g. nurses) on various particular points.

After the focus group interview and the debriefing sessions, the tape recording was listened to and all relevant conversations were transcribed verbatim. The researcher then repeatedly read through transcripts and labelled any relevant statements that he came across. Similar statements were gathered and combined into categories and subcategories. Categories were then compared to each other, and similar ones merged under one heading or theme.

4.3.6.4.3 Results of analysis

Two main themes and four categories were identified after the analysis of the in-depth individual interviews. In addition, 5 themes and 4 categories were identified during the focus group interviews. These findings were used in the second phase to inform the development of the transition service questionnaire that focused on identifying the most relevant and feasible guidelines to shape the transition service for adolescents with CF in the future. The process of developing the questionnaire will be described in detail later in this chapter, while the findings and the identified themes of the first phase will be described in the findings and results chapter (chapter 5).

4.3.7 Ensuring rigour within phase one

Criteria for ensuring rigour in qualitative studies were reported in detail in Chapter 3. These criteria include: credibility, auditability, confirmability, and applicability. This chapter will now go on to describe how these criteria were used in this study to ensure rigour.

4.3.7.1 Credibility

Prolonged engagement with study participants is reported to improve a study's credibility (Guba and Lincoln, 1985). In the case of this study, this was achieved as follows.

- Using in-depth interviews, which allowed a fuller exploration of their experience.
- Carrying out interviews in the same clinical area where the transitional care was provided. This allowed for familiarisation of researcher with the setting, the care provided and the way the CF clinic was run.
- Carrying out focus group interviews with healthcare professionals engaged with the care of adolescents with CF, which allowed further deep understanding of the transition experience.
- Allowing the researcher to conduct sufficient interviews to give adequate understanding of the phenomenon;
- Finally, the transcription was carried out by the researcher himself, which enabled immersion into the participant experience.

The collection of data from different sources, such as adolescents/young adults, their parents and from healthcare professionals, has also enhanced the credibility of the study. The collection of data from these multiple sources regarding the transition experience completed and validated each other.

The amount of data gathered during this research process was sufficient to thoroughly explore the transition experience. All this data was audio recorded and then transcribed verbatim, and checked against the original recording to ensure

accuracy. The data analysis procedure followed a systematic approach, and was described in detail. This was further enforced by detailed reporting for the study's findings, supported by the participants' personal accounts. The inclusion of evidence from participants' experience illustrated how the themes and findings arose during the analysis process.

4.3.7.2 Auditability

Auditability was enhanced by explicitly describing and justifying the decisions and the actions taken during the course of the study. This included describing the study's purpose, explaining the researcher's interest in the subject matter under investigation (the significance of the study), justifying why particular subjects were chosen and how they were recruited (inclusion and exclusion criteria and sampling procedures), describing and justifying data collection methods (including the duration and setting of data collection) and describing and justifying data analysis techniques. Finally, copies of the documents used throughout the research process were kept and attached in the appendices section where applicable.

The data analysis procedure was supervised by two experienced qualitative researchers, who reviewed the process of transcript coding, and category and theme identification. The researcher and the supervisors engaged in a continuous constructive discussion around the data analysis, and changes were made until agreement was reached.

4.3.7.3 Confirmability and applicability

To enhance confirmability, feedback was sought from participants at the end of each interview if they had any more issues to discuss and if they had expressed everything they wanted to during the interview; however, no new issues were identified in this process. Another method was to investigate any unclear issues that arose during transcription and data analysis in the following interviews.

Finally, applicability was enhanced by the use of relevant examples from the data that were representative of the phenomena being studied. Detailed descriptions of the

study's participants and the study setting would allow the application of the results in other similar contexts.

4.4 Phase two: the transition care survey

The second phase of this study was the quantitative survey questionnaire phase. The focus of this research was on developing a transition service questionnaire, based on the findings of the first qualitative phase. The questionnaire would be administered to all the transition service stakeholders in Ireland to identify best practice service guidelines.

The main goal during this phase was to recommend relevant and feasible transition service guidelines for adolescents/young adults with CF, based on the experiences of these adolescents and the perspectives of professional healthcare providers.

4.4.1 Questionnaire development

A survey instrument was developed based on data collected from in-depth interviews with adolescents with CF and focus group interviews with healthcare professionals. Initially, data from the in-depth interviews were analysed, and from that the transitional needs of CF adolescents were identified. These needs were then discussed with healthcare professionals in the focus group interviews. Data from the healthcare professional focus group interviews were analysed and suggested interventions for various CF patients needs were extracted. Each proposed healthcare intervention formed an individual item in the questionnaire. Finally, items that addressed a particular aspect of the transition service were grouped together in subscales. The participants in this phase, healthcare professionals and service users, were asked to rate every item in the survey on a four-point scale to assess its importance and feasibility, ranging from highly important to not important at all, and highly feasible to not feasible at all. Figure 8 shows a sample of the study questionnaire. (See Appendix 18 for full questionnaire).

Key:4: Strongly agree 3: Agree 2: Disagree 1: Strongly disagree					Key:4: Highly feasible 3: Feasible 2: Not Feasible 1: Not feasible at all			
Initial assessment phase								
1. Healthcare professionals should assess the adolescent's understanding of the timing of the transition	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
2. Healthcare professionals should assess the adolescent's understanding of the adult CF centres which are available for him/her to transfer to.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

Figure 8- Sample of the survey questionnaire

Consideration was given to designing the questionnaire to be as easy and user friendly as possible. Attention was paid to font size, spacing and layout. The questionnaire was printed in colour to make it visually attractive. Finally, the items within the survey were phrased in a way that focused on one issue at a time, using simple language. The questionnaire used a likert scale format, and the items within the scale were scored twice on a four-point scale, ranging from one to four. The first rating was for the relevancy of the item, and participants were asked to choose whether they agreed on the relevancy of this item or not (where 4 represented strongly agree, 3 agree, 2 disagree, and 1 strongly disagree). The second rating asked participants if they thought this item was feasible within the current CF clinical settings (where 4 means the item is highly feasible, 3 if the item is feasible, 2 if the item is not feasible, and 1 if the item is not feasible at all).

The questionnaire was divided into subsections to make it more user-friendly, and so the final version of the questionnaire was composed of 54 items that fell into six subscales (see Appendix 18). These subscales included: Initial assessment phase subscale (18 items); Planning of care subscale (11 items); Continuous evaluation of care subscale (8 items); Provision of information subscale (7);Approach that promotes independence subscale (3 items); Environment, handover to the adult hospital, and training subscale (7 items).

An example of how the subscales and the questions were derived from first phase is presented in the following figures. Figure 9 shows how the subsection has been developed, while the Figure 10 shows how the questions were developed.

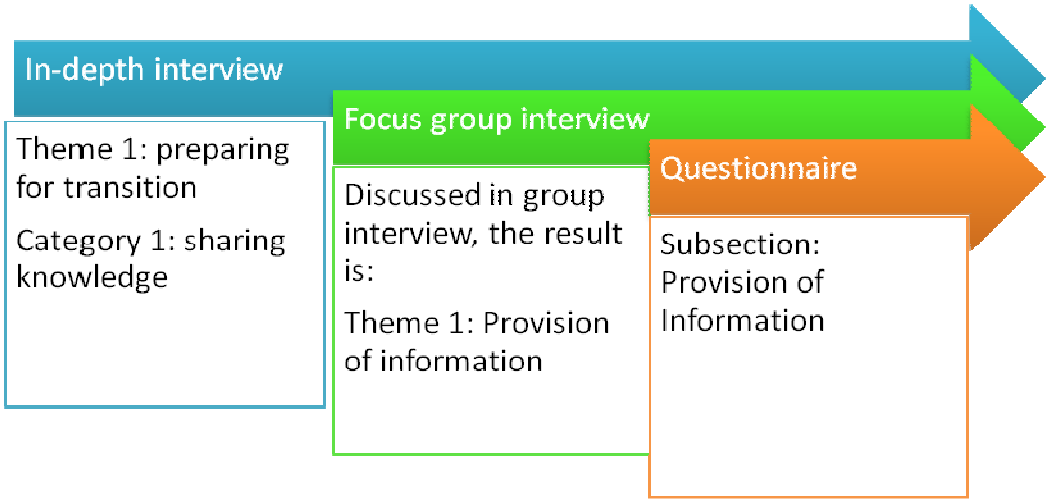


Figure 9- Development of questionnaire subsections

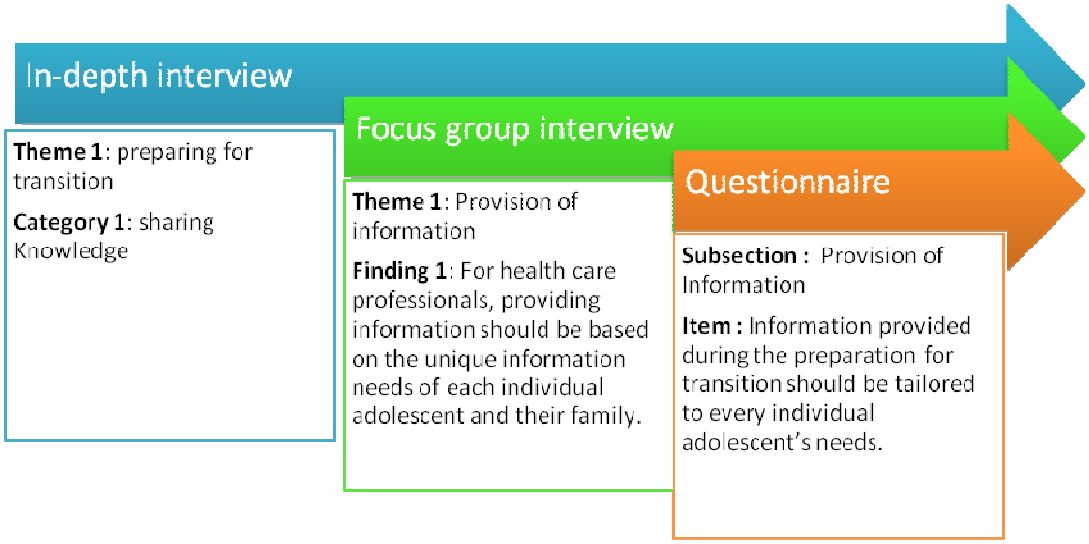


Figure 10- Development of questionnaire items

The list of items within the final survey represented guidelines for practice rather than an exhaustive list of practices and interventions of the transition service. Therefore, some of the items in the survey might appear to be general in nature, but it will be up to the healthcare professionals in each clinical setting to design specific practices and interventions that achieve these guidelines.

A content validity questionnaire was then formulated (see Appendix 15) from these items and was posted to an expert panel to assess its content validity (see below). A detailed description of this process is explained in the next "validity and reliability" section.

4.4.2 Ensuring rigour in phase two

As explained earlier in the section "**Ensuring rigour within this study (section 3.7.7)**", the content validity measure was decided to be of relevance and importance to this study. This was to ensure that the questionnaire conveyed exactly the intended ideas to the participants. This was achieved through careful phrasing of the survey items so they exactly reflected the data the study intended to collect. Furthermore, a content validity test was performed and the content validity index was calculated (Lynn, 1985). The process of content validity testing will be detailed in the next section.

4.4.2.1 Content validity testing

A content validity four-point ordinal rating scale survey was developed (Appendix 15), using all the items that would formulate the final transition service guidelines survey. The survey was then sent to an expert panel of healthcare professionals (n=10) who currently worked with CF patients during their transition from the paediatric to the adult health care setting, and have worked in this area for a period of more than 10 years.

The aim was to ask at least six experts (Lynn, 1985) to rate the items in the survey for clarity and relevance to the transition service, to see whether they thought the items should be included in the final transition service guidelines survey or not. The expert panel was asked to rate each item by choosing the number corresponding to the rating given in the following key:

1. The item is <u>not relevant</u> to be included in the transition survey.
2. The item <u>needs major revisions</u> to be included in the transition survey.
3. The item <u>needs minor revisions</u> to be included in the transition survey.

4. The item is relevant to be included in the transition survey.

When the experts rated the item as 1, 2 or 3, they were asked to comment on the reasons for their rating and/or on the revisions required. Based on the returned content validity questionnaires (n=6), the content validity index for each item and for the survey in general was calculated following these criteria (Lynn, 1985).

1. Items that received a 4 rating (highest rating) from five of the six experts were considered valid items.
2. Where items received a rating other than (4) from two or more experts, the mean value of the scores was calculated and;
    a. If the mean score was more than 3, then the item was revised based on the available comments from the experts.
    b. If the mean score was less than 3, then the item was considered invalid (n=5, table 2).
3. The content validity index for the instrument was calculated based on the proportion of the items that received a rating of 3 or 4 divided by the overall number of items.

Table 2- Items that were rated invalid by the expert panel

Items that were rated invalid by the expert panel
1. Healthcare professionals should assess whether there are possible role models to help the adolescent during the transition process.
2. Healthcare professionals should assess whether long-distance travel is involved that might require a special arrangement with the clinic *(e.g. early clinic, arranging accommodation, home visits, etc.).*
3. Assigning a key worker will help establish a supportive, open relationship with the adolescent and their family.
4. Healthcare professionals should continuously evaluate the adolescent/young adult's personal development and their capability of dealing with the majority of people in various situations.
5. Healthcare professionals in both paediatric and adult settings should arrange an evaluation meeting a few months after the completion of the transfer.

The content validity index of the survey was calculated based on the previous formula. The survey achieved a total score of 0.91, which indicates a high validity score (54/59=0.91).

4.4.3 Pilot study of the questionnaire

Although pilot testing for the survey instrument could not be carried out due to a limited population and available sample size, alternative measures were adopted to compensate for that. These included asking the expert panel who participated in the content validity testing to comment on clarity of the survey items, the appropriateness of the language used to formulate the survey items, and the time needed to finish the questionnaire. Finally, the expert panel were asked to suggest ideas to enhance these aforementioned aspects of the survey. The comments received from the expert panel were incorporated into the final survey questionnaire version.

Based on the comments of the expert panel on such issues (item clarity, language used, time needed to complete survey), the questions appeared to be clear and using appropriate language, as no comments about these issues were given by the panel. The panel indicated that the time needed to finish the survey would be approximately 20 minutes.

4.4.4 Phase two: the main study

This section describes the approaches used during sample selection, data collection and data analysis.

4.4.4.1 Sampling in the quantitative phase

All CF patients and healthcare professionals who met the study inclusion and exclusion criteria (see section **4.3.6.1.1)** from all over Ireland were considered for participation, these participants could provide useful perspectives regarding the relevance and importance of any suggested guidelines. These participants were invited to participate in the quantitative phase of this study because the development of relevant guidelines for the transition practice necessitates the participation of those involved in implementing these guidelines, as well those who will benefit from them.

The population of the healthcare professionals in this field was 108 members of staff working in different specialities (doctors, nurses, dieticians, etc.), while there were 215 adolescents within the ages of 16 to 25 (the age band eligible for participating in this study).Based on these relatively small population sizes for both health care professionals and CF adolescents in Ireland, total population sampling would be more appropriate.

The use of total population sampling would allow the inclusion of all possible participants, thus enhancing the study results. This is taking into consideration a 50% response rate (RR).

The contact details of the CF patients and for the healthcare professionals were collected from the records of the CF departments in the participating hospitals, all this after gaining ethical approval to carry out the survey study from the relevant department in each hospital.

4.4.4.1.1 Strategies to maximise response rate

Given the small size of the study population, it was essential to try everything possible to ensure participation of a maximum number of participants. This was achieved in this study using the following procedures.

- Obtaining accurate lists of all the study population, along with as much updated contact information as possible to ensure optimal delivery for the study questionnaires. This information was obtained by researcher from the CF departments in the participating hospitals.
- Posting an invitation letter to all study participants along with the study questionnaire, highlighting the importance of their participation in the study, explaining how they were selected and giving the estimated time it will take them to complete the questionnaire.
- All questionnaires were posted along with a return envelope with the necessary amount of stamps affixed.
- A second round of questionnaires was posted 3 weeks later, to allow those who didn't have the chance to respond the first time to participate in the second round.

- Finally, as highlighted in the questionnaire development section (4.4.1), the questionnaire was designed carefully to enhance participation and to with the lowest possible completion time in mind.

4.4.4.1.2 Study response rate

A total of 108 surveys were posted to healthcare professionals, and a total of 215 surveys were posted to CF adolescents, constituting the total population available for research. From these total numbers, 58 surveys were returned by the healthcare professionals (RR=54%) and 113 were returned by the CF adolescents (RR=49%) (Table 3).

Table 3- Response rate for the questionnaire

Healthcare professionals working with CF	Population size	Actual surveys posted	Completed surveys received	Response rate
Healthcare professionals	108	108	58	54%
CF patients (16-25 yrs)	215	215	113	52%
TOTAL	**323**	**323**	**171**	**53%**

4.4.4.1.3 Response bias

A review was carried out of the characteristics of those who participated in the study. This was to eliminate response bias, and to ensure that non-repondents did not possess any specific characteristics that might stop them from participating. The review did not show any particular bias, and respondents compromised of participants from different children and adult settings, of different ages, with different level of experiences, with different specialities, and from different geographical areas in Ireland.

4.4.4.1.4 Data analysis for the survey questionnaire

The goal of the data analysis was to answer the following questions:

Question 1: What percentage of participants rated this item/subscale as very relevant/relevant/less relevant/not relevant?

Question 2: What percentage of participants rated this item/subscale as highly feasible/feasible/not feasible/not feasible at all?

Question 3: Is there any significant relationship between the participant's age, experience, profession, gender, qualifications and place of work, and their rating of the item/s?

Data obtained from the survey was analysed using SPSS V11. All items within the questionnaire were coded and entered into the software database to conduct the statistical procedures. Each item was coded twice in the data set, once to represent the participant rating for item importance, while the second time was to represent the participant's rating for the item's feasibility. For example, the first item was coded as 1a and 1b, where 1a was the participant's rating of the item's importance and 1b was the participant's rating of the feasibility of the item.

To ensure accurate data entry into the statistical analysis software, the data was entered twice by the researcher. The two data sets were then tested to detect if any discrepancies existed, and any discrepancies were subsequently corrected by referring back to the original questionnaire.

The data collected demonstrated the frequency or counts of individuals or groups who chose a particular response (e.g. strongly agree, agree, disagree, strongly disagree) for each item. These counts were placed in a contingency table which had *R* rows, based on the four possible responses and *C* columns based on the number of possible groups as shown in table 4 below.

Table 4- Example of contingency table made for items in the survey

Count	Specialty							
	Doctor	Nurse	Social Worker	Dietician	Physiotherapist	Psychologist	CF Patient	Total
1	0	0	0	0	0	0	47	**47**
2	5	1	1	1	1	1	22	**32**
3	3	8	3	2	2	2	21	**41**
4	5	8	3	4	3	5	23	**51**
Total	**13**	**17**	**7**	**7**	**6**	**8**	**113**	**171**

The details of the analysis done were presented in the "**Survey questionnaire data analysis (section 3.6.3)"**; however, to recap, the percentage score was used to identify the position of the majority of survey participants from particular proposed transition guideline, in terms of its relevance and feasibility to be implemented in the proposed transition service guidelines. The mean scores were used to reflect the general trend among participants about the importance and the feasibility of subscales within the survey and of the survey as a whole.

The comparisons of scores for the subsections and the overall survey were based on analysis of variance (ANOVA).

4.4.5 Summary of chapter

This chapter presented the various research processes and methods implemented during this study. This included description of the ethical issues, data collection methods, steps to endure rigour, and data analysis procedures. The two phases of the study were described along with the pilot studies that were carried out initially in each phase.

Chapter 5: Study findings and results

5.1 Findings of phase one: Interview and focus group findings

Introduction

This chapter reports the findings from the individual interviews and the focus group interviews that were undertaken in phase one of the study. During the individual interviews, participants were asked to describe their experiences during the transition from the child healthcare setting to an adult setting. The interviews focused on the needs of the young people during their transition, as well as the factors that facilitated or hindered the process. Healthcare professionals in the focus group interview were asked to discuss what CF adolescents had reported in their in-depth interviews, and the professionals were then asked to suggest healthcare interventions to address the issues raised.

Data analysis of the individual interviews generated two main themes and four categories. These include:

- Preparing for transition. This includes another two categories as follows:
    - Sharing knowledge;
    - Overcoming patients' own concerns.
- Amorphous service. This includes two further categories:
    - No structured transition service;
    - CF adolescents and young adults and their need to be involved and listened to.

Figure 11 illustrates the themes and categories that emerged from the in-depth interviews.

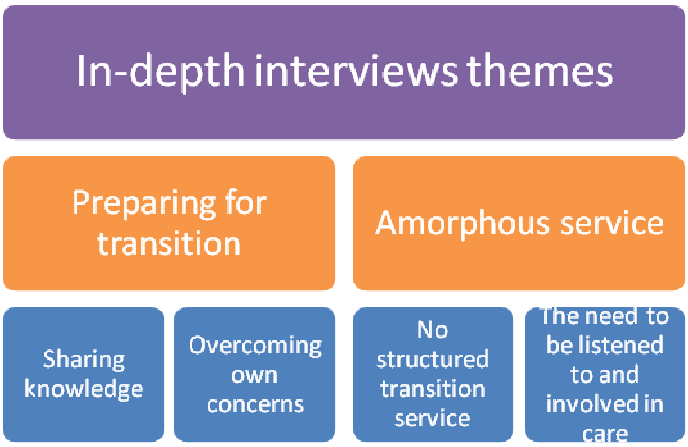


Figure 11- Themes from the in-depth interviews

Data analysis of the focus group interviews generated five themes and four categories. These include:

- An individualised comprehensive approach, which can be broken down into the following:
  - Assessment of care;
  - Planning of care;
  - Provision of information;
  - Continuous evaluation and follow up mechanisms.
- An approach that promotes independence.
- A gradual and thorough hand-over to the adult setting.
- Creating a suitable environment for adolescents and young adults.
- Continuous training for healthcare professionals.

The findings of this phase of the study will be reported under each of the previous themes and categories. Prior to reporting these findings, a description of the participants' profile will be given.

5.1.1 Individual interview and focus group interview participants' profile

In the in-depth interviews, 25 participants took part in the study, all of whom were adolescents. Of this group, 14 (56%) were female and 11 (44%) male. The age demographic was further divided as follows: aged 16 (n=9), 17 (n=6), 18 (n=7), and 19 (n=3) (ages all being correct at the time of the study). All the young people taking part had been diagnosed with CF, and were at a children's hospital being prepared for transition to an adult healthcare setting (n=15), or had been transferred to the adult clinic (n=10) sometime within the last two years. Table 5 illustrates the characteristics of the participants in the in-depth interview process.

Adolescents and young adults participating in the in-depth interviews		
Gender	**Age**	**Setting**
Male : 11 (44%)	16 Years (n=9)	Children Hospital (n=15)
	17 Years(n=6)	
Female: 14 (56%)	18 Years(n=7)	Adult Hospital (n=10)
	19 Years (n=3)	

Table 5- Demographic description of adolescents and young adults participating in the in-depth interviews

There were 16 healthcare professionals that took part in the focus group interviews. All the participants had worked for at least two years with adolescents or young adults with CF during their transition process. This group included nurses (n=6), doctors (n=4), physiotherapists (n=2), social workers (n=2) and psychologists (n=2).

Table 6 illustrates the characteristics of the healthcare professionals who participated in the focus group interview according to their speciality.

Specialty	N
Doctors	4
Nurses	6
Social Worker	2
Physiotherapist	2
Psychologist	2
Total	16

Table 6- Healthcare professionals participated in the focus group interview according to speciality

5.1.2 Findings of the in-depth interviews with adolescents and young adults

5.1.2.1 Theme one: Preparing for transition

This theme described adolescents experiences about the interventions that prepared them for taking part in a managed transition process. The majority of participants emphasised the importance of being prepared for the outcomes of their transition, and for the outcomes of their care in general. Commenting on the visit to the adult hospital as part of the preparation, one participant said,

> "They are going to take us over to the other hospitals, and talk to the other staff there, you will know them and they will know you, you will be more prepared when you move over there... that would be a huge help..." (Adolescent #24, Male)

Participants suggested that there was a lack of such preparation in the current clinical settings, which left them unable to manage the different aspects of their CF. They felt uninformed and consequently incapable of making important decisions in relation to their care and in relation to the adult settings that they are going to transfer to, as well as general decisions in relation to their future life.

One participant indicated how lack of preparation might affect her transition; she said,

> "But I haven't seen what other hospitals are like; I am not ready to move yet, if we knew all about this well before... it would have been easier for me... They just don't prepare you enough..." (Adolescent # 17, Female)

Other participants said,

> "Will... the thing that they don't talk with us enough about CF, how it will be, you know, and what it will be like in the future... I need to know" (Adolescent #15, Female)

> "Is it going to affect my college, like? I love sport... I love playing volleyball with some friends... but with CF do I need to stop..." (Young adult #12, Male)

Participants were unable to identify key issues that might come up in the future adult health service, and they felt concerned about this. One participant said,

> "yeh…. you have to move like, when you reach that age, there is no choice, whether you are ready or not …I don't know a lot about that other place... I just hope I will get used to it quickly..." (Adolescent #6, Female)

Feeling uninformed in this way triggered other negative feelings within the participants, such as feeling anxiety and distress before, during, and after the transition process. These negative feelings appeared to be in addition to the already stressful experiences these adolescents have as a result of their CF. One participant reported:

> "... that for me you have to go to different place..., when you are used to come in here most the time, that is really annoying... you know they don't see that other side... what we can do? We have to move, and that's it." (Adolescent #15, Female)

Another participant said,

> "You know with CF there are a lot of things to be done...and now they come up with this thing (transfer to the adult setting)... it is extra pressure and stress on you like... " (Adolescent #13, Male)

The study revealed that in order for adolescents to be prepared to go through the transition process, they need to know about the different aspects of their CF and its effect on their life and future. They also need to understand what is expected of them throughout the transition process itself. One participant said,

> "... like ... all they do is to tell you that you are moving... and then talk with you for 15 minutes about it.... like this is not enough at all... this is so important for me and I need to know all about it..." (Adolescent #16, Male)

Another participant said,

> "Oh ... For God's sake... this is serious... you have to tell me more... when? How? Where? I mean every thing... they just don't do that... you have to go and find out yourself..." (Parent #20)

The preparing for transition themes included two other categories, the first of which concerns sharing knowledge about CF and the transition, while the second is the need to treat the perceived negative psychological effects of the transition process. The subcategories for this theme will be described next.

5.1.2.1.1 Category one: Sharing knowledge

This category focused on CF adolescents' knowledge about their CF and about the transition process. The main issues that emerged in this category were: adolescents not knowing about the CF illness; not knowing about transition process management; feeling uninformed; and feeling like their questions were not being answered by healthcare professionals.

The need for better shared information and knowledge was a prominent issue, and was raised in most interviews by participants. Participants knew that they were going to go through the transfer process; however, many of them did not

know about key issues in the transition process, such as which hospital they might transfer to or how this might affect about their CF. One participant said:

> "… I don't really know, it might be either X hospital or Y hospital, I don't know we have to go and see. I don't know how they will be like?" (Adolescent #14, Female)

Similarly, when asking another participant if he knew the hospital or CF service to which he would be referred, he answered,

> "Ah, very little, almost nothing, I mean all they do is to tell you that you are transferring." (Adolescent #04, Male)

Another adolescent wanted more information on the effects of CF on his health and future. He explained:

> "Well the thing that they don't talk with us enough about CF, how it will be... you know, and what it will be like in the future." (Adolescent #03, Male)

Participants also reported that healthcare professionals did not adequately answer their questions, nor address issues and concerns that they raised. Participants remarked on how difficult it was when healthcare professionals could not answer their questions. One participant wanted to know about health issues that may arise during the course of her treatment. She said:

> "This is annoying thing for me, like I come up and I want them to give me an answer about something, they don't." (Adolescent #07, Female)

Another participant said,

> "Well (small pause), like when you have another health problem, you want to know what it is, they don't answer you, they just take it for granted that it is related to the CF …." (Adolescent #25, Female)

The timing of information provision in addition to the other service interventions appeared to be important. One participant reported how living away limited his ability asks questions and seek information,

> "I live two hours away from here... and by the time you finish the clinic you don't have time to do anything... we usually rush out to go back home early" (Adolescent #23, Female)

Similarly, another participant reported how the provision of information in the same clinic, where other clinical activities take place distract her and discourage her from asking questions,

> "Like... I hate to see all this medical stuff... I feel like I want to go... and when they ask me if I have questions... it's like ... NO... just let me out..." (Adolescent #22, Female)

Participants described how important it was that information was provided early, and that they were told about all the key events and changes that they would go through as a result of their CF and the transition to a new setting. About the late start, one participant described how she was informed about the transition only shortly before the Leaving Certificate, which usually occurs around age 18; she said,

> "Yeh the 'CF nurse' told me about the transfer a couple of months ago, she said it would be when I finish the Leaving Cert next year, it would not be straight away" (Adolescent #21, Female)

Another participant who has gone through the transfer, and is now receiving care in the adult centre, recalled the transition process. She confirmed the late start of the preparation for transition and further described how quick the transition process was; she said,

> "It all was so quick... I still can remember... the CF nurse told me about the transfer in November last year... and now (February) I am having my second appointment in this hospital (the adult hospital)" (Adolescent #20, Female)

At the time of the interviews, there were even some adolescents who had not received any information about their transition, despite the event being scheduled for some time that coming year. One participant commented:

> "Not yet … no, we know it might be next year, but actually, we haven't been told anything more, nobody talked to us about it…" (Adolescent #11, Male)

The lack of such information left participants frustrated with their healthcare professionals, and anxious about what would happen next and when. One participant reported:

> "It is so... frustrating... like ... like about the diabetes, is it going to get worse (the adolescent starts crying), about my voice like it got dry and I can't speak, sometimes I can't breathe, they don't name the problem they don't know what it is... or they don't tell me about it" (Adolescent #19, Male)

5. 1.2.1.2 Category two: Overcoming own concerns

This category described how adolescents needed to overcome the perceived negative psychological effects associated with adolescence, CF, and the transition to a new adult setting. These perceived negative effects are feelings like distress and anxiety over uncertainty. Participants reported these negatives effects were exacerbated by impending move to new unfamiliar healthcare settings, and the lack of preparation for doing so.

Adolescents reported that overcoming these negative feelings was very important to them. They explained that dealing with these concerns was a major difficulty that affected the outcome of their transition process, as well as the quality of their experience during the process. Participants reported that despite feeling this way, they thought that little had been done by healthcare professionals to alleviate their worries, to mitigate their concerns, or to empower them as adolescents to take responsibility for their care management.

One adolescent reported that she was always anxious about infections, and described her concerns about the difference in treatment protocols between the adult and paediatric hospitals; for example, regarding the frequency of sputum tests. She said:

> "We used to do it [a sputum test] every month in X hospital but they just do it every three months in here, so you kind of stay anxious for a long time... you don't know when the infection is going to hit…" (Young adult #02, Female)

Another participant was anxious about the possible effects of the transition on his health, because he was unfamiliar with the new setting, and uncertain about the level of service there. He said:

> "I am worried about the cutbacks in health and all, you don't know when they are going to cutback, you know that with CF patients there are some cuts that you don't know when it's going to knock off…" (Adolescent #01, Male)

Finally, another respondent's comments reflected how ambiguous this period was for her. She appeared to be uncertain about what was ahead of her, and was distressed about possible unexpected events and not being prepared for this process.

> "Now I have to move somewhere else that I don't know what they are like. So it's just like worrying about what they will be like, you know." (Adolescent #08, Female)

5.1.2.1.3 Summary of theme

This theme of being prepared for the transition also brought together two other main categories, which were perceived as contributing to preparing adolescents for participating in a managed transition process. Participants reported the need for healthcare professionals to share their knowledge and address all the concerns that were raised by the adolescents. They also reported some negative effects that they suffered as a result of going through adolescence, and having CF, and

experiencing the transition process. They stated that these negative effects needed to be addressed with interventions by the healthcare professionals. These interventions were needed to improve the outcome of the transition process, and improve the overall quality of the adolescent transition experience.

5.1.2.2 Theme two: Amorphous service

This theme discussed the current state of the transition service, which was reported by participants as lacking clear structures and organisation, and lacking the necessary focus on the needs of adolescents. They felt the current service did not place their needs at its heart. One participant said:

> " it's never changed, like ... you can't change sometime, but if they just cut down the time they spent on making over paper mountains ... ... that if they just instead focused on what I actually need... that would be better" (Adolescent #18, Female)

Participants reported that they wanted a planned, comprehensive and competent service that considered their needs. They wanted a service that was inclusive of all interventions that promoted an easy managed transition. They reported that they wanted to be involved in the planning for the transition, and wanted to be consulted about the appropriate interventions that they needed. In contrast, the current amorphous service caused participants a lot of distress as a result of the unexpected service, prevented them from preparing properly for transition, and their needs and concerns had not been identified and addressed.

> "Like... ...they don't do much for me here ... they are over reliant on paper work ... they do few things that really help... it doesn't solve problems... seriously this is so upsetting..." (Adolescent #17, Female)

Another participant said:

> "... if they listen to us (CF patients) ... instead of clinically going through or ... we would be in much better situation now.." (Adolescent #05, Female)

Therefore, the amorphous service theme included two other central categories. The first is absence of structured transition service, while the second is the need for adolescents to be listened to and involved in their care. The subcategories for this theme will be described next.

5.1.2.2.1 Category one: No structured transition service

In terms of the structural and organisational elements of the transition service, the participants' reports described how the current service has no specific interventions designed to target different aspects of the transition process. One adolescent described how difficult the current service was in term of its organisation:

> "… It is very difficult to find your way at the moment, I don't know where we are going to go from here, or what we are going to do …" (Adolescent #15, Female)

Another participant described how unpredictable the current transition service was, full of unexpected events and unwanted surprises. The participant said:

> "You know … it is like … living in a mine field… you never know when next trouble will kick off …" (Parent #10)

Many of the adolescents interviewed felt that the lack of structure within the CF service in general - and within the transition service in particular - created negative feelings on the value of the whole service. It led to some of them feeling hesitant about attending the clinic altogether, in both the child and adult settings.

> "I don't really like to come here…like, they don't do much for me…" (Young adult #10, Female)

> "Many times I thought… well..why should I come here…I can do this at home.. I can take care of myself…" (Adolescent #09, Male)

5.1.2.2.2 Category two: Adolescents and young adults and their need to be involved and listened to

Participants stressed the need to move away from the current focus on routine clinical interventions and on a task and documentation-orientated service. They stated that adolescent-focused care was needed, along with a service that listened to the patient as a human being, addressing the impact of the illness on various aspects of their life and development.

> "…sometimes things needs to be looked at with fresh pair of eyes, and people need to be listened to instead of clinically looking at or going through…the way they are looking at us now should be changed" (Parent #06)

> "… it is not the service that matters for me, it's how they are looking for me, and like, uh the more the human's side of it…" (Young adult #06, Female)

It would seem that for adolescents during this critical period, there was a greater need for consultation and being listened to before any intervention was planned or designed. There was a reliance on paperwork, to such an extent that it overshadowed other aspects of service delivery that may have been more positive. One participant reported:

> "… you know... people need to be looked at and listened to… and then you work from there, but sometimes they are over reliant on paper work that is obsolete, it doesn't solve problems..." (Adolescent #12, Male)

5.1.2.2.3 Summary of theme

The amorphous service theme was composed of two main categories, which were concerned with organising and structuring the transition service to put the adolescents as a service users in the focus of the service and to consult them about the care provided.

In conclusion, adolescents criticised the current transitional service. They found it to be unfocused, without a well modified structure. They found that it did not focus on their needs, and they felt they were not consulted enough about the type of service or information they were looking for. These shortcomings in the service exposed the CF adolescents to more distress and left them concerned about their future service and health.

5.1.3 Phase one: findings of the focus group interviews

5.1.3.1 Theme one: An individualised comprehensive approach

This is a main theme that emerged from the focus group interviews. Participants suggested the need to follow an approach of care that considered every adolescent as an individual. They reported that such an approach would be the best way to determine progress for each individual CF patient.

Participants acknowledged the fact that all CF adolescents had different needs to be met and different physical and psychosocial contexts that might affect their care. Group participants suggested that this kind of individualised approach should form a framework that guided all other components of the transition service.

This was expressed by one participant who said:

> "Absolutely, we should have an individualised comprehensive approach that cares about each individual separately and meets their needs." (G1 N1, Clinical nurse specialist)

Participants further explained that achieving this goal might require following a systematic approach that divided the transition service into distinct phases. The focus of care during these phases should be on identifying adolescents' needs, planning interventions that address these needs, providing the required information, and finally evaluating whether the adolescents' needs have been met and whether they have settled in the new environment.

Therefore, the "comprehensive, individualised approach" was composed of another four categories. These include the assessment of care, the planning of

care, the provision of information, and finally, continuous evaluation and follow up mechanisms. These categories will be presented in the following section.

5.1.3.1.1 Category one: Assessment of care

In terms of the care required, participants reported that approaching each adolescent as an individual case necessitated the assessment of the adolescent's needs throughout the course of their care. Participants described the aim of this assessment phase as to identify each adolescent's needs, and the factors that might affect their transition. One participant stated:

> "The assessment will highlight to us what the adolescents actually need, and what might affect his or her transition in terms of information, family, or any other issues." (G1C2, Paediatrician)

According to healthcare professionals, the most important things that need to be assessed during the transition process are: the child understanding of the transition process; special needs arising from other illnesses if present; the presence of family support; the type of information needed by adolescents and family; and whether other transitions or changes are taking place at the same time.

In relation to assessing the child's understanding of the transition process, participants described this as an especially important issue. They highlighted that adequate understanding would help ease the process and improve the transition's outcome. One participant stated:

> "Another very important thing is to assess if the child understands all about transition, what's going on, what the meaning of transition is, and what he/she should do during the transition…" (G2N2, Clinical nurse specialist)

Participants also reported that the external environment of the adolescents during the transition needs to be assessed. Participants suggested that experiences and achievements of the adolescents could not be separated from the environment surrounding them. As one participant said:

> "I think we need to assess the environment around the child as well and whether there are some factors that might aid in the transition process." (G1S5, Social worker)

Participants identified family support as among the most important issues that needed to be assessed within the adolescent's environment. It was suggested that the presence of a supportive family and strong social system might constitute factors that would assist adolescents through all required changes in transition, and help them to assume their new roles more easily. One participant commented:

> "I think the presence of the family to support adolescents is something worth looking at when we assess the child… if the child has no such support for any reason… we might need to look for something else to compensate that." (G2N8, Clinical nurse specialist)

Participants also stressed that to enable family to carry out the roles and duties expected of them in supporting their adolescent during the transition process, family needs should also be assessed and considered by the healthcare professionals. They stated that supporting the families of patients was essential. This might include involving the family in care, discussing clinic dates and times with them, and also considering their other commitments. This is especially the case in situations where families have other children with CF, or when their adolescent has another illness or disability beside CF which might require attending different clinics and meetings with different teams.

Some participants explained:

> "…parents are fantastic … they can give a huge support for their kids … they also need some more attention from the team…" (G2Phy4, Physiotherapist)

Participants reported that some CF adolescents also have physical disabilities or illnesses. They noted that these additional illnesses or disabilities might further complicate the transition process. The young people may need to master more

skills, or may need more knowledge about treatments for multiple illnesses, or information about symptoms and subsequent effects on daily life. One participant said:

> "Many of our patients have other problems beside CF like diabetes, so we need to assess their needs in light of these other illnesses as well." (G2N7, Clinical nurse specialist)

Group participants also stated that the individual information needs of the adolescents must be assessed. Healthcare professionals suggested that if information needs were to be met in the most competent way, patients should be asked about the nature of the information they were looking for. One participant said:

> "I mean, the patients should be asked about what type of information they are looking for, and then we will provide them with that information." (G1Phy3, Physiotherapist)

Finally, participants highlighted that it was common for many major life changes to occur at the same time in an adolescent's life. These changes can include new diagnosis of another health problem, or another complication within their current illness, or a change in treatment options, or even undergoing surgery. These changes are in addition to developmental changes that all adolescents go through, such as moving to an independent house, starting work or starting a relationship. There are also other changes that can happen at such times, like changes related to setting (starting or finishing college or a course),or treatment setting (being discharged or admitted for treatment, or experiencing new policies, practices or routines as a result of the move to a new organisation).

Assessment therefore should be carried out to identify such changes or transitions that are taking place at the same time. One participant explained:

> "I think we need to think about all the other things that are going on as well, like doing leaving cert or moving to college." (G1N4, Clinical Nurse specialist)

> "A lot of them have to go for college or might have another surgery. All these will affect them." (G2C5, Paediatrician)

5.1.3.1.2 Category two: Planning of care

According to the group participants, the planning phase is especially important as it proposes specific interventions that target the assessed needs of CF adolescents. However, participants emphasised the importance of planning the care in collaboration with the adolescents and their parents. This was emphasised by one participant who said:

> "I must say that the planning phase is especially important and should be written down well before starting preparing the child for transition …" (G2Psy6, Psychologist)

Group members confirmed the validity of assigning designated healthcare personnel to plan care interventions. Group members agreed that there were associated benefits during the planning process, and also benefits through facilitating the different aspects of the transition service; for example, assessment, planning, implementation, and evaluation. One participant reported that:

According to the group participants, successful planning for transition care can benefit all those involved. They explained that adolescents and families feel more involved, empowered and in control of their treatment, while healthcare professionals can use the process to guide the interventions they plan to adopt during the course of treatment. Group participants said:

> "I think it will be important for the adolescents and parents if they participated in this plan… It will be good for everyone … everybody will know what to do." (G1Psy8, Psychologist)

The participants recommended an early start to the planning process, to better organise the transition service and ensure the agreed plan can be achieved. One participant said:

> "Planning should start early in childhood, I think the most appropriate age is around 14 and should continue until the transition process takes place." (G1N1, Clinical nurse specialist)

The need to start the planning phase early in the care of CF adolescents was acknowledged by study participants; however, it was also noted that this also needed to consider the health condition of the adolescent. Unstable health conditions might delay this process, as confirmed by another participant:

> "… however it should consider the health status of the child, sicker kids might take longer, because not all kids are alike." (G1C2, Paediatrician)

Healthcare professionals reported that the transition plan should contain the adolescent's own future wishes and plans, such as study, career, and so on. One participant said:

> "I imagine that such a plan should contain information about adolescent's wishes, and what he is planning to do in the future, like study or career." (G2Phy4, Physiotherapist)

The plan should also contain which hospital might be the most appropriate or convenient to the adolescent, and also list any interventions that might help the adolescent take this decision later on (as some of the patients might not yet have enough knowledge about the available CF centres). Another participant commented that the adolescent might at that stage not know:

> "…which hospital would be the most appropriate for him her to move to when they get to that point…" (G1S5, Social worker)

According to the participants, the transition plan should also address issues in relation to how CF clinics usually operate, especially in adult clinics. If feasible, the plan should include special arrangements to optimise patients' experiences, maximise benefits from the clinic, and encourage clinic attendance. One participant commented:

> ".. The way the clinic is run might even be discussed with the adolescent and family and modified to suit their conditions." (G2N7, Clinical nurse specialist)

Finally, participants suggested that planned interventions should have timeframes for their implementations, and details of achievement where relevant. Participants explained that, for example, by the age of 16 adolescents should be able to attend the clinic independently without the presence of their parents. These timeframes would be mainly for evaluating the progress of adolescents in achieving their planned objectives. One participant stated:

> "One more thing to remember is to try to put dates for the achievement of the tasks. This could tell us about the progress of the child as well, which is very important." (G2N8, Clinical nurse specialist)

Finally, participants emphasised the importance of adhering to the transition plan once it was set up. This is especially true for the healthcare professionals who are mainly responsible for implementing the plan. One participant reported:

> "Once the plan is set up, there should be a degree of adherence to achieve the elements of this plan, especially from the healthcare professionals' side..." (G2S3, Social worker)

The use of this common systematic approach will give healthcare professionals the necessary tools to improve the transition service. The introduction of assessment, planning, and evaluation stages will allow the provision of relevant interventions, and also allow the evaluation of the efficacy of the outcomes of these interventions afterward.

5.1.3.1.3 Category three: Provision of information

Participants reiterated the importance of providing information that is based on the unique information needs of each individual adolescent and their family. They further highlighted that this information should be delivered in an appropriate format for the adolescent's age and developmental stage. Participants acknowledged that the current state of this process is not optimal. Participants

said this could be due to many reasons, including the way their clinic is arranged and run, or the content or type of information provided, and finally, the way the information is provided.

Participants mentioned that clinic visits were already very long for the attending adolescents and their families. They stated that part of the reason that adolescents and their families might be reluctant to ask for additional information is because they don't want to prolong these already long visits. This is especially of the CF adolescents and parents that travel long journeys to reach the hospitals. Further to this, one participant explained:

> "This issue is quite confusing. We used to ask them [adolescents and parents] whether they want to ask about anything, but they don't seem to be interested…. they are usually rushing to get in and out of the clinic and they ask very few questions … it might be the way that clinic runs." (G2C1, Paediatrician)

Participants stated that providing irrelevant information could have failed to engage the adolescents and their parents. They also stated that the way information was delivered might have discouraged clinic attendees from seeking more information or asking more questions. One participant said:

> "It could be another type of information that they are looking for, or the way we provide this information that may need to be revised, I don't know." (G2N2, Clinical nurse specialist)

To improve current practices and achieve better results in relation to information provision, special information sessions were suggested as an alternative. These sessions were proposed to enhance the process by separating it from other clinic activities that might compromise its efficiency, or that only leave a small opportunity for adolescents and parents to ask questions or seek more information.

> "Anyway, providing information should be given extra attention, and possibly information session could solve this problem." (G1N4, Clinical nurse specialist)

Another suggestion was to give complicated scientific information in a physical format - printed out on paper, or in other digital forms like, CDs, DVDs, or providing links to trusted websites. These should be designed for both adolescents and parents, with the aim to compliment the other methods for providing information rather than replacing them.

5.1.3.1.4 Category four: Continuous evaluation and follow up mechanisms

Continuous evaluation was reported by healthcare professionals in the focus group interview as a key component of the proposed transition service. The main goals of continuous evaluation are to measure the effectiveness of care, track the progress of the adolescent, and identify the need to alter or change the current service. One participant stated:

> ,"... Of course with frequent evaluation to make sure that the plan is working and the adolescent is making progress…" (G1Psy8, Psychologist)

According to the participants, this process of evaluation is usually carried out by comparing the desired or planned goals of the service against the actual achievements. They indicated that if a plan was formed initially by the designated healthcare professional working alongside the adolescent, then this plan could work as a tool to evaluate the child's progress. One participant reported:

> "The achievement of the tasks within the agreed dates could work as an evaluation tool for the progress of the child or not, which is very important." (G1N1, Clinical nurse specialist)

However, it was evident from participants that the goals for evaluating the achievement of the desired outcomes might differ slightly in the child setting – that is, before making the transition. The goals in the child setting would be to

evaluate the child's progress in acquiring the knowledge (e.g. symptoms, treatment and effect on life) and skills (e.g. communication skills, participation in care, management of care, and decision-making) necessary for transition. One participant stated:

> "Well if they are ready they will know almost all about CF - they should have initiative and participate in care and decisions about their treatment." (G1C2, Paediatrician)

While in the adult setting, participants reported that the goals should be to ensure the adolescent's achievement of a successful transition, which includes factors like clinic attendance rate, settlement in the new setting, and use of different facilities and services in the new setting. One participant reported:

> "I think we should be a bit vigilant in the first few months about their clinic attendance, and whether they settled here and started to interact with the staff, and to use the resources here" (G2S3, Social worker)

5.1.3.1.5 Summary of theme

This theme of an individualised comprehensive service included four other categories. Collectively, these categories enhance the organisation of the transition service, and make the transition more closely related to the specific needs of each individual adolescent. This is done by implementing a systematic approach of care that includes: an assessment of needs; planning care interventions; providing adequate information; evaluating; and following up the outcomes of the transition care.

5.1.3.2 Theme two: Promoting adolescent independence

Participants in the focus group interview reported that transition care should promote independence. The participants reported that this kind of approach was an important component of the transition service. They suggested that this approach could be achieved by empowering adolescents and encouraging their participation in the care setting. One participant said:

> "I think it is important to keep them involved … and take part in all decisions and activities during clinic and so on." (G2Phy4, Physiotherapist)

Promoting the independence of the adolescents and letting them practice their independence skills during their time in the paediatric setting could be of great value, as they have the supervision of the paediatric team to guide them. This means that healthcare professionals can evaluate their skills, and identify any possible weaknesses. If this process was delayed until after the transition, this might expose adolescents to potential health risks as they would not be able to manage their illness competently in the new setting. One participant said:

> "…allowing adolescents to attend clinics on their own is good idea… this will teach them to be independent … and will help them afterward when they go to the adult hospital…" (G1N2, Clinical nurse specialist)

5.1.3.3 Theme three: Gradual hand-over to the adult service

During the focus group discussions, participants stated that a gradual and thorough handover to the adult hospital could make transitions much easier; it was suggested that introducing a period of overlap in care between the child and the adult settings could satisfy this need. During this period, adolescents could practise the skills they acquired during the preparation for transition. During this period, the adult healthcare providers could be invited into the child's setting to carry out a few clinics there, to get adolescents used to the different style of clinic.

> "I think staff from the (x) hospital can come over here and do their first few clinics with adolescents … this might help… and we can give them better information about our patients." (G1S5, Social worker)

5.1.3.4 Theme four: Environment

Participants in the focus group interview emphasised the importance of the adolescent's environment in the transition process. They reported the need to provide transition care in a setting that suits the unique developmental stage of adolescents, both in the adult and child CF hospitals. Currently, this issue is not

addressed, and care is provided in a setting oriented either specifically to children or to adults. One participant reported:

> "Here, the adolescents do not feel attracted to the place… they sometimes tell us they feel like kids here… they are waiting to get out of here." (G1Psy8, psychologist)

According to healthcare professionals, providing an environment that suits the adolescents' developmental stage does not necessarily require the re-design of the physical setting. Rather, participants suggested that alternative approaches could be employed to improve current practises. Participants described an example in which stratification of the clinic according to the age group occurred (where possible). This means bringing together adolescents in the same age group to the same clinic date. One participant said:

> "We might do a special adolescents clinic… bring in all adolescents together and prepare the place as much as we can to fit their interests." (G1N1, Clinical nurse specialist)

5.1.3.5 Theme five: Continuous training for healthcare professionals

Finally during the focus group interview, healthcare professionals mentioned the importance of continuous training for healthcare workers on issues specific to adolescence. Training might be provided on variety of topics, such as communication, adolescent developmental stage, and issues related transition process. Communication in particular was mentioned as an example of a potential training topic that needed addressing urgently. Participants reported:

> "I think we are used to dealing with kids more, and indeed adolescents, being in a different and unique developmental stage may need another type of communication styles, that we are not used to." (G1C2, Paediatrician)

5.1.4 Phase one findings summary

Data analysis of the individual focus group interviews identified two themes and four categories.

The first theme was “preparing for transition” and included two other categories, “sharing knowledge” and “overcoming own concerns”. The second theme was the “amorphous service” which included two other categories, which are “no structured transition service” and “CF adolescents and young adults and their need to be involved and listened to”.

The focus group interview identified five themes and four categories. The first theme was “an individualised comprehensive approach” which included another four categories, which included “assessment of care”, “planning of care”, “provision of information” and “continuous evaluation and follow up mechanisms”. The other four themes were “an approach that promotes independence”, “a gradual and thorough hand-over to the adult setting”, “creating a suitable environment for adolescents and young adults”, and finally “continuous training for healthcare professionals”.

In conclusion, the qualitative data indicated a need for healthcare professionals to rethink in their practices during transition to make the process more organised and co-ordinated, more relevant to the CF adolescents and more informative, empowering, and finally help promote adolescents independence. Healthcare professionals need to adopt a systematic approach that assesses, plans, implements and evaluates the care for young people with CF. This approach would also provide adequate and relevant information in a suitable manner, and in an environment that considers the needs and characteristics of different adolescents. Finally the transition should occur gradually, and should be followed-up to check it was carried out successfully.

5.2 Phase two findings: Survey findings

This chapter reports findings from the survey study undertaken in phase two of the research. This phase of the study consulted with a large number of CF transition service stakeholders both staff and service users, and asked them about what they thought the most relevant and feasible service guidelines were. In order to address this research objective, a self-report questionnaire was sent to all those involved in the CF transition service in Ireland. The questionnaire was

developed to gather participants' views on the importance or relevancy and the feasibility of the suggested transition service guidelines. It also gathered some demographic data about the participants' specialities and experience, as well as information about the setting where they worked (or the setting where they were receiving care if they were CF adolescents or young adults).

The findings of the survey will be presented in the following sections. The results will be preceded by a description of the demographic data that was collected.

5.2.1 Demographic data for the survey participants

This section reports the demographic details of the survey participants, participants were asked to give information about their speciality, years of experience, setting where healthcare professionals work, or the setting where the CF adolescents are receiving their care. Each of these details will be described later.

5.2.1.1 Professional specialities of healthcare participants

Healthcare professionals who participated in the quantitative phase of the study were doctors (n=13), nurses (n=17), and a range of allied healthcare professionals, including social workers (n=7), dieticians (n=7), physiotherapists (n=6), and psychologists (n=8), in addition to the CF patients (n=113). The professional specialities of the participants are presented in figure 12.

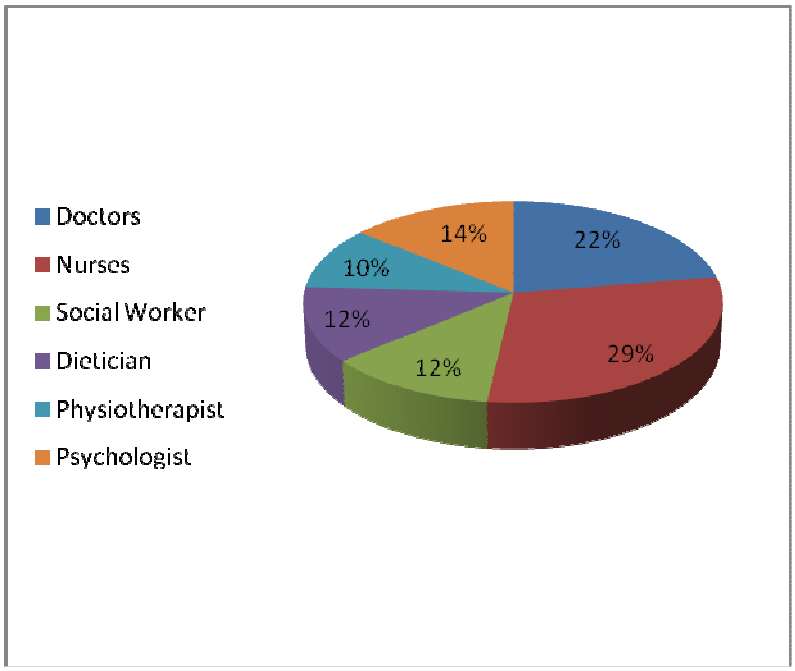


Figure 12- Healthcare professionals by speciality

5.2.1.2 Years of experience for healthcare professionals

In relation to years of experience, 65% (n=38) of participants had more than 10 years of experience, 26% (n=15) had five to 10 years of experience, while the remaining 9% had between two to five years of experience. Table 7 presents this information.

Years of experience	n	%
2-5 years	5	9%
5-10 years	15	26%
>10 years	38	65%
Total	**58**	

Table 7- Details of healthcare professionals that participated in the survey study according to years of experience

5.2.1.3 Healthcare professionals according to setting

Finally, 45% of healthcare professionals (n=26) were working in a child healthcare setting at the time of the questionnaire, 22% (n=13) were working in an adult setting, while 33% (n=26) were working in a setting that treated

children, adolescents and adults with CF. Figure 13 present healthcare professionals according to their work setting.

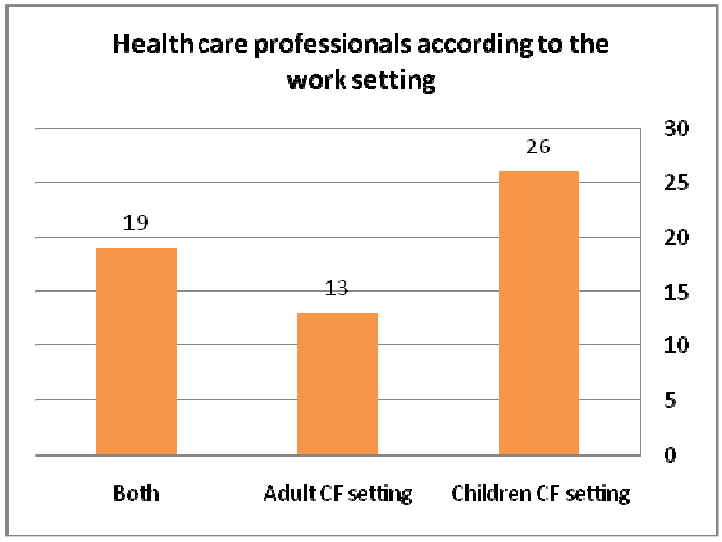


Figure 13- Healthcare professionals according to the work setting

5.2.1.4 CF adolescents and young adults according to setting

CF patients who were eligible to participate were recruited from different child and adult centres for CF treatment in Ireland. The sample included those who were either candidates for transition to the adult setting (n=64), or who had transferred to an adult centre within the last two years (n=49). Figure14 shows the distribution of CF patients according to the care setting.

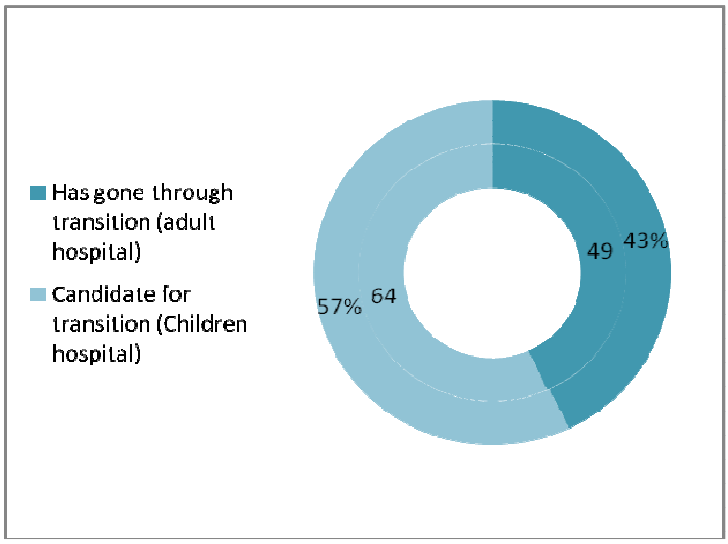


Figure 14- CF adolescents according to setting

5.2 .2 The results of the survey study

The goal of the survey questionnaire was to identify CF transition service guidelines, which were considered by the majority of CF transition service stakeholders as relevant to and feasible for implementation in the clinical setting. Items in the survey were considered for inclusion in the proposed transition service guidelines if they received a rating of four (highly important or highly feasible) or three (important or feasible) by ≥ 70% of participants.

Each item within this survey represented ***a proposed transition service intervention***, while the survey subsections, represented a group of similar interventions that targeted an aspect of the proposed transition care. In the following sections, the term 'important' will be used to refer to the importance of a particular item to the transition service, while the term 'feasible' will be used to indicate the degree to which that particular item or intervention can be implemented in practice.

The following sections present the results of the survey questionnaire. A description of the importance and the feasibility dimensions of the different transition service aspects of care will be presented, as will descriptions of the survey individual items.

5.2.2.1 Participants' perceptions on the transition aspects of care

The survey included six aspects of transition care. (1) "promoting independence", (2) "planning of care", (3) "initial assessment phase", (4) "provision of information", (5) "environment, gradual handover, and training of healthcare professionals" and (6) "continuous evaluation of care".

The agreement and differences between survey participants about the importance and feasibility of the different aspects of care within this survey will be presented next.

5.2.2.1.1 Aspect of care (1): Promoting independence

There was no significant difference in mean score between the CF patient group and Healthcare professionals (HCP) group about the importance (CF m=3.41

SD=0.38 and HCP m=3.53 SD=0.5) and feasibility (CF m=3.29, SD=0.43 and HCP m=3.288, SD=0.38) of the interventions suggested to promote the independence of CF adolescents and young adults. Both groups considered this aspect of care to be important and feasible for the transition service.

The importance of this aspect of care for all participants was evident from the high mean scores for both groups, which was 3.41 for the CF patients group, and 3.53 for the HCP group. The CF patients group scored slightly lower (m=3.41, SD=0.38) than the HCP group (m=3.53, SD=0.5) on rating the importance of this subscale. In relation to the feasibility of this aspect of care, it was rated equally feasible by all participants in both groups; with a feasibility mean score of 3.29 (SD=0.43) for the CF patients group and 3.29 (SD=0.38) for the HCP group.

5.2.2.1.2 Aspect of care (2): Planning of care

Both the HCP group and the CF patient group agreed on the importance of this aspect of care. The mean score for the CF patients group was 3.39 (SD=0.42), while it was 3.42 (SD=0.5) for the HCP group. However, the two groups had different mean scores on the feasibility of this aspect of care. The analysis showed a significant difference ($p<0.001$, CI 95%) between the CF patients group and the HCP group, as the mean score of the CF patient group (m=3.42, SD=0.32) was significantly higher than the HCP mean score (m=2.65, SD=0.1), meaning the CF patients think planning of care is more feasible.

5.2.2.1.3 Aspect of care (3): Initial assessment phase

All participants agreed on the importance and feasibility of this aspect of care. The CF patients group's mean score for the importance of this aspect of care was 3.69 (SD=0.4), while the HCP group's mean score was 3.37 (SD=0.36). In terms of feasibility, CF patients attached more feasibility to this aspect of care, evidenced by their high mean score (m=3.51, SD 0.29) compared to the healthcare professionals, who rated it as just feasible (m=3.06, SD=0.41).

5.2.2.1.4 Aspect of care (4): Provision of information

The CF patients considered this aspect of care as highly important to them with a mean score approaching the top score of 4 (m=3.87, SD=0.15), while the healthcare professionals marked it as moderately important (m=3.43, SD=0.38). The analysis illustrated a significant difference between the two groups when considering the feasibility of this aspect of care. The HCP group marked the feasibility of this scale as low (m=2.83, SD=0.28), while the CF patient group rated it as highly feasible, with a score approaching the maximum of four (m= 3.72, SD=0.29).

5.2.2.1.5 Aspect of care (5): Environment, gradual handover and training and education

The data analysis illustrated that the CF patients group thought this aspect of care was very important, as demonstrated by their high mean score of 3.8 (SD=0.3). This aspect of care was also considered important by the HCP group, whose results gave a mean score of 3.43 (SD=0.56).

In term of feasibility there was a significant difference between the mean score of the HCP group (m=2.36, SD=0.24) and the CF patients group (m=3.549, SD=0.41). The HCP group's mean score was close to two, which means that the item was perceived as not feasible by the majority of the group. By contrast, this aspect of care was considered moderately to highly feasible by the CF patients group whose mean score was 3.55 (SD=0.41).

5.2.2.1.6 Aspect of care (6): Continuous evaluation of care

The analysis of this subscale shows agreement between the HCP group and the CF patient group about the importance and the feasibility of this scale.

The CF patients attached a high importance for this subscale (m=3.75, SD=0.24), though this declined slightly when they rated its feasibility (m=3.549, SD=0.3). The results of the healthcare professionals followed the same pattern, rating the aspect of care as important (m=3.35, SD=0.35), but their score declined slightly

when it came to feasibility (m=3.06, SD=0.18), rating the item as moderately feasible.

5.2.2.1.7 Summary of aspects of care evaluation (survey sub-sections)

In conclusion, the healthcare professionals considered the different aspects of the transition service as proposed in the survey as important or moderately important with mean scores ranging from 3.166 to 3.533.

They ranked the aspects of care in relation to importance as follows, promotion of independence was considered the most important, followed by provision of information, then planning of care, initial assessment phase, continuous evaluation of care, and finally, gradual handover and training for healthcare professionals.

In relation to feasibility, promotion of independence was again rated the most feasible aspect of care, followed by the initial assessment of care, continuous evaluation of care, provision of information, then planning of care, and finally the gradual handover and the training for healthcare professionals. Table 7 details the rankings that the healthcare professionals gave to the importance and feasibility of the different aspects of care.

The CF patient group considered the provision of information aspect of care as the most important and the most feasible subscale. This was followed by environment, gradual handover and training for healthcare professionals (which was rated as second in terms of importance and feasibility). Continuous evaluation of care and the initial assessment phase were rated in third and fourth place respectively in relation to importance, but this order was reversed when it came to feasibility.

The promotion of independence aspect came in fifth place for importance and feasibility, followed by the planning of care subscale, which was rated by CF patients as the least important and the least feasible of all items. The patients were more concerned and enthusiastic about the practices that directly affected their care, like the provision of information, the environment where they receive

the care, and the skills of the healthcare professionals (training element). In contrast, the healthcare professionals rated the more organisational elements of the care as being more important to them.

Table 8 presents the mean score ratings that were given by participants for different aspects of transition care in terms of importance and feasibility.

Survey participants rating for the transition aspects of care								
Subscale	**CF patients group**				**HCP group**			
	Importance		**Feasibility**		**Importance**		**Feasibility**	
	M	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Promotion of independence	3.41	0.38	3.29	0.43	3.53	0.5	3.29	0.38
Planning of care	3.39	0.42	3.42	0.32	3.42	0.5	2.65	0.1
Initial assessment phase	3.69	0.4	3.51	0.29	3.374	0.36	3.06	0.41
Provision of information	3.87	0.15	3.72	0.29	3.43	0.38	2.83	0.28
Environment, gradual handover, and training of healthcare professionals	3.8	0.3	3.55	0.41	3.43	0.56	2.36	0.24
Continuous evaluation of care	3.75	0.24	3.55	0.3	3.35	0.35	3.06	0.18

Table 8- Survey participants' ratings for aspects of care during the transition process

5.2.3 Participants' perceptions on the proposed transition interventions (survey items)

The analysis of the data identified 36 proposed guidelines that were considered by the majority of CF patients groups and HCP group (≥70%) as both important and feasible (with a rating of four or three) (see next table). These interventions included items concerning the assessment of care (n=16), planning of care (n=4), continuous evaluation of care (n=7), provision of information (n=5), promotion of independence (n=2), and follow-up mechanisms and training of healthcare professionals (n=2). Table 9 presents the interventions that were considered important and feasible by the majority (≥70%) of survey participants.

There were 11 interventions in the survey that were considered not important and/or not feasible by the majority of participants in the healthcare professionals

group, although in contrast these interventions were considered of importance and to be feasible by the majority of the CF patients groups.

These items include interventions about the assessment of care (n=2), planning of care (n=2), continuous evaluation of care (n=1), provision of information (n=1), suitable environment for adolescents (n=1), and gradual and thorough handover to the adult hospital (n=4). Table 10 presents the interventions in the survey that were ***not*** considered important or feasible by the majority of survey participants.

There were three interventions considered not feasible and not important or feasible and not important by the CF user group. However, the healthcare professionals found these same interventions to be as important and feasible. The first intervention is the need to continue planning until the transition to the adult setting takes place, while the other two items were planning for the transition service and a shift toward an adolescent-oriented care at age 14. Table 11 presents these items.

Finally, both CF patients and healthcare professionals agreed on the non-importance and/or non-feasibility of four interventions in the survey. These included three interventions related to the assignment of a key worker for each individual CF adolescent. These key workers would be assigned to facilitate the transition process, to carry out the initial assessment of care and the evaluation of the effectiveness of care, and finally to carry out planning for further interventions during the transition process. The final intervention proposed the information provision process be carried out in separate sessions allocated for that purpose only. These four items are presented in table 12.

Table 9- Interventions that were considered important and feasible by the majority (>70%) of survey participants

	Importance		Feasibility	
	CF	HCP	CF	HCP
Healthcare professionals should assess the impact of adolescent development to adulthood *(e.g. moving to an independent house, starting work, starting relationship, etc)* on the transition to the adult CF hospital.	**80.5% (n=91)**	**100% (n=58)**	**80.5% (n=91)**	**72.4% (n=42)**
Healthcare professionals should assess the adolescent's understanding of the timing of the transition	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should assess the adolescent's understanding of the adult CF centres that are available for him/her to transfer to	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should assess the adolescent's understanding of what is required from him/her during the transition process	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should assess the adolescent's understanding of the differences in terms of care between their current setting and the adult setting	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should assess the types of information that the adolescent and their family would like to receive more of during the preparation for the transition, the actual transition and after the transition	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should assess the availability of family support for the adolescent during the preparation for transition and the actual transition	**75.2% (n=85)**	**100% (n=53)**	**100% (n=113)**	**82.8% (n=48)**

Healthcare professionals should assess the sources of information about CF and CF centres that are available to the adolescent and his/her family during course of treatment and preparation for transition	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should assess the impact of other major events *(e.g. starting or finishing college or a course, or being discharged or admitted for treatment)* that are taking place on the transition to the adult CF hospital	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should assess whether other health-related events *(e.g. a new diagnosis of another health problem, another complication within the current illness, a change in treatment options, undergoing surgery, etc.)*will affect preparation for transition to the adult CF hospital	**100% (n=113)**	**98.3% (n=57)**	**100% (n=113)**	**98.3% (n=57)**
Healthcare professionals in an adult setting should assess the effects of the change of treatment setting on the adolescent *(e.g. their experience of new policies, practices or routines as a result of the move to a new organisation)*	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**93% (n=54)**
Healthcare professionals should assess whether there are any specific cultural needs to be considered during the adolescent's preparation for transition	**75.2% (n=85)**	**100% (n=53)**	**83.2% (n=94)**	**100% (n=53)**
Healthcare professionals should assess the adolescent's social status, which may impact on the transition or the preparation for the transition *(e.g. separated parents, single parent, guardians, etc.)*	**75.2% (n=85)**	**72.4% (n=42)**	**83.2% (n=94)**	**72.4% (n=42)**
Healthcare professionals should assess whether or not the adolescent has another physical disability that means they require special assistance *(e.g. home visit, available support during visit, etc)*	**100% (n=113)**	**82.8%(n=48)**	**100% (n=113)**	**82.8% (n=48)**
Healthcare professionals should assess whether the adolescent has another sibling with CF, which might require a special arrangement with the clinic *(early clinic, same day clinic for both sibling, co-ordinating appointment dates if siblings are attending different clinics)*	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**

Healthcare professionals should assess whether the adolescent has another chronic illness that might mean that they require special assistance *(multi-speciality meetings, co-ordinated tests and clinic dates, etc)*	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**82.8% (n=48)**
Planning for the transition should involve the adolescent and their family working with the healthcare professionals	**100% (n=113)**	**100% (n=53)**	**98.2 (n=111)**	**100% (n=53)**
The plan for the future should guide healthcare interventions, in order to make these interventions more relevant and more effective	**75.2% (n=85)**	**100% (n=53)**	**100% (n=113)**	**98.3% (n=57)**
The plan for the future should incorporate the adolescent's wishes and needs *(e.g. educational needs, possible work, choice of adult care facility, what is important to the adolescent, etc.)*	**100% (n=113)**	**91.4% (n=53)**	**100% (n=113)**	**72.4% (n=42)**
Where possible, the plan for the future should contain dates and timelines in order to achieve the agreed-upon tasks and activities	**81.4% (n=92)**	**82.8% (n=48)**	**81.4% (n=92)**	**82.8% (n=48)**
Healthcare professionals should observe the adolescent's gradual progress in acquiring the communication skills necessary for dealing with healthcare professionals	**81.4% (n=92)**	**100% (n=53)**	**81.4% (n=92)**	**100% (n=53)**
Healthcare professionals should observe the gradual increase in the adolescent knowledge of CF *(e.g. symptoms, treatment, etc.)*	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should seek feedback from the adolescent/young adult, their family and other healthcare professionals about the adolescent/young adult's participation in care	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals should seek feedback from the adolescent/young adult, their family and other healthcare professionals about the adolescent's achievement of the planned objectives	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**82.8% (n=48)**

Healthcare professionals should continuously evaluate the adolescent/young adult's abilities to manage his/her own care, and master all that is required from him/her to the level of competent self-care.	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**72.4% (n=42)**
Healthcare professionals in the adult setting should evaluate whether the young adult feels settled in their new adult-focused setting	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Healthcare professionals in the adult setting should evaluate whether the young adult is achieving a satisfactory attendance rate at the clinic	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Information provided for adolescents during the preparation for transition should be appropriate for their developmental stage	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**89.7% (n=52)**
Information provided during the preparation for transition should be tailored to every individual adolescent's needs	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**93.1% (n=54)**
Information provided for adolescents during the preparation for transition should be delivered using age-appropriate communication techniques	**100% (n=113)**	**93.1% (n=54)**	**100% (n=113)**	**100% (n=53)**
Information provided for adolescents during the preparation for transition should be provided to both the adolescent and their family	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Helpful written material should be conveyed in a way that is understandable for both the adolescents and their parents	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Throughout their time in care, healthcare professionals should empower adolescents/young adults and promote their independence using various strategies *(e.g. providing information, considering their opinions, etc)*	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**

Throughout the preparation for transition, adolescents should be listened to, involved and encouraged to ask questions, express their opinions and make decisions	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**100% (n=53)**
Follow-up mechanisms that are agreed upon between both the children and adult settings should be used to ensure safe post-transition period	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**84.5% (n=49)**
Healthcare professionals who are involved in the care of adolescents should receive training on issues specific to adolescent developmental stages *(e.g. communication skills, developmental needs, care during transitional period, sexual health, etc)*	**100% (n=113)**	**100% (n=53)**	**100% (n=113)**	**96.6% (n=56)**

Table 10- Interventions in the survey that were considered not important nor feasible by the majority of survey participants

	Importance		**Feasibility**	
	CF	**HCP**	**CF**	**HCP**
Healthcare professionals should assess the economic status of the adolescent's family, as this might affect the transition or the preparation for the transition *(e.g. poor economic background, cannot afford the travel to a particular facility, etc.)*	**75.2% (n=85)**	**72.4% (n=42)**	**100% (n=113)**	**25.9% (n=15)**
Healthcare professionals should assess the need of adolescents with CF for other resources that aid during the care and transition (*e.g. additional government resources, funds, assistance etc.)*	**100% (n=113)**	**48.3% (n=28)**	**100% (n=113)**	**15.5% (n=9)**
The key worker will act as a source of information for the adolescent and their family during the preparation for the transition and the actual transition	**100% (n=113)**	**100% (n=58)**	**100% (n=113)**	**53.4% (n=31)**
The key worker should participate in the process of the handover of care to the adult service	**100% (n=113)**	**100% (n=58)**	**100% (n=113)**	**39.7% (n=23)**

Healthcare professionals should evaluate the adolescent/young adult's use of the services and resources available to him/her within this setting (*e.g. contacting staff in the new setting when needed, requesting a particular service, joining a particular support group, etc.)*	**100% (n=113)**	**72.4% (n=42)**	**100% (n=113)**	**34.5% (n=20)**
During information sessions, opportunities should be provided for adolescents to ask questions and share their opinions	**100% (n=113)**	**100% (n=58)**	**100% (n=113)**	**36.2% (n=21)**
Where possible, transitional care should be provided in dedicated facilities that are suitable for the adolescent/young adult's developmental stage.	**100% (n=113)**	**100% (n=58)**	**75.2% (n=85)**	**25.9% (n=15)**
A period of overlap - where the care is provided jointly by the children and the adult professionals – is helpful to adolescents until they settle into adult care	**100% (n=113)**	**56.9% (n=33)**	**100% (n=113)**	**1.7% (n=1)**
During the period of overlap, adolescents will practice and develop their independence skills	**100% (n=113)**	**56.9% (n=33)**	**100% (n=113)**	**1.7% (n=1)**
Constructive feedback from the adolescent and their family during this period of overlap should be promoted to help to improve the care provided	**100% (n=113)**	**56.9% (n=33)**	**100% (n=113)**	**19% (n=11)**
During this time of overlap between the children and the adult settings, maintaining good communication between teams in both settings is essential to improving the service provided to the adolescent	**100% (n=113)**	**84.5% (n=49)**	**100% (n=113)**	**29.3% (n=17)**

	Importance		Feasibility	
	CF	HCP	CF	HCP
Healthcare professionals should start planning for the transition to the adult CF hospital when the child is aged around 14 years old	**38.9% (n=44)**	**82.8% (n=48)**	**53.1% (n=60)**	**100% (n=58)**
When an adolescent approaches the age of 14, there should be a gradual shift towards an adolescent orientated care, making sure to include the parents	**38.9% (n=44)**	**100% (n=58)**	**63.7% (n=72)**	**98.3% (n=57)**
Planning is a continuous process and should continue until the transition to the adult CF hospital takes place	**58.4% (n=66)**	**79.3% (n=46)**	**100% (n=113)**	**100% (n=58)**

Table 11- Items that were considered not feasible and/or not important by the CF patients group

	Importance		Feasibility	
	CF	HCP	CF	HCP
The planning for the transition service should include assigning a key worker for each adolescent in order to facilitate the transition service	**80.5% (n=91)**	**100% (n=58)**	**43.4 (n=49)**	**15.5% (n=9)**
During the planning process, the key worker should carry out the initial assessment of care, and afterwards the evaluation of the effectiveness of interventions	**80.5% (n=91)**	**100% (n=58)**	**43.4% (n=49)**	**22.4% (n=13)**
The key worker should modify plans or plan any further interventions based on the results of the continuous evaluation of care	**80.5% (n=91)**	**98.3% (n=57)**	**63.7% (n=72)**	**24.1% (n=14)**
Information provided for adolescents should be delivered in information sessions that are held periodically and regularly for this purpose only.	**55.8% (n=63)**	**96.6% (n=56)**	**55.8% (n=63)**	**8.6% (n=5)**

Table 12- Interventions in the survey that were considered by both CF patients and healthcare professionals as non-important and/or non-feasible

5.2.3.1 Summary of the individual intervention results

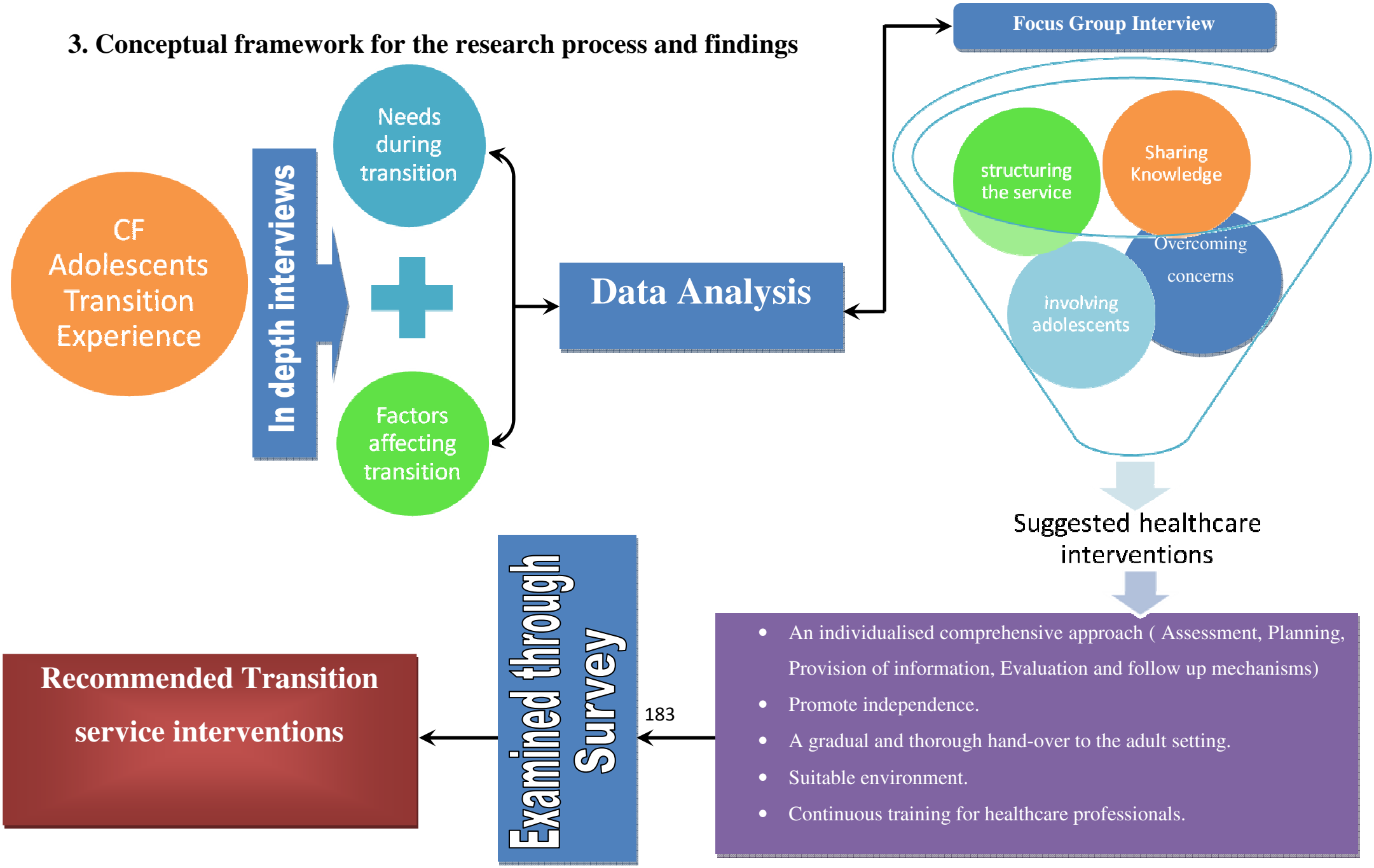
The calculation of the percentage score for the proposed transition interventions allowed the classification of these interventions based on a level of agreement between the service stakeholders on the importance and feasibility of these interventions. The results identified 36 items of the survey that were perceived as important or feasible by the majority of the survey participants. There were also items that were considered not important and/or feasible by either the healthcare professionals (n=11), or by the CF patients (n=3), or by both groups (n=4).

5.2.4 Phase two results summary

This chapter presented the results of the transition service guidelines questionnaire. Respondents agreed on the importance and feasibility of 36 interventions that cover nearly the different aspect of the transition service. These interventions considered highly important or important, and also as highly feasible or feasible for implementation in the clinical settings as part of the transition service.

There were 18 interventions in the survey that were considered not important and/or not feasible by the majority of participants in one or both groups.

3. Conceptual framework for the research process and findings



5.4 Overview of comparison of findings from interviews data and questionnaire data

Introduction

This chapter compares the findings of phase one of the study with the findings from phase two, and explores how the data in both phases confirms the overall findings. The two phases of the study were carried out sequentially, with the first qualitative phase shaping and informing the questions that were asked in the second survey phase. The questions within the survey were derived from the analysis of both the in-depth interviews and the focus group interviews, and the questionnaire was then administered to all CF transition service stakeholders in Ireland.

5.4.1 Comparisons of findings

The findings from both phases of the study will be presented below, and a comparison of data will be made. The comparison will be made using a table format to allow easier comparisons of the results from the different phases. The table is composed of three columns; the first column presents the findings from the first in-depth interviews, the second column presents the findings from the focus group interviews, and the last column presents the findings from the survey questionnaire.

Table 13- Comparing findings in phase one and two of the study

Theme 1: Amorphous service: Category 1: No structured transition service.		
In-depth interview	**Focus group interview**	**Quantitative survey**
Adolescents indicated that the transition interventions provided in the paediatric and the adult settings are currently incoherent and not comprehensive.	Healthcare professionals confirmed the need to use a systemic or structured approach that is divided into distinct phases and composed of particular specific interventions to guarantee the provision of a more comprehensive service.	The results of the survey indicated support from the transition stakeholders for the need for a structured approach to care.
Adolescents reported that the required support and skills needed for transition (like independence, self-management and decision-making skills) cannot be acquired through the current transition service.	The HCP group confirmed that the proposed systematic approach should provide adolescents with skills required for transition (like independence, self-management) and therefore should be a more co-ordinated service.	The need to restructure the service was reflected by high ratings for the majority of survey items and the survey in general.

Current interventions to address the transition were reported as very beneficial. However, they need further development and integration within a structured service.	The HCP in the focus group interview confirmed the need for restructuring the current service and developing a service that is tailored to every individual adolescent's unique situation and needs.	The considerable support indicated a need to develop the current service and incorporate the elements recommended in the survey to be part of the service provided for in the clinical setting.

Theme 1: Amorphous service: Category 2: adolescents and young adults… the need to be listened to and involved in care		
In-depth interview	**Focus group interview**	**Quantitative survey**
The healthcare professionals' practices and attitudes were key issues reported by CF adolescents. Some healthcare providers currently focus on finishing paperwork and carrying out routine clinic activities rather than focusing on the actual individual needs of the adolescent.	Healthcare professionals acknowledged and confirmed the need to move to an adolescent-oriented approach of care that attended adolescents' needs first before any other activities in the clinic. They stated it was important that adolescents were listened to and involved in their own care.	Participants in the questionnaire supported the previous need to focus on the CF adolescent and place his/her developmental requirements at the centre of the transition service. The positively-ranked proposed interventions were ones that assessed every individual adolescent's needs, and plan and evaluate achievements.
CF adolescents reported that healthcare professionals need to listen to them in order to provide more relevant care, and that appropriate communication styles need to be used.	Healthcare professionals reported the need to receive training in issues related to adolescents' developmental stages, and also on communication with adolescents and transition care in order to provide a more competent service.	The wider transition service stakeholders also confirmed these issues by positively ranking the proposed aspects of care that encourage adolescent-focused care, and also encouraging continuous training for healthcare professionals.

Adolescents in the in-depth interview reported the need to change the environment to one that suits their developmental stage and meets their needs.	In the focus group interview, healthcare professionals highlighted the importance of providing transition care in an adolescent-friendly environment that nurtures their growth and development.	The survey participants also positively ranked proposed aspects of care that propose the provision of care in a suitable environment for adolescents.

Theme 2: Preparing for transition Category 1: Sharing knowledge.		
In-depth interview	**Focus group interview**	**Quantitative survey**
The need for information was very prominent in reports from the adolescents. A considerable number of adolescents reported a lack of adequate information with regards to the different aspects of the transition process. This lack of information and understanding of the transition process contributed to additional distress experienced during their transition.	Healthcare professionals acknowledged that information was a need for adolescents and young adults and confirmed that it should be given extra prominence.	The importance of providing information with regard to care was again confirmed by the survey participants. The CF group voted for the provision of information as the most important aspect of transition care, while the HCP group deemed it the second most important aspect of care.
The CF adolescents in the in-depth interview reported the need for specific information that was relevant to their individual disease process and needs.	Healthcare professionals confirmed that information provision should be tailored to the needs of each adolescent or young adult. This information could help to remove ambiguity, decrease uncertainty, and empower the child and family and facilitate decision-making.	The survey participants stated there was a strong need to tailor the provision of information to the specific needs of adolescents. This was indicated by agreeing on the importance of assessing the CF adolescents' information needs, the different sources of information available, the adolescent's understanding of the transition process, his/her knowledge about adult CF

		centres, including the differences between the current setting and the adult setting, and finally, providing opportunities for adolescents to ask questions and share opinions
Adolescents reported that currently, information provision is carried out in the clinical setting where other tests and procedures take place, which distracted their attention.	Focus group interviews participants asserted that enough time should be provided for the process of information provision, and also suggested that this process should be carried out in an independent session for this purpose only where possible.	The survey participants considered the introduction of separate information clinics as important, despite relative difficulty in implementation within some settings.
CF adolescents reported varied unmet educational needs (e.g., with regard to relationships, independence, studies, etc.), this forced them to seek information from different sources, such as the internet, or relatives. These alternative sources, however, were often inadequate for their specific needs.	Focus group interview participants suggested the provision of information in variable formats and on different mediums such as printed material, specialised web sites, CDs, DVDs and games to maximise the adolescents' exposure to the different aspects of CF and transition.	Survey participants confirmed the importance of delivering information in clear language using appropriate formats and communication techniques for both adolescents and their families.

Theme 2: Preparing for transition: category 2: Easing the process of transition.		
In-depth interviews	**Focus group interview**	**Quantitative surveys**
The findings of the interviews demonstrated areas of distress and concern in relation to the transition process. Among these was the provision of care that disregarded the adolescent's needs, and dealt with their fears about the new adult setting, and fears about leaving the current familiar setting, and the possible differences in the quality of care.	Healthcare professionals in the group interviews related the negative psychological concerns with multiple gaps within the current transition service. They suggested the use of a systemic approach that included an assessment, planning, interventions, implementation, and evaluation elements as appropriate methods for addressing these different issues and decreasing the associated distress.	The CF patients confirmed the importance of the assessment, planning, and evaluation aspects of care. Study participants supported the importance of the majority of interventions proposed to address these domains of care.

The study showed that the participants who did not receive enough support in both settings experienced more distress and were also less satisfied with the care they were receiving.	Healthcare professionals proposed a systematic process to address all the issues that might impact on the adolescent's transition process, and thus provide adequate care and support. This would help alleviate distress and improve satisfaction.	
Some participants in this study who reported dissatisfaction with care also felt reluctant to attend clinics on a regular basis. Therefore, it appears to be important that healthcare professionals optimise this experience for their patients.	Healthcare professionals in the focus group interview reported that the systematic approach of care would improve satisfaction and therefore decrease this risk. They further suggested that follow up mechanisms should be introduced in both the children and the adult setting to ensure adequate clinic attendance for CF adolescents and young adults.	

5.4.2 Overview of data comparison

The previous table compared the main findings of the phases of the study. Both the qualitative and the quantitative phases of the study identified factors that affected the transition of CF adolescents from child to adult healthcare settings, as well as identifying their needs during this transition phase. These factors and needs were then addressed through healthcare interventions that were suggested by healthcare professionals in the focus group interviews stage. These were verified by transition service stakeholders. The results of the survey phase confirmed and agreed with the results of both the in-depth interviews and the focus group interviews in the first qualitative phase.

In the first qualitative phase, the results of the in-depth interview formulated the guide for the focus group interview, with issues raised in the former being discussed in the latter. The results of the focus group interview were used to formulate a transition service care guideline questionnaire, which was quantitatively verified by a larger group of CF service stakeholders. It was intended to explore their opinions about the importance and feasibility of the various intervention guidelines proposed within the survey.

Within the findings of the two phases of the study there were broad similarities and agreements that were identified. Both phases identified the importance of reorganising the transition service in a way that considered the different factors that affect the transition process as well as considering the needs of adolescents while they prepare for and carry out this process. Both phases revealed the dimensions of the transition process and the healthcare practices and interventions that might address these different dimensions. Finally, transition service stakeholders revealed their feelings about the relevancy and feasibility of these interventions.

The relationship between the results of the in-depth interview, the focus group interviews and the survey questionnaire was noted during the research process and highlighted in the previous table.

Chapter 6: Discussion of research findings

6.1 Introduction

This chapter presents a discussion of the research findings in the context of the current literature. The research study focused on CF adolescents' experiences and their reported needs during the transition from the child healthcare setting to the adult one. The study also looked at the views and experiences of healthcare professionals as service providers. This qualitative exploration informed the formulation of transition service guidelines, which were based on the consensus of transition service stakeholders who participated in the second quantitative phase of the study. Issues raised by this research are discussed, and the chapter concludes with presentation of recommendations for education, practice development and management. Finally, the limitations of this research are identified, along with future research directions.

6.2 Discussion

Utilising the phenomenological tradition during in-depth interviews with CF adolescents and young adults was of particular importance. It allowed deep navigation and thorough exploration of the multiple dimensions of the transition experience, as perceived by CF adolescents and young adults themselves. The identification of transition needs, and the factors that facilitate or hinder this process, consequently led to the identification and recommendation of a set of clinically relevant and feasible transition service interventions.

This study revealed that adolescents with CF have four main issues that arise during their transition from child to adult healthcare setting. These are addressed by the following needs.

1. The need for an organised and structured service.
2. The need for adequate information to be provided.
3. The need to refocus the transition service to put adolescents at its centre.

4. The need for reducing the negative psychological effects of this considerable change on the adolescent.

The findings of this study resonate with the findings of other studies about the transition experiences of children with CF and other chronic and life limiting illnesses (While, 2004; Reiss, 2005; Lotstein *et al*., 2008; Steinbeck *et al*., 2008; Tuchman *et al*., 2010; Towns and Bell, 2011). These studies indicate that, until recently, healthcare providers have failed to provide a competent transition service for children with chronic and life limiting illness that facilitates a smooth and managed transition to the adult service. The research also noted that healthcare practices and interventions in this area remain incoherent and fragmented, and that the need to develop the transition service was essential.

In their review for the current transition service for CF patients in Australia, Towns and Bell (2011) indicated that the service is a challenge to the healthcare system and should be approached and managed in a co-ordinated and well-planned way. The authors explained that the current service is still based on the practitioner's opinions and departmental resources, and lacks a holistic approach to the problem.

This was also an issue noted within this study, where healthcare professionals' views were influenced by the limited resources available for their departments. They noted that this had limited their ability to initiate change and improve their practices. This is especially true for the Department of Health and Children in Ireland, which has been severely affected by the current economic situation in the country.

Reflective of the Towns and Bell (2011) study, it is evident from the course of this research that the development of the desired transition service for adolescents with CF warrants further work from healthcare professionals involved in this field. More input is needed from them in the areas of decision making and service planning for the future. This was confirmed by the Tuchman *et al*. (2010) examination of the current transition service for adolescents with CF in the United States, and the Steinbeck *et al*. (2008) study that took place in

Australia. Their data indicate that transition remains an important topic within the CF community, and that the current service provision is variable; it lacks defined transition policies and procedures, there is a lack of formal links with adult services, and a lack of formalised guidance in this regard. Finally, there is also the problem of the continuous practice of transferring CF children based on age, without considering other developmental and psychosocial aspects.

The previous literature highlights an international failure to address transition care for CF, but this is even truer for the Irish case, where the country suffers the highest global incidence of the disease. The results of the study present similar data to the international literature about the failure of the healthcare system to provide adequate service for the CF patients in terms of access, links and guidance on transition, and in terms of tackling one of the main health challenges that the country faces.

It has been stated that there is an urgent need to develop the transition service for CF patients in Ireland, because the country has the highest incidence rate in the world. Further to that, the current CF service in general in Ireland – particularly during the transition phase – has been described as 'underdeveloped' by scientific research and media reports (Pollock 2005; RTE 2007, 2008). Further, the Health Service Executive as governing body has also reported that it is seeking to improve the currently provided service (Health Service Executive, 2009).

This study has shown that within the current service there are fragmented practices and a late start in terms of planning and preparation for the transition. These factors left adolescents lacking support, and put them under considerable pressure to make important decisions about their future treatment without being adequately prepared or informed. These findings are supported by the international literature, which reports adolescents as lacking the necessary tools to accomplish the transition process, such as adequate information (Ghosh *et al*., 1998; Nixon *et al*., 2003; Rutishauser *et al*., 2010). In this latter study, Rutishauser (2010) confirmed that anxiety and lack of information were the main barriers to transition, in addition to the lack of managed care planning.

6.2.1 Developing a structured transition programme

The literature on the transition process for patients with CF and other life limiting and chronic illnesses clearly indicates that the adolescents' experience in the transition to the adult clinic requires them to have the necessary independent, self-management and decision-making skills that enable them to navigate through the different aspects of the service. These skills in turn require a structured programme for transition in the paediatric setting that helps them achieve their objectives and acquire these skills (Meleis, 1991; Blum *et al*., 1993; McDonagh, 2005; Kralik *et al*., 2006; Tuchman *et al*., 2008; Meleis, 2010).

The findings of this study are in line with this evidence; however, it appears that such structured programmes do not currently exist in Ireland. Research literature reveals the incoherent nature of transition care that is currently employed in most clinical settings in Ireland and internationally (Lotstein *et al*., 2008; Steinbeck *et al*., 2008; Tuchman *et al*., 2010; Towns and Bell, 2011). In Ireland, this was evidenced by reports from most of the study's participants. On an international level, While *et al*., (2004) reviewed current transition practices in the UK and discussed some transition models that guided the transition interventions provided in the paediatric and the adult settings. Their study demonstrated that these models were limited because they appeared to focus on one aspect of care only.

Another example for the lack of structure in the transition service, is the qualitative study by Tuchman *et al*. (2008). Their study described expectations and concerns of American adolescents with chronic illness regarding transition from paediatric to adult care. Researchers reported a lack of any structured transition programme to guide the health professionals' care. The majority of participants in the study felt unprepared, and failed to complete the transition process. However, other participants in the study who participated in a more structured transition service felt more prepared, and completed the transition successfully. The study emphasised the importance of early engagement for all the transition process parties, especially the CF adolescents themselves. The study also focused on the need for a structured and systematic process that

planned for the necessary preparations, interventions, evaluation and follow up mechanisms that guarantee a managed and less stressful transition.

6.2.2 A systematic approach to transitional care service

In spite of the reported variability in provision of transition healthcare interventions, such interventions (for example, a tour of the adult hospital) were still welcomed by CF adolescents and young adults in this study, who perceived them as both helpful and beneficial. However, they also reported that it would be better to offer these interventions within a whole programme, which also addressed the other issues that adolescents encounter during their care in the hospital and during the transition. The absence of such a service could hinder adolescent engagement and progress in one or more ways. There is clear action that is needed from this study, which is that healthcare providers need to address a multiple dimensional approach to planning and managing transition care which balances practical, psychological and social transitions simultaneously.

Discussion in the focus group interviews between healthcare professionals regarding the most appropriate interventions to address the reported needs of adolescents focused on the use of a systemic or structured approach for the provision of the transition service. Such an approach, if divided into distinct phases composed of particular specific interventions, could guarantee the provision of a more comprehensive, predictable, and outcome-oriented approach.

This need for a structured transition service that follows a comprehensive approach for care concurs with the evidence in the literature (Nasr *et al*., 1992; Steinkamp *et al*., 2001; Tuchman *et al*., 2008). These studies suggested that when the transition service was provided as part of a proposed transition programme, it assisted the adolescents to complete the transition successfully, improved the service and was perceived positively from the patients through increased their sense of satisfaction.

The focus group interview participants explained that the approach would be comprehensive in the sense that most of the elements reported in the literature and reported by the adolescents and their families could be included in the

programme. It would also be predictable, in the sense that service users, in addition to the healthcare professionals, would be able to predict what the next steps in the service would be, and therefore what would be expected from them. Consequently, they could prepare themselves accordingly. Arising from the findings of this study, it is contended that such predictability in the approach might decrease the stress felt by adolescents and their parents that results from lack of information and an unexpected service.

6.2.3 Needs-based approach of transitional care

The focus group interview discussion also highlighted that the structure and organisation of the transition programme should always be based on the needs of the adolescent or young adult. This would make it more relevant and effective in terms of its efforts to achieve the desired outcomes for every patient based their individual needs, circumstances, culture, and other factors that might affect the transition process. The benefits of this needs-based approach to address the transition service has been confirmed by Rapley and Davidson (2009), who reported that healthcare professionals should change their philosophy of care provision to a one that supports the provision of a service that is based on their patients needs rather than on their diagnosis.

This need for organising and structuring the service based on individual patient's needs is equally evident within the literature (Gustafson *et al*., 2001; Roumie *et al*., 2011). The Gustafson *et al*. (2001) study suggests that some of the important aspects of care from the patient's point of view were missed or ignored, as healthcare professionals were using an assessment checklist or survey to measure the patient's satisfaction of care that did not match the actual needs of the patient. The study (Gustafson *et al*.2001) therefore recommended that effective assessment strategies for patients' needs are required to improve the current practices.

This notion supports the recommendations of this study for structured, adolescent-centred care within the proposed transition service guidelines. These approaches to care would focus more on the humanistic nature of the service, and thus improve treatment outcomes. This is achieved through focusing on patient

needs and designing the care around them, instead of focusing on a list of tasks and interventions that should be achieved during a particular clinic visit. This is in agreement with evidence in the literature (Dijkstra *et al*. 2006; Roumie *et al*. 2011),which reports that patient-centred care - which involves patients in planning, goal setting, problem solving and decision making - could enhance the patient adherence to treatment and improve health outcomes.

Although enthusiasm was evident from participants regarding the importance of the proposed transition service guidelines, this enthusiasm was sometimes affected by their expectations of possible barriers to putting these guidelines into practice. This was especially true of the healthcare professionals who were interviewed. These concerns were reflected by participants' lower scores for the feasibility of some of these proposed transition service guidelines. This is a result of the current financial difficulties that Ireland in general and the Irish healthcare system particularly are experiencing. This downturn in the current economic situation has impacted on the quality of service that is provided for patients in general across the country. This was of particular concern to the Cystic Fibrosis Association of Ireland, whose annual report (2009) expected and warned about the negative impact the continuous cutting of funding would have on the CF service, and the embargo on recruitment in health service sector (CFAI, 2009)

However, as this situation is expected to continue to affect all public health services for some years to come, healthcare professionals and service planners should stay committed to improving their service in order to achieve adolescents' aspirations in a better-structured transition service. All the concerns and difficulties that were raised by healthcare professionals need to be addressed, and in some cases it might be possible to suggest alternative interventions that require fewer resources but would achieve similar outcomes. For example, instead of redesigning the current clinic environment (which might be too focused on either children or adults) to suit the developmental needs of adolescents, an alternative might be to organise clinic appointments by grouping certain adolescents together on certain days where some environmental modifications can be carried out to make locations more adolescent appropriate.

6.2.4 Placing patients at the centre of service

The need to listen to adolescents and to focus on their needs and utilise appropriate communication styles were also considered essential parts of the service, especially during the transition process. Therefore, there is an urgent need to review and rearrange the current service, placing adolescents at the centre and providing a patient-oriented service rather than a task-oriented service. Such an approach of care ensures that adolescents are listened to, involved in their care, and encouraged to ask questions, express their opinions, and make decisions themselves. This kind of approach should promote independence and empower adolescents and improve transition outcomes and satisfaction.

This need for a more patient-focused approach was also reported in a study by Haughney *et al*. (2004). In this study, researchers explored asthma patients' understanding of their condition, and their preferences regarding the care provided to them. During the study 40 patients with mild to moderate asthma were interviewed to develop a questionnaire about the patient's attitudes toward asthma, perceptions about their treatment, perceptions about the review process, and finally, patient's preferences about treatment. The questionnaire then was distributed to a larger sample of asthma patients (517). The study showed that the majority of patients were disappointed with their asthma care, which they considered a routine functional interaction rather than something that focused on their condition and helped them get through it. A high percentage (80%) of patients in the same study reported that they had never been provided with a written, personal, asthma action plan, and more than half of them reported the need for more information.

However, without an adolescent-oriented environment, it is not easy to achieve the desired adolescent focused care (Soanes and Timmons, 2004; Zack *et al.*, 2003). Therefore, whenever possible, the care for these adolescents should be provided in an adolescent and young adult-friendly environment, which is directed to the needs of patients at this age, as well as their preferences and interests. This is in contrast to the current environments, which are either too

childish or too serious and adult-oriented. Where such changes to the physical environment are not possible, alternative measures should be considered to offer minimally accepted levels of environmental quality that are not hostile to this unique developmental stage.

In conclusion, healthcare professionals in the focus group interviews in this study confirmed the need for an adolescent-focused approach to care, despite the limited resources available to them within the current Irish healthcare system. Although they noted that limited resources might hamper the provision of the desired level of service, they supported the need to redesign the service in a way that ensures patients' needs and concerns are attended to first, before any other activities in the clinic.

6.2.5 Sharing knowledge and the need for information

The need for information was among the most prominent factors that adolescents reported during this study, an issue well supported in the literature (Westwood *et al*., 1999, Nixon *et al*., 2003, Farrant and Watson 2004, Gregory *et al*., 2007;Braithwait, 2011). Participants in the current study and in these previous studies were dissatisfied with the CF and transition service provided to them, especially in regard to the provision of information. They lacked basic information, such as who their healthcare providers would be in the future.

In this study, a number of adolescents reported a lack of adequate information with regards to the CF or the transition process. Most were concerned about this, and had neither gained understanding nor felt they had adequate information about the different aspects of this process. This confirms the results of the previously mentioned literature (Gregory *et al*., 2007; Nixon *et al*., 2003) that reported an inadequate information provision process and unmet education needs in the areas of self-management and future planning (Gregory *et al*., 2007), and the sexual information needs of CF adolescents and their parents (Nixon *et al*., 2003). In the context of this study, study participants attributed the flawed information provisioning process to factors such as the timing of information provision, the methods of conveying information, the setting where the information was provided, and finally, the content of the information. It was

evident that most of these components of the information provision process had not been carefully considered by healthcare professionals when performing such an important intervention. Currently, information provision is carried out in the clinical setting, where other tests and procedures take place, which distracted adolescents' attention. Furthermore, this process was not based on the actual information needs of CF adolescents, which made the information given to them less relevant.

The results of this study demonstrated that this inadequate process of exchanging information had a detrimental effect on other aspects of the whole transition process. The lack of information left adolescents unable to identify some key issues with regard to their care or the transition, and subsequently they experienced more distress. Furthermore, a lack of information compromised processes like developing independence, decision making and self management. The benefits of successful information exchanges with CF adolescents have been confirmed in a large study in the UK carried out by Abraham and Gardner (2009). The study was carried out to evaluate the benefits of programmes providing information for patients with chronic illnesses. The study illustrated that this process of teaching resulted in changes in self-efficacy, self-acceptance, health behaviours, and communication styles. The authors reported that at the end of the study there was evidence of greater knowledge among participants that boosted self-efficacy, and participants felt more knowledgeable regarding healthcare resources and more confident about discussing their illness with other health professionals.

To gain the benefits of information exchange and compensating for the current inadequate process, most participants in this study had independently sought information from different sources, such as the internet, or relatives. These sources were relatively beneficial and improved (to some extent) the adolescents' knowledge about their condition and the transition. But these alternative sources were often described by participants as inadequate, being too general and not fitting their individual needs, circumstances or disease progress.

One of these alternative measures or sources for information provision was investigated by Oliver *et al*. (2011). The study tried to identify whether providing illness-related information through libraries would improve participants' satisfaction in relation to the information provision aspect of their care. The study included patients with breast cancer and parents of infants in PICU, and showed that there was no significant difference in the satisfaction score between the control and the intervention group in patients with breast cancer. While parents with the infants in PICU reported more satisfaction scores in relation to information at the end of the study, the study highlighted that this alternative measure for providing information could not replace traditional routes of information exchange from healthcare professionals. This supports the assertion made by this study: that the exchange of information (1) on an individual basis, (2) through direct contact with healthcare professionals, and (3) in an appropriate setting is the most beneficial and the most favoured method of information exchange for adolescents with CF and their parents.

In this study, participants reported unmet educational needs that were varied, and included, for example, information on CF (e.g., symptoms, management, etc.), its effect on adolescents' lives and activities (e.g., relationships, independence, studies, etc.) and information regarding the transition and the new adult setting provided directly and orally from healthcare professionals. This reflects the need for providing more in this domain of the service, and for a more effective approach to information provision to replace the current system.

During the focus group interviews, healthcare professionals acknowledged that this element of care was a prominent need for adolescents, young adults, and their parents. To achieve the optimal and most efficient information exchange between healthcare professionals and CF patients and parents, healthcare professionals suggested that any information provision should be tailored to the needs of each adolescent or young adult. According to Jansen *et al*. (2008), tailored information or information of particular interest or relevance to the patient can be remembered and recalled more easily in contrast to irrelevant, generalised data. In the same study, the authors found that elderly cancer patients

can only recall a small amount of the data given to them about their chemotherapy and treatment by their nurses; however, the authors reported that relevant information could be stored and recalled more easily.

In addition, the same study by Jansen *et al*. (2008) also revealed that the provision of information should be carried out in an independent session for this purpose only. This is in contrast to the current Irish practice of providing information in the context of the regular clinics, which include other tests and procedures that may disturb this important intervention.

Healthcare professionals further highlighted that information delivered to both adolescents and their families should be delivered using an appropriate communication style and age-appropriate language. They explained that enough time for absorption should be allowed, as this could help to remove ambiguity, decrease uncertainty, empower the child and family, facilitate decision-making and clarify the future.

The provision of information in variable formats and on different mediums such as printed material, trusted websites, CDs, DVDs and games was also suggested to maximise the adolescents' exposure to the different aspects of CF. This is not intended to replace the direct face-to-face communication and exchange of information, but rather to complement and complete it.

The importance of providing information with regard to care was again confirmed by CF patients during the survey questionnaire, as they voted for the provision of information as the most important aspect of the transition care. This was followed by the "environment, training and gradual handover" aspect of care. The case for healthcare professionals was not very different, as they kept the provision of information aspect of care among their top two, but voted for the promotion of independence aspect as their top issue. This essentially represents an agreement between all the service stakeholders in considering the provision of information to be a highly important aspect of transition care.

Considering the level of importance attached to this aspect of care from both groups, this study calls a careful consideration of the factors that hamper its

application. Healthcare professionals, service planners and managers should address this aspect of care in a more competent way, despite the significant challenge in the clinical setting. To overcome the challenge facing the implementation of information provision as recommended within this study, some aspects of this intervention, such as the length of the information session and the frequency of this clinic, are all factors that can be adjusted to make the implementation of these proposed guidelines more feasible for within the current service resources.

6.2.6 Easing the transition process and mitigating the negative psychological effects of transition

The negative psychological effects of CF on adolescents are well documented in the literature. These negative effects can include stress, delayed achievement of developmental tasks, and so on, as evidenced in the studies of Thomas and Gaslin (2001), Moos (2002), Schmidt *et al*. (2003), and Michele and Sawyer (2005). What is equally important is how these negative effects might be complicated as a result of the transition to adulthood and to a new adult healthcare setting (Somerville, 1997; Watson, 2000; Kipps *et al*., 2002).

These studies show how an unplanned and unmanaged transition to the adult setting for children with congenital heart disease (Somerville, 1997), post transplant patients (Watson, 2000), or diabetes (Kipps *et al*., 2002) could be a threat to their wellbeing or even their life in some cases.

The findings of this CF study confirmed the findings of previous studies and demonstrated common areas of concern in relation to the transition to an adult setting. These concerns exacerbated the negative psychological symptoms associated with CF and contributed to a more stressful transition process. Among areas of concerns most often reported were the provision of care that was just oriented to either children or mature adults, disregarding the ‘in between’ adolescent developmental stage.

Adolescents mentioned factors that worried them, like: fear of risk of exposure to an infection in the new adult setting; leaving the current setting where healthcare

professionals were familiar with their illness and condition for a new setting in which they did not know the healthcare providers; possible differences in the quality of care; and differences in the new hospital policy. These all suggest that a stronger reciprocal relationship between the two healthcare settings would be helpful in maintaining trust and confidence in the transition service.

There were recent efforts in Ireland to improve the paediatric service for CF patients and those with other health conditions, by providing more appropriate care for different age groups, in one place, under the same guiding policy, and within a closer co-ordination and stronger reciprocal relationship. These aspects were all to be addressed by the building of a national hospital for children in Ireland. The proposal for the hospital was to co-locate the main children, adult and maternity hospitals in the same area, thus improving the transition experience of children to adult services, specifically those with CF. However, the hospital was never built, and so these benefits have not been realised. Thus the current in-adequate and underdeveloped service for CF patients remains, along with the failure of the health service to provide an improved setting where CF services can take place (Pollock, 2005; RTE, 2007, 2008; HSE, 2009).

These results correspond with the recent study by Rutishauser *et al*. (2010) noted earlier. This study reported the most common barriers that children with CF faced when transferring to the new adult setting were factors like anxiety through not knowing the providers, in addition to leaving familiar paediatric specialist, and finally a lack of information about the new healthcare setting.

It was evident in this study that the lack of adequate support for adolescents and young adults with CF in different aspects of care resulted in a less satisfying and potentially more distressing transition experience. Both the current study and evidence in the literature (Annunziato *et al*., 2007; Somerville, 1997; Watson, 2000; Kipps *et al*., 2002) suggest that extra distress imposed by a clinical transition may affect the young patients' compliance with treatments like physiotherapy, dietary regimens, and also affect their attendance for clinic appointments. Some participants in this study who reported dissatisfaction also reported that they sometimes felt reluctant to attend clinics on a regular basis or

adhere to their treatment plans as a result of this dissatisfaction and frustration of the service. Therefore, it appears to be important that healthcare professionals optimise this experience for their patients.

6.2.7 Addressing concerns

In the focus group interviews, healthcare professionals reported that most of these negative psychological concerns were a result of multiple flaws or defective practices within the current transition service, such as the current methods for providing information. Participants suggested that a multi-dimensional approach was needed to address the different factors that caused these negative effects. The most appropriate method for addressing these different issues from the healthcare professionals' point of view was to use a systemic approach that included assessment, planning, implementation, and evaluation elements, in addition to other need-specific interventions.

The effectiveness of using the systematic care approach in the transition service was supported in the study carried out by Vanhaecht *et al*. (2009) to assess whether care processes organised in systematic clinical pathways are more effective than non organised care. The study carried out in Belgium and Germany used a cross-sectional approach in multiple centres and involved 309 healthcare workers, 103 care processes and 49 hospitals. During the study, the care processes in the participating hospitals were evaluated using the "Care Process Self Evaluation Tool" to look at the presence of patient-focused organisations, the co-ordination of care, communication with patients and family, collaboration with primary care providers, and finally, the presence of follow-up mechanisms for care. The study highlighted that the organisation of care in systematic clinical care pathways has a significant impact on the co-ordination of care and a positive impact on the organisation of care provided in the clinical setting.

The outcome of the activities in the proposed approach would inform or trigger specific healthcare interventions that treat the underlying factors of these psychological symptoms of the transition process. Within this study, the suggested multi-dimensional approach for care included assessment elements,

planning elements, an evaluation element, an environment element, and knowledge elements.

The initial assessment process includes gathering information from CF adolescents with regard to areas that concern them in the service, their needs (which, if not met, might have negative consequences), or, finally, areas within their environment that might impact their care and cause potential negative consequences. Among these issues (that can be detected in the assessment phase) is the adolescents' knowledge regarding the timing for the transition, the transition process, the available adult CF centres and the differences between these settings in terms of the services provided in each one.

Other areas that were reported for assessment were: the availability of family support; the adolescents' need for additional resources (e.g., additional funds, assistance etc.) that help during transition; the impact of other transitions currently taking place (e.g., moving to an independent house, starting work, starting relationship, new health complication, a change in treatment, undergoing surgery, etc.); the presence of any specific cultural needs; and finally, assessing the effects of the change of treatment setting on the adolescent (e.g., their experience of new policies, practices or routines as a result of the move to a new healthcare setting).

A number of concerns raised by adolescents and their parents may occur through ignoring one of these important issues regarding the progress of the transition process, or by a lack of knowledge as indicated earlier in this section. In contrast, a good assessment for such issues can provide healthcare workers with a database for potential targets that, if addressed, might treat the majority of the concerns that have been listed. This was confirmed in studies mentioned earlier in this section (Gustafson *et al*., 2001; Roumie *et al*., 2011), which indicated that ignoring patients' needs (or inadequately assessing them) might lead to dropping some healthcare interventions that are considered important for patients or their families.

The Roumie *et al*. (2011) study also showed that involving patients in planning their care, goal setting, problem solving and decision making could enhance patient adherence to treatment and improve health outcomes. Reflecting on this finding by Roumie *et al*. (2011), this study also supports the assertions made, and further asserts that the planning process is especially important, as it determines care pathways in the future, thus making the service and the patient journey throughout their care more predictable and less stressful.

This is in keeping with the joint report by the Royal College of General Practitioners in London, Royal College of Physicians of London, and the NHS Alliance (2004).The report stated that patients with chronic illnesses should be involved in their care and enabled to manage their own chronic conditions, and should be encouraged to make positive choices about their lives and how they will live them (RCGP, 2004). The position of this study is clear in indicating the importance of involving adolescents and young adults in the management of their care and the decision making process about the various treatment options. This was supported by the Department of Health and Children in their Policy Framework for managing chronic diseases (2008). The report indicated that patient participation in managing their condition has been demonstrated to improve health outcomes. The report further indicated the need to develop an education programme specific to each chronic illness. Such programmes will include all the skills required for self-monitoring and self-treatment.

Following the assessment of a patient's needs (ideally involving all the participating parties), the planning process would then follow. This phase is especially important as the different interventions proposed in the plan will establish most of the future care. This process of planning was endorsed by the Department of Health and Children in Ireland in their report about managing chronic illnesses (2008), where they stated the planning was a principle that should guide the management of chronic illness. Internationally, this was reflected in the position statement of the American Academy of Paediatrics, American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine (2002). Within the statement, the

involved associations asserted that a written healthcare transition plan should be prepared for each adolescent and young adult with a chronic and life limiting condition. They stated that the plan should be formulated in collaboration with the young person and their family, and should include at a minimum, the care that needs to be provided, details of the person/s providing this care, along with planning about how the care would be funded. According to the same statement, this plan should be reviewed and updated annually, and especially during the transition process.

In line with this Irish and international guidelines, the results of this study stressed the need for a care plan to be agreed between healthcare professionals and the CF adolescents and their parents. This plan should be agreed early during care, and the implementation of the agreed plan should be followed up by evaluation procedures to make sure that the desired outcomes were achieved. The specific components of each plan should be established based on the previously assessed areas, and should include, where relevant and possible, dates and timelines for guiding the implementation of these interventions from the relevant person/s.

In the UK, the ACT[1] association is a well established organisation concerned with the provision of high quality care for life-limited and life-threatened children, and young people. They published a report about transition care (ACT, 2007) that stressed the importance of formulating a transition plan, in addition to carrying out continuous planning activities throughout the service. The association further highlighted that the transition plan should be person centred, and should contain the adolescent/young adult's wishes and future plans.

Evaluation is the final component of the process, which should complement the previous assessment and planning phases. Evaluation interventions as evident in this study would help assure that the needs of patients and their care objectives are met and achieved. Furthermore, such interventions should be carried out regularly (not only at the end of care) as they might inform the planning of further interventions.

[1] ACT recently changed it's name to "Together for Short Lives"

On an international level, the results of the Fletcher-Johnston *et al*. (2011) study reported that identifying mechanisms or interventions to evaluate transition service outcomes was the second most important aspect of the service as rated by participating clinicians. Within this study, the researcher used a Delphi technique in which 32 clinicians completed at least one of the three phases of the process, to identify the clinician's perceptions about important aspects of the transition service for adolescents with chronic conditions to inform research activities in Canada.

Again, this is in agreement with the Irish Department of Health and children's recommendations (2008) about managing chronic illness. Their report emphasised the importance of establishing evaluation interventions, and monitoring and quality assurance mechanisms that measure the effectiveness of any care interventions.

6.2.8 Training for healthcare professionals

It was evident in the course of this study that there is a problem in the lack of training for healthcare professionals in issues related to the nature of the adolescence developmental stage. This is supported by the international literature (Veit *et al*., 1995; McDonagh *et al*., 2006). Within this study, the interpersonal characteristics of healthcare professionals and their practices and attitudes were key issues reported by some adolescents as more important for the majority of them than other service aspects. The focus of some healthcare providers on finishing paperwork and carrying out routine clinic activities, rather than focusing on the actual individual needs of the adolescent, were reported as significant sources of frustration and dissatisfaction with the service.

To provide a competent and adolescent-friendly service, it is crucial that healthcare professionals understand the nature of adolescence and then intervene and communicate accordingly, whether with regard to illness-related issues or issues in the wider social context. This is something that was of interest to some participants, who explained how the use of inappropriate words and communication styles caused them a lot of stress and anxiety.

This was also asserted by studies in the literature, which reported on the presence of unmet training needs among healthcare professionals regarding issues related to the needs of adolescence and its developmental stages (Veit *et al*., 1995; McDonagh *et al*., 2004; McDonagh *et al*., 2006). Similarly, Trummer *et al*. (2006) argued that effective communication and interaction can lead to a better exchange of information, and consequently, a more effective care. This was highlighted in their study, which aimed to examine whether an improved communication to empower patients could improve clinical outcomes and improve patient recovery after surgery. The results of the study demonstrated a decreased length of hospital stay, a decreased incidence of post-surgery tachyarrhythmia (reduced by15%), faster discharge from intensive care and higher patient satisfaction ratings for the communication and quality of care provided by healthcare professionals.

Finally, training healthcare professionals who are involved in the care of adolescents with regard to issues specific to adolescents' developmental stages (e.g., communication skills, developmental needs, care during transitional period, sexual health, etc.) was perceived as an issue of high importance by both CF patients and healthcare professionals in the transition service. They also agreed on the feasibility of this issue in the clinical setting.

6.2.9 The need for guidelines to improve the transition service

It is evident in this study, that the development of transition care practice requires the introduction of practice guidelines. Such guidelines are capable of bridging the gap between the available evidence in the literature and healthcare professionals practice in the clinical setting. It was noted, that despite the availability of international literature regarding the reported needs of adolescents with CF and other life limiting and chronic health care illnesses, the actual transition care provided in the clinical setting fails to meet these needs and requires further improvement.

The findings of this study are in agreement with the literature (Bero et al., 1998; Grimshaw *et al.*, 2006) emphasizing that the provision of information only to

health care professionals about patients needs is not necessarily sufficient to warrant or stimulate change by itself (Bero et al., 1998). However, it is increasingly evident that developing and adopting clinical practice guidelines is more beneficial and efficient (Grimshaw *et al.*, 2006). In the study by Grimshaw *et al.*, (2006), the authors aim was to determine the effectiveness and cost difference of the implementation of clinical guidelines through different strategies. After reviewing 235 studies, that evaluate the results of implementing particular health service guidelines, the authors found that the majority (86.6%) of the reviewed studies reported an improvement in care outcomes. The studies further suggest that the implementation of clinical guidelines can promote compliance with recommended practices.

Therefore, the main goal of the current study was to develop practice guidelines for transition care, aiming to improve transition care in Ireland and internationally by bridging the gap between the needs of CF adolescents and the actual service provided for them. These best practice guidelines and study recommendations for an improved transition service are presented in the next section.

Chapter 7: Study recommendations and transition service guidelines

7.1 Study recommendations

This section will present the recommendations of this study, which cover the main characteristics and components of the recommended transition service. These will be followed by the presentation of guidelines for healthcare professionals working in the transition service.

The mixed methodology used in this study allowed the inclusion of all stakeholders within the transition service. The first part of the study allowed for detailed understanding of the perspectives of adolescents and young adults with CF, and what they thought about the current state of the transition service. This part of the study also investigated their needs during the preparation for and throughout the transition process, and the factors that affected this process. The first qualitative phase also included consulting healthcare professionals, who were asked about their suggested interventions for addressing the reported needs of the adolescents with CF. The deep understanding achieved in the first qualitative phase was further expanded through the inclusion of a larger number of healthcare professionals, who participated in the evaluation of the suggested transition service interventions and marked them on importance and feasibility.

This thorough and comprehensive approach allowed the identification of main transition service components that are capable of improving the transition service. These components are vital, as the need for them was derived directly from those who have experienced the transition service as users and providers of the service.

The conclusions of this study were derived from and based on considerable amount of data. This was shaped into four main components that are recommended to shape the transition service. These are as follows.

First, the provision of the transition service in a comprehensive, systematic and organised approach of care composed of distinct phases that contain specific interventions.

Such an approach was supported by a wide range of transition service stakeholders who participated in this study. This recommended approach of care would aid the provision of a more comprehensive and coherent care, that would provide adolescents with CF the required support and skills needed for transition.

Second, there is a persistent need to move to an adolescent-oriented approach of care that attends adolescents needs first, before any other activities in the clinic.

This approach needs to attend to adolescents in a way that provides relevant care through listening to their needs and opinions, and also by involving them in their own care. This adolescent oriented approach requires competent healthcare professionals who are trained in adolescent specific care, so there should be a process of continuous training and development for these professionals. Finally, the adolescent oriented approach requires the provision of transition care in an adolescent friendly environment that nurtures the growth of adolescents, and helps them develop while also contributing toward a more successful transition.

Third, the recommended transition service should encourage and enhance the process of exchanging information.

This study acknowledged that this element of care is a prominent need for adolescents and young adults with CF before, during and after the transition process. It is especially important to ensure that the information provided (and the mode of provision) is suitable for the needs of the adolescent and their developmental stage. It should be tailored to the specific needs of each adolescent or young adult.

If this process was carried out in an independent session, it would be vital to adopt an appropriate communication style and age-appropriate language, and provide information in a variety of formats to maximise the benefits (such as printed material, websites, CDs, DVDs or games).

Fourth, The transition service should address the different areas of concern experienced by adolescents with CF and treat them with effective care interventions.

It was evident from this study that the negative psychological effects of CF on adolescents were complicated as a result of the transition to adulthood and to a new adult healthcare setting. These could be concerns addressing adolescence-specific needs, or the fear of risk of exposure to an infection in the new adult setting, or leaving the current familiar setting, or possible differences in the quality of care. It is worth highlighting that this is a highly important issue, as the study demonstrated that adolescents with CF who did not receive enough support in both settings experienced more distress, were less satisfied with the care they were receiving, and felt reluctant to attend clinics on a regular basis. Healthcare professionals in the focus group interview related the negative psychological concerns with multiple gaps within the current transition service. They suggested the use of a systemic approach - that included assessments, planning, interventions, implementation, and evaluation elements - as an appropriate method for addressing these different issues, thus decreasing the associated distress.

Next section present the study recommended guidelines for the transition service as concluded by this study. These proposed guidelines are based on implementing an assessment, planning, intervention, and evaluation process to address the multiple needs and concerns of the adolescents with CF. As explained earlier, the assessment process would gather information from adolescents with regard to areas that concerned them in the service, or their needs, or, finally, areas within their environment that might impact their care and cause potential negative consequences. The planning phase would then propose interventions that target the previously assessed areas. This plan would be then implemented and evaluated through proper procedures to make sure that the desired outcomes were achieved.

7.2 Guidelines for the transition service for healthcare professionals.

Assess

- assess the impact of adolescent development to adulthood *(e.g. moving to an independent house, starting work, starting relationship, etc)* on the transition to the adult CF hospital.
- assess the adolescent's understanding of the timing of the transition
- assess the adolescent's understanding of the adult CF centres that are available for him/her to transfer to

Assess

- assess the adolescent's understanding of what is required from him/her during the transition process
- assess the adolescent's understanding of the differences in terms of care between their current setting and the adult setting
- assess the types of information that the adolescent and their family would like to receive more of during the preparation for the transition, the actual transition and after the transition

Assess

- assess the availability of family support for the adolescent during the preparation for transition and the actual transition
- assess the sources of information about CF and CF centres that are available to the adolescent and his/her family during course of treatment and preparation for transition
- assess the impact of other major events *(e.g. starting or finishing college or a course, or being discharged or admitted for treatment)* that are taking place on the transition to the adult CF hospital

Assess	Assess	Assess
• assess whether other health-related events *(e.g. a new diagnosis of another health problem, another complication within the current illness, a change in treatment options, undergoing surgery, etc.)*will affect preparation for transition to the adult CF hospital • in the adult setting, assess the effects of the change of treatment setting on the adolescent *(e.g. their experience of new policies, practices or routines as a result of the move to a new organisation)* • assess whether there are any specific cultural needs to be considered during the adolescent's preparation for transition	• assess the adolescent's social status, which may impact on the transition or the preparation for the transition *(e.g. separated parents, single parent, guardians, etc.)* • assess whether or not the adolescent has another physical disability that means they require special assistance *(e.g. home visit, available support during visit, etc)* • assess whether the adolescent has another sibling with CF, which might require a special arrangement with the clinic *(early clinic, same day clinic for both sibling, co-ordinating appointment dates if siblings are attending different clinics)*	• assess whether the adolescent has another chronic illness that might mean that they require special assistance *(multi-speciality meetings, co-ordinated tests and clinic dates, etc)*

Planning	Planning	Evaluation
• Planning for the transition should involve the adolescent and their family working with the healthcare professionals • The plan for the future should guide healthcare interventions, in order to make these interventions more relevant and more effective	• The plan for the future should incorporate the adolescent's wishes and needs *(e.g. educational needs, possible work, choice of adult care facility, what is important to the adolescent, etc.)* • Where possible, the plan for the future should contain dates and timelines in order to achieve the agreed-upon tasks and activities	• observe the adolescent's gradual progress in acquiring the communication skills necessary for dealing with healthcare professionals • observe the gradual increase in the adolescent knowledge of CF *(e.g. symptoms, treatment, etc.)*

Evaluation	Evaluation	Evaluation
• seek feedback from the adolescent/young adult, their family and other healthcare professionals about the adolescent/young adult's participation in care • seek feedback from the adolescent/young adult, their family and other healthcare professionals about the adolescent's achievement of the planned objectives	• continuously evaluate the adolescent/young adult's abilities to manage his/her own care, and master all that is required from him/her to the level of competent self-care. • evaluate whether the young adult feels settled in their new adult-focused setting	• in the adult setting, evaluate whether the young adult is achieving a satisfactory attendance rate at the clinic

Information Provision

- Information provided for adolescents during the preparation for transition should be appropriate for their developmental stage
- Information provided during the preparation for transition should be tailored to every individual adolescent's needs

Information Provision

- Information provided for adolescents during the preparation for transition should be delivered using age-appropriate communication techniques
- Information provided for adolescents during the preparation for transition should be provided to both the adolescent and their family

Information Provision

- Helpful written material should be conveyed in a way that is understandable for both the adolescents and their parents

Promot independence

- Throughout their time in care, healthcare professionals should empower adolescents/young adults and promote their independence using various strategies *(e.g. providing information, considering their opinions, etc)*
- Throughout the preparation for transition, adolescents should be listened to, involved and encouraged to ask questions, express their opinions and make decisions

Follow-up mechanisms

- Follow-up mechanisms that are agreed upon between both the children and adult settings should be used to ensure safe post-transition period

Training of healthcare professionals

- Healthcare professionals who are involved in the care of adolescents should receive training on issues specific to adolescent developmental stages *(e.g. communication skills, developmental needs, care during transitional period, sexual health, etc)*

7.3 Study originality and contribution to knowledge

This study has contributed to the current knowledge about the transition service on the national Irish level and on an international level.

In Ireland,

1. This study is the first study in Ireland that addresses the transition of adolescents with CF in particular and life-limiting and chronic illnesses in general, from children to the adult health care setting. It identified the current state of the transition service for adolescents and young adults with CF in Ireland.

2. This study has explored the current service provided for adolescents and young adults with CF, in particular during the transition process. It identified the needs of adolescents and young adults with CF during their preparation for the transition process, their needs while they are carrying out this process, and their needs while they are settling into their new setting.

3. The study identified the factors that facilitate or hinder the transition process as they are reported from those who have experienced this process.

4. Finally the study developed a set of agreed CF transition service elements that were systematically developed and agreed by CF transition service stakeholders.

Despite its importance for the treatment outcomes for adolescents and young adults with CF, this area of research has not been scientifically studied before in Ireland.

On an international level,

1. This study has developed the current knowledge about transition. It has shifted the focus on transition research from being just centred on the needs of adolescents and young adults with CF, or on the factors that affected the transition process, to a different level that addresses those needs and provides a clinically competent and feasible set of interventions that address the different aspects of this process in a coordinated and comprehensive

approach. These proposed interventions can help patients manage this process with minimal negative effects on their health.

2. Ireland has the highest incidence of CF in the world; the results and recommendation of this study have the potential to demonstrate leadership in the promotion of best practice for adolescents making the transition to adult-care services.

3. Finally, the methodology used in this study may be of relevance to services where children with other life-limiting conditions may need referral to an adult care pathway at some point in their lives.

7.4 Implications for practice and service planning

The findings of this study inform the clinical practice of health care professionals both in Ireland, and in the international context, through a focus on embedding the voiced needs of young adults into service delivery to provide more relevant and effective care for CF young adults during transition.

This study addresses the transition process using a comprehensive, organized and systematic approach – such an approach should help ensure that a competent transition service is provided. To ensure that they provide a relevant and comprehensive service to their CF patients, health care professionals and policymakers should focus on the implementation of systematic and person-centred transition service guidelines.

This study can also inform the practices of health care professionals working with young adults with other life limiting and chronic illness, whose needs might be similar to those of young adults with CF.

Health care managers and policy makers who are in charge of decision making and service planning in the clinical setting can use the findings of this study to plan their transition service, and for the optimal development of the desired transition service guidelines and standards of clinical care.

7.5 Dissemination of study findings

The findings of this study will be disseminated to health care professionals in the clinical setting in order to improve practice. The results and findings of this study will be presented at relevant scientific conferences, discussed with healthcare professionals in group meetings and presentations in CF settings from all over Ireland. The results will also be sent to relevant governmental and voluntary health organisations to be disseminated to its members, and, finally, the results of this study will be published in relevant peer-reviewed medical and nursing journals. In relation to the latter, two scientific papers have already been published and an additional one submitted for consideration. The published articles provide useful information about the needs of CF adolescents and young adults during the transition process and the factors that affect their transition. They also provide methodological information for health researchers who intend to carry out research studies with similar participants.

7.6 Future research

This study highlighted the importance of consulting young adults with life limiting and chronic illnesses (service users) to uncover the elements of the transition service as expressed by those who have experienced it. This consultative approach is highly recommended for any future research as it would make the research outcomes more relevant and effective by taking into consideration individual patient needs.

Further research will be needed in relation to the transition service, and such research should be focused on those studies with clinically applicable recommendations and results. In addition, new studies should focus on implementing the transition service interventions identified in this research study; these studies should evaluate the outcomes of implementing or adopting these service interventions or guidelines in the clinical setting.

7.7 Limitations of research

This section identifies some limitations within the study. A critique of methodological approaches and a review of the study rigour have already presented

in earlier chapters. This section will consider the limitations imposed by the research design, and any potential weaknesses are discussed.

7.7.1 Methodological issues

This research explored the perceptions of the transition service stakeholders in order to recommend best practice guidelines. This was achieved through the use of a mixed method design. While this methodology is gaining increasing support (Dzurec and Abraham, 1993; Sandelowski, 2000; Kelle, 2001; Creswell, 2009; Morse and Niehaus, 2009), it has also received criticism from opponents due to many issues (Moccia, 1988). One of these issues is the complications of using different and conflicting methodologies within one study – methodologies that are underpinned by different philosophical assumptions. Some researchers (e.g. Moccia, 1988) argue that such methodologies cannot, and should not be mixed in a single study. This stance was refuted by other researchers, who have insisted that rigour should judge research quality rather than adhering to only one single philosophy (Green, 2008).

The research framework used in this study draws on the pragmatic paradigm, which supports the use of mixed method research, paying extra attention to ensuring rigour in each phase of the study. Within this study, the rationale for using the mixed method approach was explicitly explained, along with a clear description of how the data was triangulated and analysed during the course of the study.

7.7.2 Methods issues

There was only time to conduct one interview per participant, which may have affected the quality of data obtained. During this short time, there may not have been the chance to develop the trust relationship fully in a way to allow the study participants to share their experiences. Measures were taken to reduce the possibility of this, and these were highlighted in the research framework and methods chapters. The research acknowledges that conducting more than one interview per participant could improve the interview data; however, this was not possible for this study due to time and cost constraints.

Within the focus group interviews, the participation of healthcare professionals who worked in the same department may have posed a challenge in engaging participants

in the discussion about practices that might be related to their own departments. The presence of healthcare professionals from different specialities (nurses, dieticians, paediatricians) may have added to the challenge. Different measures were taken to decrease this effect, and these methods were highlighted in the research framework and the methods section. They included the use of notes written anonymously by participants to initiate discussion, rather than asking participant to publicly voice issues.

Finally, the small population size might also have affected the study data. Total population sampling was used to overcome this issue, and different strategies were used to enhance the response rate. The researcher acknowledges that a larger sample size would have improved the generalisability of the study results.

7.8 Study conclusion

This thesis presented the findings of a two phased research study, carried out to address specific research objectives. A mixed method sequential exploratory design was used. Interview and focus group data were gathered in phase one, and were used to inform the development of a survey questionnaire. The findings of the study provided healthcare professionals with a relevant and feasible set of guidelines that can guide their service while caring for adolescents with CF during their transition from a child healthcare setting to an adult one. The transition service guidelines that were proposed during the course of this study are applicable to all CF clinical settings in Ireland.

Adolescents and young adults with CF reported their needs during the transition process, as well as the factors that affected this process. The healthcare professionals acknowledged these issues and reported the need to follow a more comprehensive and systematic service that was tailored to the needs of individual patients. The findings of this study propose the main components of the transition service, and should be considered as part of any transition service for CF patients.

References:

Abdale, B., Kuhl, K. &Tullis, D. (1994) Evaluation of patient satisfaction with the transition from a pediatric hospital to an adult centre. *Poster Session Abstracts from the Cystic Fibrosis Conference*, 1994, 291 – 292

Abrahama, C. & Gardner, B. (2009) What psychological and behaviour changes are initiated by 'expert patient' training and what training techniques are most helpful?.*Psychology and Health,* 24 (10), 1153–1165

ACT (2007) *The transition care pathway*. Bristol, UK

ACT (2012) *Categories of life-limiting and life-threatening conditions*, [online] 20/09/2012 http://www.act.org.uk/page.asp?section=164&sectionTitle=Categories+of+life-limiting+and+life-threatening+conditions

Adam, G., Montemayor, R. & Gullota, T. (1996) *Psychosocial development during adolescence: progress in developmental contextualism*. Thousand Oaks, CA, Sage

Adami, M. & Kiger, A. (2005) The use of triangulation for completeness purposes. *Nurse Researcher,* 12 (4), 19-29

Adlersberg, M. & Thorne, S. (1990) Emerging from the chrysalis: Older widows in transition. *Journal of Gerontological Nursing,* 16 (1), 4-8

Alderson, P. (1995) *Listening to children. Children, ethics and social research*. London, Barnardos

Altman, D. G. (1991) *Practical Statistics for Medical Research*. London, Chapman & Hall

Al-Yateem, N. (2012) The effect of interview recording on quality of data obtained: a methodological reflection. *Nurse Researcher*. 19 (4), 31-35

American Academy of Pediatrics, American Academy of Family Physicians & American College of Physicians-American Society of Internal Medicine (2002) A

Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs, *Pediatrics*, 110 (6), 1304

American Psychological Association (APA)(1985) *Standards for educational and psychological testing*. Washington DC, APA

Annunziato, R. A., Emre, S., Shneider, B., Barton, C., Dugan, C. A., & Shemesh, E. (2007) Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. *Pediatric Transplantation,* 11, 608–614

Arnett, J. J. (2000) Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist,* 5 (55), 469–80

Atkin, K. & Ahmad, W. (2001) Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science & Medicine,* 53, 615–626.

Atkinson, I. (2008) Descriptive Statistics, in McKenna, H., Cowman, S. &Keady, J. (2008) *Nursing Research Designs and Methods*, Churchhill Livingston Elseveir, Philadelphia PA

Baillie, L. (1995) Ethnography and nursing research: critical appraisal. *Nurse Researcher,* 3 (2), 5-21

Bailey, P. H. (1997) Finding your way around qualitative methods in nursing research. *Journal of Advanced Nursing,* 25, 18-22

Beresford, B. (1997) *Personal Accounts: Involving Disabled Children in Research.* New York, Social Policy Research Unit

Bero, L. A. Grilli, R., Grimshaw, J. M., Harvey, E., Oxman A. D. and Thomson, M. A. (1998) Getting Research Findings into Practice: Closing the Gap between Research and Practice: An Overview of Systematic Reviews of Interventions to Promote the Implementation of Research Findings, *British Medical Journal*, 317(7156), 465-468

Bjorklund, R. (2009). *Cystic fibrosis*. New York, Marshall Cavendish Benchmark.

Black, T. R. (1999) *Doing quantitative research in the social sciences: an integrated approach to research design, measurement and statistics*. London, Sage Publications

Bloom, K. & Trice, L. (2010) Sampling, in Boswell, K. & Cannon, S. (2010) *Introduction to Nursing Research: Incorporating Evidence Based Practice*. 2nd ed. London, Jones and Bartlett Publishers

Blum, R.W.M., Garell, D., Hodgman, C.H., Jorissen, T.W., Okinow, N.A., Orr, D.P., Slap, G.B. (1993) Transition from child-centered to adult health-care systems for adolescents with chronic conditions: A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health,* 14 (7), 570-576

Botti, M. &Endacott, R. (2005) Clinical research 5: Quantitative data collection and analysis. *Intensive and Critical Care Nursing,* 21, 187-193

Boyd O. C. (2001) Phenomenology The method. in: Munhal, P. (2001) *Nursing Research. A Qualitative Perspective,* 3d ed. Jones and Bartlett, Sudberry, MA

British Psychological Society (1991) *Code of Conduct, Ethical Principles and Guidelines*. London

Bridges, W. (1980) *Transitions: making sense of life's changes, Reading*. MA: Addison-Wesley

Bridges, W. (1986) Managing organizational transitions. *Organizational Dynamics,* 14, 24-33

Braithwaite, M., Philip, J., Tranberg, H., Finlayson, F., Gold, M., Kotsimbos, T. & Wilson, J. (2011) End of life care in CF: Patients, families and staff experiences and unmet needs. *Journal of Cystic Fibrosis,* 10 (4), 253-257

Brown, S., Teufel, J., Birch, D. & Kancherla, V. (2006) Gender, age and behavior differences in early adolescent worry. *Journal of School Health,* 76, 430–437

Britto, M.T., Garrett, J.M., Dugliss, M.A., Daeschner, C.W., Johnson, C.A., Leigh, M.W., Majure, J.M., Schultz, W.H. & Konrad, T.R. (1998) Risky behavior in teens

with cystic fibrosis or sickle cell disease: a multicenter study. *Pediatrics,* 101 (2), 250-6

Brumfield, K. & Lansbury, G. (2004) Experiences of adolescents with cystic fibrosis during their transitions from paediatric to adult health care: a qualitative study of young Australian adults. *Disability and Rehabilitation,* 26, 223-234

Bruce, J. C., Langley, G. C. & Tjale, A. A. (2008) *The use of experts and their judgments in nursing research: an overview*. Curationis, 31(4), 57-61

Burns, N. & Grove, S. (2005) *the practice of nursing research: conduct, critique and utilization*. Missouri, Elsevier Saundars

Burns, N. & Grove, S. K. (2009) *The practice of nursing research: appraisal, synthesis, and generation of evidence*. St. Louis, Mo, Saunders Elsevier

Carey, M.A. (1995) Comments concerns in the analysis of focus group data. *Qualitative Health Research,* 5, 487-495

Catanzaro, M. (1990) Transition in midlife adults with long-term illnesses. *Holistic Nursing practice,* 4 (3), 65-73

Charmaz, K. (2006) *Constructing Grounded Theory: A Practical Guide Through Qualitative Analysis*. Thousand Oaks CA, Sage Publications

Chaudhry, S. R., Keaton, M. and Nasr, S. Z. (2012), Evaluation of a cystic fibrosis transition program from pediatric to adult care. Pediatric Pulmonology. doi: 10.1002/ppul.22647

Chick, N. & Meleis, A.I. (1986) Transitions: A nursing concern. In Chinn, P. L. (Ed.) *Nursing research methodology: Issues and implementation*. Rockville, MD: Aspen

Christie, D. & Viner, R.M. (2005) ABC of adolescence: adolescent development. *British Medical Journal,* 330 (5), 301–304

Christensen, P. & James, A. (2000) *Research with Children: Perspectives and Practices*. London, Routledge

Clark, A. M. (1998) The qualitative-quantitative debate: moving from positivism and confrontation to post-positivism and reconciliation. *Journal of Advanced Nursing,* 27 (6), 1242-1249

Coffey, A. & Atkinson, P. (1996) *Making sense of qualitative data: complementary research strategies*. Thousand Oaks CA, Sage publications

Colaizzi, P. F. (1978) Psychology research as the phenomenologist views it. In Valle, R. S. & Kings, M. (Eds) *Existential phenomenological alternatives for psychology.* New York, Oxford university press

Coleman, E. A., Smith, J. D., Frank, J. C., Min, S. J. Parry, C. & Kramer, A. (2004) Preparing Patients and Caregivers to Participate in Care Delivered Across Settings: The Care Transitions Intervention. *Journal of the American Geriatric Society,* 52, 1817–1825

Collingridge, D. & Gantt, E. (2008) The quality of qualitative research. *American Journal of Medical Quality,* 23 (5), 389-395

Cowlard, J. (2003) Cystic fibrosis: transition from paediatric to adult care. *Nursing Standard,* 18 (4), 39-41

Cooney, A. (2010) Choosing between Glaser and Strauss: an example.*Nurse Researcher*, 17 (4), 18-28

Corbin, J. & Morse, J. (2003) The unstructured, interactive interview: Issues in reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry,* 9 (3), 335-354

Creswll, J. (2003) *Research design: qualitative, quantitative, and mixed method approaches*. 2nd ed. Thousands Oak CA, Sage Publication

Creswell, J., Fetters, M. & Ivankova, N. (2004) Designing A Mixed Methods Study In Primary Care. *Annals of Family Medicine,* 2 (1), 7-12

Creswell, J. W. (2007) *Qualitative inquiry & research design: choosing among five approaches*. Thousand Oaks CA, Sage Publications

Creswell, J. & Clark, V. (2008) *The mixed method reader*. Thousands Oak, Sage Publications

Creswell, J. W. (2009) *Research design: qualitative, quantitative, and mixed methods approaches*. Thousand Oaks CA, Sage Publications

Crossan, F. (2003) Research Philiosophy: Towards an Understanding. *Nurse Researcher,* 11 (1), 46-55

Crowley, R., Wolfe, I., Lock, K, & McKee, M. (2011) Improving the transition between paediatric and adult healthcare: a systematic review, *Archive of Disease in Childhood,* 96, pp 548–553

Curtis, E. & Redmond, R. (2007) Focus Groups in Nursing Research. *Nurse Researcher,* 14 (2), 25-37

CFRI Annual report (2006) Dublin, [online] 15/04/2011 http://cfri.ie/docs/annual_reports/annual_report_2006_registry.pdf

Darbyshire, P., Oster, C. & Henning, P. (2006) Children's and young people's experiences of chronic renal disease: a review of the literature, methodological commentary and an alternative proposal. *Journal of Clinical Nursing,* 15, 751–760

Davidson, M., Penney, E. D., Muller, B. & Grey, M. (2004) Stressors and self-care challenges faced by adolescents living with type 1 diabetes. *Applied Nursing Research,* 17, 72–80

Davies, R. (2006) The potential of integrated multi-agency care pathways for children, *British Journal of Nursing*, 15 (14), 764-768

Denzin, N. K. & Lincoln, Y. S. (1994) Competing Paradigms in Qualitative Research. In Guba, E. G. & Lincoln, Y. S. (eds.) *Handbook Of Qualitative Research*. London, Sage

Denzin, N. K. & Lincoln, Y. S. (1994) *Handbook of qualitative research*. Thousand Oaks CA, Sage publication

Denzin, N. K. and Y. S. Lincoln (eds.) (2003) *The Landscape of Qualitative research: theories and issues*.2nd ed. London, Sage

Denzin, N. K. & Lincoln, Y. S. (2005) *The Sage handbook of qualitative research*. Thousand Oaks CA, Sage publications

Department of Health and Children Health in Ireland (2008) *Key trends in 2007*. DOHC, Dublin

Department of health and children (2008) *Tackling Chronic Disease - A Policy Framework for the Management of Chronic Diseases*. Dublin

Department of health and children (2009) *Palliative care for children with life limiting conditions in Ireland- A National Policy*. Dublin

DeVaus, D. (2002) *Surveys in social research*. 5thed. Oxan, Routledge

Dijkstra, R., Niessen, L., Braspenning, J., Adang, E., & Grol, R. (2006) Patient-centred and professional-directed implementation strategies for diabetes guidelines: a cluster-randomized trial-based cost-effectiveness analysis. *Diabetic Medicine,* 23 (2), 164-170

Docherty, S. & Sandelowski, M. (1999) Focus on qualitative methods: interviewing children. *Research in Nursing and Health,* 22, 177–85

Donalek, J. (2005) Demystifying nursing research: The Interview in Qualitative Research. *Urologic Nursing,* 25 (2), 124 -125

Doug, M., Adi, Y., Williams, J., Paul, M., Kelly, D., Petchey, R. & Carter, Y. H. (2009) Transition to adult services for children and young people with palliative care needs: a systematic review. *Archive of Disease in Childhood* , 96, pp78–84

Dowling, L. (2007) From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies,* 44 (1) 131–142

Dzurec, L. & Abraham, I. (1993) The nature of inquiry :linking quantitative and qualitative research. *Advances of Nursing Science,* 16 (1), 73-79

Fletcher-Johnston, M., Marshall, S. K. & Straatman, L. (2011) Healthcare transitions for adolescents with chronic life-threatening conditions using a Delphi method to identify research priorities for clinicians and academics in Canada. *Child: Care, Health and Development,* 37, 875–882

Flume, P. A., Taylor, L. A., Anderson, D. L., Gray, S. & Turner, D. (2004) Transition Programs in Cystic Fibrosis Centers: Perceptions of Team Members, *Pediatric Pulmonology*, 37, 4–7

Easterby-Smith, M., Thorpe R. &Lowi A. (2002) *Managment Research: An Introduction*. London, Sage

Eldridge, J. (2010) Validity, reliability and trustworthness, in Boswell, K. & Cannon, S. (2010) *Introduction to Nursing Research: Incorporating Evidence Based Practice*. 2nd ed. London, Jones and Bartlett Publishers

Farrant, B. & Watson, P. D. (2004) Health care delivery: perspectives of young people with chronic illness and their parents. *Journal of Paediatrics and Child Health,* 40 (4), 175-9

Flemming, G. V., O'Connor, K. G. & Sanders, J. M. (1994) Pediatricians' views of access to health services for adolescents. *Journal of Adolescent Health,* 15, 473–478

Forbes, D. A., King, K. M., Eastlick Kushner, K., Letourneau, N. L., Myrick, A. F. & Profetto-McGrath, J. (1999) Warrantable evidence in nursing science. *Journal of Advanced Nursing,* 29, 373–379

Ford-Gilboe, M., Campbell J. & Berman H. (1995) Stories and numbers: Coexistence without compromise. *Advances in Nursing Science,* 18 (1), 14-26

Foss, C. &Ellefsen, B. (2002) The value of combining qualitative and quantitative approaches in nursing research by means of method triangulation. *Journal of advanced nursing,* 40 (2), 242-248

Frank-Stromborg, M. & Olsen, S. J. (2004) *Instruments for Clinicl Health-Care Research*,3d ed., Sudbury, Massachusetts, Jones and Bartlett Publishers

Gadamer, H. G. (1975) *Truth and Method*. London, Sheed and Ward stagbooks

Garrett, B. (2007) New pragmatism in nursing: The value of revisiting the age of popular science. *Nurse Education in Practice,* 7, 355–357

Gennep, A. (1960) *The rites of passage*. Chicago: University of Chicago

Ghosh, S., Drummond, H. E. & Ferguson, A. (1998) Neglect of growth and development in the clinical monitoring of children and teenagers with inflammatory bowel disease: review of case records. *British Medical Journal,* 317 (7151), 120-1

Gil, K., Wilson, J. & Edens, J. L. (1997) The Stability of Pain Coping Strategies in Young Children, Adolescents, and Adults with Sickle Cell Disease Over an 18-Month Period. *The Clinical Journal of Pain,* 13(2), 110-115

Ginsburg, K. R. & Jablow, M. M. (2006) *A parent's guide to building resilience in children and teens: Giving your child roots and wings*. USA, American Academy of Pediatrics

Giorgi, A. (1989) some theoretical and practical issues regarding the psychological phenomenological method. *Saybrook Review,* 7 (2), 71-85

Glaser, B. G. & Strauss, A. L. (1965) *Awareness of Dying*. Chicago IL, Aldine

Glaser, B. G. & Strauss, A. L. (1967) *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Hawthorne NY, Aldine de Grutyer

Gliner, J. A., Morgan, G. A. & Leech, N. N. (2009) *Research methods in applied settings an integrated approach to design and analysis*. 2nd ed. Mahwah, NJ, Lawrence Erlbaum Associates

Goljan, E.F. (2007) *Pathology*. Mosby Elsevier, Philadelphia, PA

Godin, M.A. & Glants, L.H. (eds) (1994) *Children as Research Subjects: Science, Ethics, and Law*. Oxford, Oxford University Press

Madge, S. & Bryon, M. (2002) A Model for Transition from Pediatric to Adult Care in Cystic Fibrosis. *Journal of Pediatric Nursing*, 17 (4), 283-288

McCann, T. V. & Clarice, E. (2003) Grounded theory in nursing research: part 1 – methodology. *Nurse Researcher,* 11 (2), 7-18

McLaughlin, S. E., Diener-West, M. Indurkhya, A., Rubin, H., Heckmann, R. & Boyle, M. P. (2008) Improving Transition From Pediatric to Adult Cystic Fibrosis Care: Lessons From a National Survey of Current Practices. *Pediatrics*, 121;e1160-e1166

Graue, M., Wentzel-Larsen, T., Hanestad, B. R. Batsvik, B & Sovik, O. (2003) Measuring self-reported, health-related, quality of life in adolescents with type 1 diabetes using both generic and disease-specific instruments. *ActaPaediatrica,* 92, 1190-1196

Greene, J. C. (2008) *Mixing methods in social inquiry*.San Francisco, CA, Jossey-Bass

Greene, J. & Gracelli, V. (2003) Making paradigmatic sense of mixed method practice. In Tashakkori, A. & Teddlie, C. *Handbook of mixed methods in social & behavioral research*. Thousands Oak CA, Sage Publication

Grimshaw, J., Eccles, M. Thomas, R. MacLennan, G., Ramsay, G., Fraser, G. & Vale, L. (2006) Evidence (and its Limitations) of the Effectiveness of Guideline Dissemination and Implementation Strategies 1966-1998. *Journal of General Internal medicine,*21(S1), I4-20

Gross, C. E., Jia, H. & Larson, E. (2009) Evaluation of Statistical Approaches in Quantitative Nursing research. *Clinical Nursing Research,* 18, 223-241

Grootenhuis, M. A., Stam, H., Last, B. & Groothoff, J. W. (2006) The impact of delayed development on the quality of life of adults with end-stage renal disease since childhood. *Pediatric Nephrology,* 21, 538–544

Guba, E.G. & Lincoln, Y.S. (1981) *Effective Evaluation*. San Francisco CA, Jossey-Bass

Guba, E. G. & Lincoln, Y. S. (1989) *Fourth Generation Evaluation.* Newbury Park CA, Sage Publications

Guba, E. & Lincoln, Y. (1994) Competing paradigms in qualitative research. In N. Denzin& Y. Lincoln (Eds.) *Handbook of qualitative research*. (pp. 105-177). Thousand Oaks, CA: Sage

Gustafson, D. H., Arora, N. K., Nelson, E. C. & Boberg, E.W. (2001) Increasing understanding of patient needs during and after hospitalization. *The Joint Commission Journal on Quality Improvement,* 27 (2), 81-92

Hague, P. (1993) *Interviewing*. London, Kogan Page

Hallowell, E. (2002) *The childhood roots of adult happiness*. New York: Random House Publishing Group

Hampel, P. & Petermann, F. (2005) Age and gender effects on coping in children and adolescents.*Journal of Youth and Adolescents,* 34,73–83

Hannersley, M. (1992) *What's wrong with ethnography: methodological exploration*. London, Routledge

Haughney, J., Barnes, G., Partridge, M. & Cleland, J. (2004) The living & breathing study: a study of patients' views of asthma and its treatment. *Primary Care Respiratory Journal,* 13, 28-35

Health service executive (2009) Services for People with Cystic Fibrosis in Ireland 2009, pages 27 and 34, Dublin - Ireland

Hill, M. (1997) Participatory research with children. Child and Family Social Work, 2, 171–83

Hokkanen, H., Eriksson, E., Ahonen, O. & Salantera, S. (2004) Adolescents with cancer: experience of life and how it could be made easier. *Cancer Nursing,* 27 (4), 325–335

Hollander, J. & Haber, L. (1992) Ecological transition: Using Bronfenbrenner's model to study sexual identity change. *Health Care for Women International,* 13, 121-129

Holton, G. (1993) *Science and Anti-Science*. London, Harvard University Press.

Houser J. (2008) *Nursing research: reading, using and creating evidence*, Sudbury, Massachusetts, Jones and Bartlett Publishers

Howard-Glenn, L. (1992) Transition to home: Discharge planning for the oxygen-dependent infant with bronchopulmonary dysplasia. *Journal of Perinatal and Neonatal Nursing,* 6 (2), 85-94

Hughes, J. A. (1997) *The Philosophy of Social Research*. Essex, Longman

Husserl, E. (1970) *The crisis of European science and transcendental phenomenology, an introduction to phenomenological philosophy*. Evanston, North West university Press

Hutchinson, S. A. & Wilson, H. S. (2001) Grounded theory: the method, in Munhall, P. L. (ed) *Nursing research: a qualitative perspective*. Sudbury, Mass, Jones and Bartlett Publishers

Huus, K. & Enskar, K. (2007) Adolescents' experience of living with diabetes.*Paediatric Nursing,* 19, 29–31

Imle, M. A. (1990) Third trimester concerns of expectant parents in transition to parenthood. *Holistic Nursing Practice,* 4 (3), 25-36

Jakobsson, U. (2004) Statistical presentation and analysis of ordinal data in nursing research. *Scandinavian Journal of Caring Science,* 18, 437–440

Jansen, J., Van Weert, J., Van Der Meulen, N., Van Dulmen, S., Heeren, T. & Bensing, J. (2008) Recall in Older Cancer Patients: Measuring Memory for Medical Information. *The Gerontologist,* 48 (2), 149-157

Jessor, R. (1984) Adolescent development and behavioral health. In Matarazzo, J. D. Weiss, S. M. Herd, J. A. Miller, N. E. & Weiss, S. M. (Eds) *Behavioral health: A handbook of health and disease prevention*.. New York, John Wiley and Sons, pp. 69–90

Johnson, B. & Onwuegbuzie, A. J. (2004) Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher,* 33 (7), 14-26

Johnson, M. A., Morton, M. K., & Knox, S. M. (1992) The transition to a nursing home: Meeting the family's needs. Family members face their own transition when a loved one enters a nursing home. *Geriatric Nursing,* 13, 299-302

Keeney, S., Hasson, F. & McKenna, H. P. (2001) A critical review of the Delphi technique as a research methodology for nursing. *International Journal of Nursing Studies,* 38(2),195-200

Kennedy, A., Sloman, F., Douglass, J. A. & Sawyer, S. M. (2007) Young people with chronic illness: the approach to transition.*Internal Medicine Journal,* 37 (8), 555–560

Kenner, C. & Lott, J.W. (1990) Parent transition after discharge from the NICU. *Neonatal Network,* 9 (2), 31-37

Kerfoot, K., Serafin-Dickson, F., & Green, S. (1988) Managing transition: Resigning with style from the nurse manager position. *Nursing Economics,* 6, 200-202

Kim, S.J. & Kang, K.A. (2003) Meaning of life for adolescents with a physical disability in Korea. *Journal of Advanced Nursing,* 43, 145–157

Kipps, S., Bahu, T., Ong, K., Ackland, F. M., Brown, R.S., Fox, C.T., Griffin, N.K., Knight, A.H., Mann, N.P., Neil, H.A., Simpson, H., Edge J.A. &Dunger, D.B. (2002) Current methods of transfer of young people with Type 1 diabetes to adult services. *Diabetic Medicine,* 19 (8), 649-54

Kirk, S. (2007) Methodological and ethical issues in conducting qualitative research with children and young people: A literature review. *International Journal of Nursing Studies,* 44, 1250–60

Kirk, S. (2008) Transitions in the lives of young people with complex healthcare needs. *Child: care, health and development,* 34 (5), 567–575

Kitzinger, J. & Barbour, R. S. (1999) *Introduction: the challenge and promise of focus groups. In Developing Focus Group Research.Politics, Theory and Practice*. London, Sage

Knapp T. R. (1998) *Quantitative nursing research*, . Thousand Oaks, CA, Sage

Koch, T. (2006) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing,* 53 (1), 91–103

Kortesluoma, R., Hentigen, M. & Nikkonen, M. (2003) Conducting a qualitative child interview: Methodological considerations. *Journal of Advanced Nursing,* 42 (5), 434- 44

Kralik, D. (2002) The quest for ordinariness: transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing,* 39 (2), 146-154

Kralik, D., Visentin, K. & Van Loon, A. (2006) Transition: a literature review. *Journal of Advanced Nursing,* Volume 55 (3), 320–329

Kreuger, R. A. (1994) *Focus groups, a practical guide for applied research*. Thousand Oaks, CA, Sage

Krueger, R. A. (1998) *Analyzing and reporting focus group results*. London, Sage Publication

Krueger, R. A. & Casey, M. A (2000) *Focus Groups. A Practical Guide for Applied Research.* Thousand Oaks CA, Sage Publications

Kuhn, T. (1996) *The structure of scientific revolutions*. 3rd ed. Chicago, University of Chicago Press

LaBrie, N., Kiefer, K., Miettunen, P., Fahlman, N., Johnson, N., Crawford, A. & Lupton, T. (2008) Review of the success of a transition clinic for young adults with rheumatic diseases. *Pediatric Rheumatology,* 6 (Suppl. 1), 148.

Ladden, M. (1990) The impact of preterm birth on the family and society. Part 2: Transition to home. *Pediatric Nursing,* 16, 620-622, 626

Lauer, K. (1990) Transition in adolescence and its potential relationship to bulimic eating and eight control pattern in women. *Holistic Nursing Practice,* 4 (3) , 8-16

Leininger, M. M. (1988) Culture Care Diversity & Universality :A Theory of Nursing. *Nursing Science Quarterly,* 1 (4), 152-60

Letourneau, N. & Allen M. (1999) Post-positivistic critical multiplism : a beginning dialogue. *Journal of Advanced Nursing,* 30, 623–630

LeVasseur, J. (2002) A phenomenological study of the art of nursing: experiencing the turn. *Advances in Nursing Science,* 24 (4), 14–26

Levinson, D. J. (1978) *The seasons of a man's life*. New York, Ballantine

Lobiondo-Wood, G. & Haber, J. (2002) *Nursing Research: Methods, Critical Appraisal and Utilization*. Missouri, Mosby-Elsevier Health Sciences

Loiselle, C. G. (2004) *Canadian essentials of nursing research*. Philadelphia, Lippincott Williams & Wilkins

Lotstein, D. S., Ghandour, R., Cash, A., McGuire, E., Strickland, B. & Newacheck, P. (2009) Survey of Children With Special Health Care Needs Planning for Health Care Transitions: Results From the 2005-2006 National Survey of Children With Special Health Care Needs, *Pediatrics,* 123 (1), e145-52

Loveys, B. (1990) Transitions in chronic illness: the at risk role. *Holistic Nursing practice,* 4 (3), 56-64

Lynn, M. (1986) Determination and quantification of content validity. *Nursing Research,* 35 (6), 382-386

Macnee, C. L. & McCabe S. (2008) *Understanding Nursing Research: Using Research in Evidence-Based Practice*, 2nd ed., Philadelphia, Lippincot Williams & Wilkins

Madden, S., Hastings, R. & Hoff, W. (2002) Psychological adjustment in children with end stage renal disease: the impact of maternal stress and coping. *Child Care, Health & Development,* 28, 323–330

Madden, S.J., Ledermann, S.E., Guerrero-Blanco, M. & Bruce, M. (2003) Cognitive and psychosocial outcome of infants dialysed in infancy. *Child Care, Health and Development,* 29, 55–61

Maggs, J. L., Patrick, M. E., Feinstein, L. (2008) Childhood and adolescent predictors of alcohol use and problems in adolescence and adulthood in the National Child Development Study. *Addiction,*103 (s1), 7–22

Magnusson, D. & Allen, V. L. (1983) *Human development: an interactionist perspective*. New York, Academic Press

Mahon, A., Glendinning, C., Clarke, K. & Craig, G. (1996) Researching Children: Methods and Ethics. *Children & Society,* 10 (2), 145-154

Malbrunot-Wagner, A. C., Bonnemains, C., Troussier, F., Darviot, E., Chiffoleau, M., Person, C., Urban, T. & Giniès, J. L. (2009) Transition from pediatric to adult care: experience of a cystic fibrosis care center. *Archives de Pediatrie,* 16 (3), 235-42

Martin, P. & Stayer, M. A. (1990) The experience of micro and macroevents: A life span analysis. *Research on Aging,* 12, 294–310

Mauthner, M. (1997) Methodological aspects of collecting data from children: lessons from three research projects. *Children and Society,* 11, 16–28

Maxcy, S. (2003) Pragmatic thread in mixed method research in the social sciences:the search for multiple modes of inquiry and the end of the philosophy of formalism. In Tashakkori, A. &Teddlie, C. *Handbook of mixed methods in social & behavioral research*. Thousands Oak CA, Sage Publication

Mays, N. & Pope, C. (2000) Assessing quality in qualitative research. *British Medical Journal,* 320 (7226), 50-52

McCance, K., Forshee, B. & Shelby, J. (2006) Stress and disease. In K. L. McCance, & S. E. Huether (Eds.) *Pathophyiology: The biologic basis for disease in adults and children.* 5th ed. St Louis: Mosby

McDonagh, J. E., Southwood, T. R., Shaw, K. L. & British Paediatric Rheumatology Group. (2004) Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. *Rheumatology,* 43, 737–743

McDonagh, J. E. (2005) Growing up and moving on: transition from pediatric to adult care. *Pediatric Transplantation,* 9 (3), 364-72

McDonagh, J. E., Minnaar, G., Kelly, K. M., O'Connor, D. & Shaw, K. L. (2006) Unmet education and training needs in adolescent health of health professionals in a UK children's hospital. *ActaPaediatrica,* 95, 715–719

McGee, J. O. (1992) *Oxford Textbook of Pathology Vol. 1.,General Principles of Pathology*. Oxford, Oxford University Press

Medical Research Council (1991) *The ethical conduct of research on children*. London, MRC

Meleis, A.I. (1991) *Theoretical nursing: Development and progress*.2nd ed. Philadelphia. J.B. Lippincott

McEwan, M.J., Espie, C.A., Metcalfe, J., Brodie, M.J. & Wilson, M.T. (2004) Quality of life and psychosocial development in adolescents with epilepsy: a qualitative investigation using focus group methods. *Seizure,* 13, 15–31

Meleis, A., Sawyer, L., Im, E., HilfingerMessias, K. & Schumacher, K. (2000) Experiencing Transitions: An Emerging Middle-Range Theory. *Advances in Nursing Science,* 23 (1) 12-28

Melies, A. (2010) *Transitions Theory: Middle-range and situational-specific theories in nursing research and practice*. New York, Spring Publishing company

Michele, Y., Sawyer, S. (2005) ABC of adolescence Chronic illness and disability. *British Medical Journal,* 330 (26), 721–723

Mickunas, A. & Stewart, D. (1990) *Exploring phenomenology*. Athens, Ohio University Press

Millstein, S. G. (1989) Adolescent health.Challenges for behavioral scientists. *American Psychologist,* 44 (5), 837-42

Moos, R. H. (2002) Life stressors, social resources, and coping skills in youth: applications to adolescents with chronic disorders. *Journal of Adolescent Health,* 30 (4 Suppl), 22-9

Morgan, D.L. (1997) *Focus Groups as Qualitative research*.2nd ed. Thousand Oaks, CA, Sage

Morgan, D. L. (1998) Practical strategies for combining qualitative and quantitative methods: Applications to health research. *Qualitative Health Research,* 8 (3), 362–376

Morgan, D. (2007) Paradigms Lost and Pragmatism Regained: Methodological Implications of Combining Qualitative and Quantitative Methods. *Journal of Mixed Methods Research,* 1, 48-76

Morrow, V. & Richards, M. (1996) The ethics of social research with children: An overview, *Children & Society,* 10, 90–105

Morse, J. M. (1991) Approaches to qualitative-quantitative methodological triangulation. *Nursing Research,* 40, 120–123

Morse, J. (1999) Myth #93: Reliability and Validity Are Not Relevant to Qualitative Inquiry. *Qualitative Health Research,* 9 (6), 717- 718

Morse, J. (2000) Determining sample size. *Qualitative health research,* 10 (3), 3-5

Morse, J. (2005) What is qualitative research. *Qualitative Health Research,* 15 (7), 859-860

Morse, J. (2006) Reconceptualizing Qualitative Evidence. *Qualitative Health Research,* 16 (3), 415- 422

Morse, J. & Niehaus, L. (2009) *Mixed method design: principles and procedures*. Walnut Creek CA, Left Coast

Morse J.M. & Field P.A. (1996) *Nursing Research: The Application of Qualitative Approaches.* Chapman & Hall, London

Munhall, P. L. (ed) (2001) *Nursing research: a qualitative perspective*. Sudbury, Mass, Jones and Bartlett Publishers

Nasr, S., Campbell, C. & Howatt, W. (1992) Transition program from pediatric to adult care for Cystic Fibrosis patients. *Journal of Adolescent Health,*13 (8), 682-685

National Children's Bureau (1993) *Guidelines for Research*. London, NCB

Nielson, L. (1991) *Adolescence: A contemporary view*. FortWorth, Holt, Rinehart and Winston

Nixon, G. M., Glazner, J. A., Martin, J. M. & Sawyer, S. M. (2003) Female sexual health care in cystic fibrosis. *Archive of Disease in Childhood,* 88 (3), 265-266

Oliver, K., Lehmann, H., Wolff, A., Davidson, L., Donohue, P,.Gilmore, M., Craven, C. & Roderer, N. (2011) Evaluating information prescriptions in two clinical environments. *Journal of the Medical Library Association,* 99 (3), 237-246

Pai, A. & Ostendorf, H. (2011) Treatment Adherence in Adolescents and Young Adults Affected by Chronic Illness During the Health Care Transition From Pediatric to Adult Health Care: A Literature Review. *Children's Health Care,* 40 (1), 16-33

Palmer, M.L. & Boisen, L. (2002) Cystic Fibrosis and the Transition to Adulthood. *Social Work in Health Care*, 36 (1),45-58

Parahoo, K. (1997) *Nursing Research: Principles, Process and Issues*. New York, Palgrave Macmillan

Parahoo, K. (2006) *Nursing research: principles, process and issues*. New York, Palgrave Macmillan

Parkes, C. M. (1971) Psycho-social transitions: A field for study. *Social Science & Medicine,* 5, 101-115

Patton, M. Q. (2002) *Qualitative research & evaluation methods*.3rd ed. Thousand Oaks CA, Sage

Patton, M. Q. (2004) *Qualitative research & evaluation methods*. Thousand Oaks CA, Sage Publications

Piaget, J. (2008) Intellectual Evolution from Adolescence to Adulthood. *Human Development*, 51, 40-47

Pless, I. P., Power, C. &Peckham, C. S. (1993) Long-term Psychosocial Sequelae of Chronic Physical Disorders in Childhood, *Pediatrics*, 91 (6), 1131 -1136

Polgar, S. & Thomas, S. A. (1995) *Introduction to research in the health sciences*.3rd ed. Melbourne, Churchill Livingstone

Polit, D.F. & Hungler, B.P. (1999) *Nursing Research: Principles and Methods.* 6thedition.Philadelphia PA, JB Lippincott

Polit, D. & Hungler, B. (2000) *Essentials of Nursing Research: Methods, Appraisal, and Utilization*. 4th ed. Philadelphia, Lippincott-Raven Publishers

Polit, D. & Beck, C. (2006) *essentials of nursing research method, appraisal, and utilization*.6th ed. Philadelphia, Lippincott Williams and Wilkins

Pollock, R. M. (2005) *Treatment of Cystic Fibrosis in Ireland: Problems and solutions*. The Cystic Fibrosis Association of Ireland, Dublin – Ireland

Poursanidou, K., Garner, P., Stephenson, R. & Watson, A. (2003a) Educational difficulties and support needs of children following renal transplantation: student, parent and teacher perspectives. *International Journal of Adolescence & Youth,* 11, 157–180

Poursanidou, K., Garner, P., Watson, A. & Stephenson, R. (2003) Difficulties and support at school for children following renal trans-plantation: a case study. *Support for Learning,* 18, 170–176

Powers, A. & Knapp, T. (2006) *Dictionary of nursing theory and research*. New York, Springer publication company

Price, B. (2001) Laddered questions and qualitative data research interviews. *Journal of Advanced Nursing,* 37 (3), 273-281

Pridham, K.F., Lytton, D., Chang, A.S. & Rutledge, D. (1991) Early postpartum transition: Progress in maternal identity and role attainment. *Research in Nursing and Health,* 14, 21-31

Proctor, S. (1998) Linking philosophy and method in the research process: the case for realism. *Nurse Researcher,* 5 (4),73–89

Radio Telefis Eireann (2007) Prime Time, 3 May. http://tinyurl.com/c89z585 (accessed 18 July 2012)

Radio Telefis Eireann (2008) Prime Time, 15 January. http://tinyurl.com/bugt7t7 (accessed 18 July 2012)

Rapley, P. & Davidson, P. M. (2009) Enough of the problem: a review of time for health care transition solutions for young adults with a chronic illness. *Journal of Clinical Nursing,* 19, 313–323

Reiss, J. G., Gibson, R. W. & Walker, L. R. (2005) Health care transition: youth, family, and provider perspectives. *Pediatrics,* 115 (1),112-20

Rhee, H., Wenzel, J. & Steeves, R.H. (2007) Adolescents' psychosocial experiences living with asthma: a focus group study. *Journal of Pediatric Health Care*, 21, 99–107

Roisman, G. I., Masten, A. S., Coatsworth, J. D. & Tellegen, A. (2004) Salient and emerging developmental tasks in the transition to adulthood. *Child Development,* 75 (1), 123-33

Rosaler, M. (2007). *Cystic fibrosis*. New York, Rosen Pub. Group

Roumie, C., Greevy, R., Wallston, K., Elasy, T., Kaltenbach, L., Kotter, K., Dittus, R. & Speroff, T. (2011) Patient centered primary care is associated with patient hypertension medication adherence. *Journal of Behavioral Medicine,* 34 (4), 244-253

Royal College of Physicians (London), Royal College of General Practitioners (London) & the NHS Alliance (2004) *Clinicians, services and commissioning in chronic disease management in the NHS The need for coordinated management programmes*.[online] Available from http://www.rcgp.org.uk/PDF/Corp_chronic_disease_nhs.pdf [Accessed 29th October 2011]

Rubin, H. J. & Rubin, I. (2005) *Qualitative interviewing: the art of hearing data*. Thousand Oaks CA, Sage publications

Russell Bernard, H. (2000) *Interviewing: unstructured and semi structured. In Social Research Methods: Qualitative and Quantitative Approaches*. Sage, Thousand Oaks, CA, pp. 189-225

Rutishauser, C., Akré, C. & Surìs, J. C. (2010) Transition from pediatric to adult health care: expectations of adolescents with chronic disorders and their parents. *European Journal of Pediatrics,* 170, 865–871

Ryan-Nicholls, K. & Will, C. (2009) Rigour in qualitative research: mechanisms for control, *Nurse Researcher*, 16 (3), 70-85

Sandelowski, M. (1986) The problem of rigour in qualitative research. *Advances in Nursing Science,* 8 (3), 27-37

Sandelowski, M. (1993) Rigor or rigor mortis: The problem of rigor in qualitative research revisited.*Advances in Nursing Science,* 16 (2), 1-8

Sandelowski, M. (2000) Combining qualitative and quantitative sampling ,data collection, and analysis techniques in mixed-method studies. *Research in Nursing and Health,* 23, 246-255

Sawicki, G. S., Sellers, D. E., McGuffie, K. & Robinson, W. (2007) Adults with cystic fibrosis report important and unmet needs for disease information. *Journal of Cystic Fibrosis,* 6 (6), 411-416

Scal, P. (2002) Transition for Youth with Chronic Conditions: Primary Care Physicians' Approaches. *Pediatrics,* 110 (6), 1315-1321

Schumacher, K.L. & Meleis A. (1994) Transitions: a central concept in nursing. *Journal of Nursing Scholarship*, 26 (2), 119–27

Scott, S. & Haydon, D. (2005) *Barnardo's Statement of Ethical Research Practice*. Barnardo- London

Seiffge-Krenke, I. & Stemmler, M. (2003) Coping with everyday stress and links to medical and psychosocial adaptation in diabetic adolescents. *Journal of Adolescent Health,* 33, 180–188

Shaw, K., Southwood, T. &McDonagh, J. (2004a) User Perspective of Transitional Care for Adolescents with Juvenile Idiopathic arthritis. *Rheumatology,* 43 (6), 770–8

Shaw, K. L., Southwood, T. R., McDonagh, J. E. & British Paediatric Rheumatology Group (2004b) Transitional care for adolescents with juvenile idiopathic arthritis: a Delphi study. *Rheumatology,* 43 (8), 1000-6

Schmidt, S., Petersen, C. & Bullinger, M. (2003) Coping with chronic disease from the perspective of children and adolescents – a conceptual framework and its implications for participation. *Child: Care, Health and Development,* 29 (1), pp 63–75

Schneider, Z. (2003) *Nursing research: methods, critical appraisal and utilisation.* Sydney, Mosby

Schumacher, K. &Meleis, A. (2010) Transitions: A central concept in nursing. In Melies, A. (2010) *Transitions Theory: Middle-range and situational-specific theories in nursing research and practice*. Spring Publishing, New York

Sheslow, D. & Stehl, M. (2005) *Childhood stress*. [Online] available from: http://kidshealth.org/parent/emotions/feelings/stress.html[Accessed 16th march 2011]

Shih, F.J. (2001) Triangulation in nursing research: issues of conceptual clarity and purpose. *Journal of Advanced Nursing,* 28 (3), 631-641

Shea, L.E., Adamzczak, P., & Flanagan, T.J. (1987) Transition to flight nursing: Three experiences. *Journal of Emergency Nursing,* 13 (4), 31A-35A

Silverman, D. (2005) *Doing qualitative research : a practical handbook*. Los Angeles, Sage Puplications

Sim, J. (1998) Collecting and analysing qualitative data: issues raised by focus group. *Journal of advanced nursing,* 28 (2), 345-352

Singer, J. (1984) *The human personality*. New York, Harcourt Brace Jovanovich Publishers

Silverman, P. (1982) Transitions and models of the interventions. *Annals of the American Academy of Political and Social Science,* 464, 174-187

Skinner, E. A. & Zimmer-Gembeck, M. J. (2007) The development of coping. *Annual Review of Psychology,* 58, 119–144

Snethen, J. A., Broome, M. E., Bartels, J. & Warady, B. A. (2001) Adolescents' perception of living with end-stage renal disease. *Pediatric Nursing*, 27, 159–167

Soanes, C. & Timmons, S. (2004) Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *Journal of Child Health Care*, 8 (2), 102-112

Somerville, J. (1997) Near misses and disasters in the treatment of grown-up congenital heart patients.*Journal of the Royal Society of Medicine*, 90, 124-127

Spear, H. J. & Kulbok, P. A. (2001) Adolescent health behaviors and related factors: a review. *Public Health Nursing,* 18 (2), 82-93

Spiegleberg, R. M. (1978) *Phenomenological movement: A historical introduction*. Boston, Martinus Nijhof publishers

Stam, H., Hartman, E. E., Deurloo, J. A., Groothoff, J. & Grootenhuis, M. A. (2006) Young Adult Patients with a History of Pediatric Disease: Impact on Course of Life and Transition into Adulthood. *Journal of Adolescent Health,* 39 (1), 4-13

Steinkamp, G., Ullrich, G., Muller, C., Fabel, H. & Von Der Hardt, H. (2001) Transition of adult patients with cystic fibrosis from paediatric to adult care the patients' perspective before and after start-up of an adult clinic. *European Journal of Medical Research,* 28, 6 (2), 85-92

Steinbeck, K. S., Brodie, L. & Towns, S. J. (2008) Transition in chronic illness: Who is going where?.*Journal of Paediatrics and Child Health,* 44(9), 478–482

Suris, J. C., Michaud, P. A. & Viner, R.M. (2004) The adolescent with a chronic condition. Part 1: developmental issues. *Archives of Disease in Childhood,* 89, 938–942

Suris, J. C. & Parera, N. (2005) Sex, drugs and chronic illness: health behaviours among chronically ill youth. *European Journal of Public Health*, 15 (5), 484-488

Swarczinski, C. &Graham, P. (1990) From ICU to rehabilitation: a checklist to ease the transition for the spinal cord injured. *The Journal of Neuroscience Nursing,* 22 (2), 89-91

Smith, J. K. & Heshusius, L. (1986) Closing down the conversation: The end of the quantitative qualitative debate among educational inquiries. *Educational Researcher,* 15, 4–12

Snyder-Halpern, R., Thompson, C. B. & Schaffer, J. (2000) Comparison of Mailed vs. Internet Applications of the Delphi Technique in Clinical Informatics Research, *Proceeding of American medical informatics association (AMIA) Symposium*. 2000, 809–813

Taanila, A., Murray, G. K., Jokelainen, J., Isohanni, M. and Rantakallio, P. (2005), Infant developmental milestones: a 31-year follow-up. Developmental Medicine & Child Neurology, 47, 581–586

Tashakkori, A. & Teddlie, C. (1998) *Mixed methodology: combining qualitative and quantitative approaches*. Thousand Oaks CA, Sage Publication

Tashakkori, A. & Teddlie, C. (2003) *Handbook of mixed methods in social &behavioral research*. Thousands Oak CA, Sage Publication

Taylor, R. M., Gibson, F. & Franck, L. S. (2008a) The experience of living with a chronic illness during adolescence: a critical review of the literature. *Journal of Clinical Nursing,* 17 (23), 3083-91

Taylor, R. M., Gibson, F. & Franck, L. S. (2008a) A concept analysis of health-related quality of life in young people with chronic illness. *Journal of Clinical Nursing,*17(14), 1823-33

Tedlock, B. (2000) Ethnography and ethnographic presentation, in Denzin, N. K. & Lincolin Y. S. (2000) *Handbook of qualitative research*. 2nded. Thousand Oaks CA, Sage publications

Thomas, D. & Gaslin, T.C. (2001) 'Camping up' self-esteem in children with hemophilia. *Issues in Comprehensive Pediatric Nursing,* 24, 253–26

Thomas, N. & O'Kane, C. (1998) The ethics of participatory research with children. *Children and Society,* 12, 336–48

Thomas, R. (2003) *Blending qualitative & quantitative research methods in theses and dissertations*. Thousand Oaks CA, Corwin press

"transition noun" The Oxford Dictionary of English (revised edition). Ed. Catherine Soanes and Angus Stevenson. Oxford University Press, 2005. Oxford Reference Online.Oxford University Press. National University of Ireland Galway. 16 May 2010
http://www.oxfordreference.com/views/ENTRY.html?subview=Main&entry=t140.e81453

Towns, S. J. & Bell, S. C. (2011) Transition of adolescents with cystic fibrosis from Paediatric to Adult care. *The Clinical Respiratory Journal,* 5 (2), 64–75

Trummer, U. F., Mueller, U. O., Nowak, P., Stidl, T. & Pelikan, J. M. (2006) Does physician–patient communication that aims at empowering patients improve clinical outcome? A case study. *Patient Education and Counselling,* 61 (2), 299–306

Tuchman, L. K., Schwartz, L. A., Sawicki, G. S. &Britto, M. T. (2010) Cystic Fibrosis and Transition to adult medical care. *Pediatrics,* 125 (3), 566-73

Tuchman, L. K. Slap, G. B. & Britto, M. T. (2008) Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child: care, health and development,* 34(5), 557–563

Turner, V. W. (1995) *The ritual process: structure and anti-structure*. New York, Aldine de Gruyter

Vanhaecht, K., DeWitte, K., Panella, M. & Sermeus, W. (2009) Do pathways lead to better organized care processes?. *Journal of Evaluation In Clinical Practice,* 15 (5), 782-788

Van Kaam, A. L. (1969) *Existential foundation of psychology*. Pittsburgh, Duquesne University Press

Van Manen, M. (1996) Phenamenological pedagogy and the question of meaning. In Vandenberg, D. (ed.) (1997) *Phenomenology and educational discourse*. Johannesburg, Heinemann

Van Walleghem, N., MacDonald, C. & Dean, H. J. (2008) Evaluation of a Systems Navigator Model for Transition From Pediatric to Adult Care for Young Adults With Type 1 Diabetes. *Diabetes Care,* 31 (8), 1529–1530

Veit, F. C., Sanci, L.A., Young, D.Y. & Bowes, G. (1995) Adolescent health care: perspectives of Victorian general practitioners. *The Medical Journal of Australia,* 163, 16–18

Washington, T. D. (2009) Psychological Stress and Anxiety in Middle to Late Childhood and Early Adolescence: Manifestations and Management. *Journal of Pediatric Nursing,* 24 (4) , 302-313

Watson, A. R. (2000) Non-compliance and transfer from paediatric to adult transplant unit. *Pediatric Nephrology,* 14 (6), 469-72

Webb, C. & Kevern, J. (2000) Focus group as a research method: a critique of some aspects of their use in nursing research. *Journal of advanced nursing,* 33 (6), 798-805

Webster dictionary, 1993 Merriam-Webster, retrieved online from http://gateway.proquest.com/openurl/openurl?ctx_ver=Z39.88-2003&xri:pqil:res_ver=0.2&res_id=xri:ilcs&rft_id=xri:ilcs:ft:websters:Z201102713:2We

Westwood, A. T. Henley, L. D. & Willcox, P. (1999) Transition from paediatric to adult care for persons with cystic fibrosis: Patient and parent perspectives. *Journal of Paediatrics and Child Health*, 35 (5), 442–445.

While, A., Forbes, A., Ullman, R., Lewis, S., Mathes, L. & Griffiths, P. (2004) Good practices that address continuity during transition from child to adult care: synthesis of the evidence. *Child: Care, Health and Development,* 30 (5), 439-52.

World Health Organization (2004) The Solid Facts: Palliative Care. Davies E. Higgiason IJ. WHO, Geneva

Wong, D. L. (1991) Transition from hospital to home for children with complex medical care. *Journal of Pediatric Oncology Nursing,* 8, 3-9

Wolfe, A. (1999) the missing pragmatic revival in American social science, In M, Dickstien (Ed.), *the revival of pragmatism: new essay in social thought, Law, and Culture*.Durham, Duke University Press

Wysocki, T., Hough, B. S., Ward, K. M. & Green, L. B. (1992) Diabetes mellitus in the transition to adulthood: adjustment, self-care, and health status. *Development and Behavioural Paediatrics,* 13, 194–201

Yang, L. & Fox, K. (1999) Ethnography in health research and practice. *Ambulatory child health,* 5, 339-349

Yoshikawa, H., Weisner, T., Kalil, A. & Way, N. (2005) Mixing Qualitative and Quantitative Research in Developmental Science: Uses and Methodological Choices. *Developmental Psychology,* 44 (2), 344–354

Zack, J., Jacobs, C. P., Keenan, P. M., Harney, K., Woods, E. R., Colin, A. A. & Emans, S. J. (2003) Perspectives of Patients With Cystic Fibrosis on Preventive Counseling and Transition to Adult Care. *Pediatric Pulmonology*, 36, 376–383

Appendixes

Appendix 1: Adolescent information sheet - in depth interview

We will be there listening to you … see you

NUI Galway
OÉ Gaillimh

Developing Guidelines for best practices, that address the transition of children with CF from children to adult healthcare setting in Ireland.

Information Sheet For Adolescents

Hi ,

I am Nabeel Al-Yateem, I am doing a study to find out what you and your parents need to help your transition (movement) from the care in a children's hospital to care in an adult hospital.

The study will involve you , your parents and those health care professionals who usually take part in the care given to you usually, and will be in the form of an interviews for about 40-60 minutes. You and your parent will be interviewed separately at the day of the clinic appointment, unless you would prefer to be interviewed together with them.

The information that you and your parent give us during the interview will be used to:

1. Know your needs during the transition (or movement) from children to adult health care settings.

2. Know the factors that affect this transition (or movement) from children to adult health care settings.

3. Advise health care professionals who are working with you about the most appropriate and important actions that they have to do to provide you with the best possible care, based on what you and your parents have told us during the interview.

All information that you will provide during the interview will be kept strictly confidential, that means that no one except the research team will know anything about those who took part in the study.

It is absolutely the decision of you and your parents whether to take part or not in this study, and your decision will in no way influence or affect your care or treatment.

If you decided to take part in the study you will have the right to :

1. Refuse to answer any particular question.

2. Withdraw from the interview or the study without giving any explanation

3. Ask any question about the study or about what happens during the study.

4. To have a copy of the study results when it is ready.

Your participation in this study will be extremely appreciated as it will help improve the service provided to you and will help others who are receiving similar care elsewhere in Ireland. However – as previously stated- I would like to assure you that your decision to participate or otherwise will not in any way affect the level of service provided for you .

If anything comes up which you find distressing or upsetting, you will be offered a break you will be reminded that you can withdraw at any time temporarily or permanently. If necessary, counselling support will be arranged.

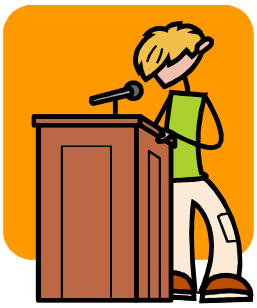
If you need any further information or want to ask any question please contact me by any of the following mean:

E-Mail: n.al-yateem1@NUIGALWAY.IE

Mobile: 086-2189457

Thanking you for the time you given to read this information sheet.

Nabeel Al-Yateem RN. MSN.
PhD Candidate
College of Medicine, Nursing, & Health Sciences
National University of Ireland – Galway.



Appendix 2: Young adult information sheet-in depth interview

Developing Guidelines for best practices that address the transition of children with CF from children to adult healthcare setting in Ireland.

Information Sheet for Young Adult

Hi ,

I am Nabeel Al-Yateem, I am doing a study to find out what you and your parents need to help your transition (movement) from the care in a children's hospital to care in an adult hospital.

The study will involve you , your parents and those health care professionals who usually take part in the care given to you usually, and will be in the form of an interviews for about 40-60 minutes. You and your parent will be interviewed separately at the day of the clinic appointment, unless you would prefer to be interviewed together with them.

The information that you and your parent give us during the interview will be used to :

4. Know your needs during the transition (or movement) from children to adult health care settings.
5. Know the factors that affect this transition (or movement) from children to adult health care settings.

6. Advise health care professionals who are working with you about the most appropriate and important actions that they have to do to provide you with the best possible care, based on what you and your parents have told us during the interview.

All information that you will provide during the interview will be kept strictly confidential , that means that no one except the research team will know anything about those who took part in the study.

It is absolutely the decision of you and your parents whether to take part or not in this study, and your decision will in no way influence or affect your care or treatment.

If you decided to take part in the study you will have the right to :

5. Refuse to answer any particular question.
6. Withdraw from the interview or the study without giving any explanation
7. Ask any question about the study or about what happens during the study.
8. To have a copy of the study results when it is ready.

Your participation in this study will be extremely appreciated as it will help improve the service provided to you and will help others who are receiving similar care elsewhere in Ireland. However – as previously stated- I would like to assure you that your decision to participate or otherwise will not in any way affect the level of service provided for you .

If anything comes up which you find distressing or upsetting, you will be offered a break you will be reminded that you can withdraw at any time temporarily or permanently. If necessary, counselling support will be arranged.

If you need any further information or want to ask any question please contact me by any of the following mean:

E-Mail:

n.al-yateem1@NUIGALWAY.IE

Mobile:

086-2189457

Thanking you for the time you given to read this information sheet.

Nabeel Al-Yateem RN. MSN.
PhD Candidate
College of Medicine, Nursing, & Health Sciences
National University of Ireland – Galway.

Appendix 3: Parent and guardian information sheet - in depth interview

Developing Guidelines for best practices, that address the transition of children with CF from children to adult healthcare setting in Ireland.

Parent/Guardian Information Sheet

Dear Parent/Guardian:

I am Nabeel Al-Yateem, a PhD Nursing candidate at the School of Medicine, Nursing , and Health sciences , NUI – Galway.

I am working currently on a research project to identify the needs of teenagers/young adults and their families during transition from children's hospital care to adult care institution or hospital.

The study will try to achieve the following goals:

1. Identify teenagers and their parents needs during transition from paediatric to adult health care settings.
2. Identify factors that facilitate or hinder teenagers transition from paediatric to adult health care settings.
3. Recommend a relevant and feasible Transition service guidelines , based on the perspectives of a professional health care providers and informed by the teenagers and their parents experiences.

I propose to conduct an interview of between 40-60 minutes to discuss your views and experiences of the current service , the preparation provided to you about the future service in the adult hospital .

From this research I aim to produce guidelines for best practice for health care professionals working both in the child and adult health services during the periods of transition between the two settings .

Only the researcher and the research supervisors will be able to access the research data, and no personal information at all will be made available to the hospital involved.

Your participation in this study will in no way influence or affect any part of your care and treatment.

If you take part in the study you have the right to:

- Refuse to answer any particular question.
- Withdraw from the interview temporarily or permanently at any time without giving an explanation .
- Ask any further questions about the study that occurs to you during your participation.
- Be given access to a summary of the findings from the study, when it is concluded.

Your participation in this study will be extremely appreciated as it will help improve the service provided to our children in hospitals and will contribute to the advancement of health care service in general, However – as previously stated- I would like to assure you that your decision to participate or otherwise will not affect the level of service provided for you and your child/teenager.

The perceived health risk of your participation is minimal since the project does not involve any medical intervention, however , the risk of distress through recalling an upsetting event or experience is noted , in such instances you will be offered a break,

and rules for process consent will apply, whereby you will be reminded that you can withdraw at any time temporarily or permanently. If necessary counseling support will be arranged.

For any further information , Please do not hesitate to contact me as follows:

E-Mail:

n.al-yateem1@NUIGALWAY.IE

Mobile:

086-2189457

Thanking you for the time you given to read this information sheet.

Nabeel Al-Yateem

Appendix 4: Consent form for participation for adolescents and young adults - in depth interview

Developing Guidelines for best practices, that address the transition of children with CF from children to adult healthcare setting in Ireland.

Consent Form For Adolescents

Reference Number:

1. I confirm that I have read and understand the information leaflet dated …….. for the above study and received an explanation of the nature, purpose, duration, and foreseeable effects and risks of the study and what my involvement will be.

2. I have had time to think and consider participation in this study. My questions have been answered satisfactorily and I have received a copy of the Patient Information Leaflet.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without my medical care or legal rights being affected.

4. I am willing to allow access to my medical records by researchers, Ethics Committee or local or foreign regulatory authorities but understand that strict confidentiality will be maintained. The purpose of this is to check that the study is being carried out correctly.

5. I agree to take part in the above study.

_____ _____

Name of Adolescent **Date**
Signature
(in block letters)

_____ _____

Name of Person taking consent **Date**
Signature
(if different from doctor/researcher)

1 copy for research participant
1 copy for researcher

Appendix 5: Consent form for participation- Parent and guardian-in depth interview

Developing Guidelines for best practices, that address the transition of children with CF from children to adult healthcare setting in Ireland.

Consent Form For Parents/Guardian.

Reference Number:

6. I confirm that I have read and understand the information leaflet dated …….. for the above study and received an explanation of the nature, purpose, duration, and foreseeable effects and risks of the study and what my/my child's involvement will be.

7. I have had time to consider whether to take part in this study. My questions have been answered satisfactorily and I have received a copy of the Patient Information Leaflet.

8. I understand that my/my child's participation is voluntary and that I am/we are free to withdraw at any time without my/my child's medical care or legal rights being affected.

9. I am willing to allow access to my/my child's medical records by representatives of the sponsor, Ethics Committee or local or foreign regulatory authorities but understand that strict confidentiality will be maintained. The purpose of this is to check that the study is being carried out correctly.

10. I agree to allow my child to take part in the above study.
11. I agree to take part in the above study.

_____ _____

_____

Name of Research Parent/Guardian **Date**
Signature
(in block letters)

_____ _____
_____

Name of Person taking consent **Date**
Signature
(if different from doctor/researcher)

1 copy for research participant
1 copy for researcher

Appendix 6 :Consent form for participation for health care professionals – Focus group interview

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Consent Form For Health Care Professionals

Reference Number:

12. I confirm that I have read and understand the information leaflet dated …….. for the above study and received an explanation of the nature, purpose, duration, and foreseeable effects and risks of the study and what my involvement will be.

13. I have had time to consider whether to take part in this study. My questions have been answered satisfactorily and I have received a copy of the Research Information Leaflet.

14. I understand that my participation is voluntary and that I am free to withdraw at any time from the study.

15. I am willing to allow access to the interview information to the researchers, Ethics Committee or local or foreign regulatory authorities but understand that strict confidentiality will be maintained. The purpose of this is to check that the study is being carried out correctly.

16. I agree to take part in the above study.

_____ _____ _____

Name of Research Participant **Date** **Signature**

(in block letters)

_____ _____

_____

Name of Person taking consent **Date**
Signature
(if different from doctor/researcher)

1 copy for research participant
1 copy for researcher

Appendix 7: Ethical protocol- in depth interview

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Ethical Protocol

The researcher will intervene if:

- Adolescent is experiencing a severe psychological discomfort that exceeded the expected level or exceeded the adolescent toleration as a result of recalling an upsetting event or experience.
- The adolescent reported the need to receive some support after talking about an upsetting event or experience.

The interview will be terminated if:

- Adolescent is too distressed to continue the interview.
- Adolescent requested that.

The researcher will, with the persons consent, refer to others:

- When major health or safety issues are raised within the interview which require further investigation or intervention.

The researcher intervention will include:

1. Consult the in charge medical consultant who is involved with this study (Dr.Gerry Canny) for his medical advice**.**
2. Request the service of the social worker in the department.
3. Consult the research supervisory team for any modification on the interview table to minimise possible risk

Appendix 8: Interview guide for Adolescents and young adults- in depth interview

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Introduction:

- Introduce yourself for the participant.
- Confirm that the tape recorder is working.
- Thank the interviewee for his/her agreement to take part of this study.
- Remind the interviewee with his/her rights during the interview as per the consent form and the patient information sheet, and assure him /her that he/she can stop recording, stop the interview, or withdraw from the interview at any time.

Exploration question:

- Tell me about your experience of moving from X hospital to SVUH?

Objective 1:

1. **Identify the needs of adolescents with CF and their parents during transition from paediatric to adult health care settings.**

Questions that will achieve the objective:

Before the transfer

- Can you talk to me about your care at X hospital?

- What did you find most helpful and supportive?
- What was least helpful and supportive?

During the transfer

- What was most important to you when moving from X to SVUH?
- Can you describe the experience of moving to the adult hospital ?
- what was that like for you ?

After the transfer

- What were your needs when you first transferred to SVUH?
- What was your first experience of care like at SVUH?
- Can you tell me what was different to the care you received at X hospital?

Objective 2:

2. **Identify factors that facilitate or hinder the transition of adolescents with CF from paediatric to adult health care settings.**

Questions that will achieve the objective:

- Can you tell me /describe/ share any experiences about the transfer that went well?
- Can you tell me /describe/ share any experiences about the transfer that did not go so well?
- Was there any action/intervention/ event that did not help you during the transfer?

Objective 3:

4. **Recommend a set of relevant and feasible transition service guidelines , based on the perspectives of a professional health care providers and informed by the adolescents and their parents experiences.**

Questions that will achieve the objective:

- Considering your experiences , what practices or actions would you recommend to health care professionals that would help you to move from one hospital /care setting to another?

Appendix 9: Interview guide for parents/guardians - in depth interview

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Introduction:

- Introduce yourself for the participant.
- Confirm that the tape recorder is working.
- Thank the interviewee for his/her agreement to take part of this study.
- Remind the interviewee with his/her rights during the interview as per the consent form and the patient information sheet, and assure him /her that he/she can stop recording, stop the interview, or withdraw from the interview at any time.

Exploration question:

- Tell me about your experience during the movement of your son/daughter from X hospital to SVUH?

Objective 1:

3. **Identify the needs of adolescents with CF and their parents during transition from paediatric to adult health care settings.**

Questions that will achieve the objective:

Before the transfer

- Can you talk to me about your son/daughter care at X hospital?

- What did you find most helpful and supportive?
- What was least helpful and supportive?

During the transfer

- What was most important to you during the movement of your son/daughter from X to SVUH?
- Can you describe the experience of moving to the adult hospital ?
- what was that like for you ?

After the transfer

- What were your needs when your son/daughter first transferred to SVUH?
- What was your first experience of care like at SVUH?
- Can you tell me what was different to the care your son/daughter received at X hospital?

Objective 2:

4. **Identify factors that facilitate or hinder the transition of adolescents with CF from paediatric to adult health care settings.**

Questions that will achieve the objective:

- Can you tell me /describe/ share any experiences about the transfer that went well?
- Can you tell me /describe/ share any experiences about the transfer that did not go so well?

- Was there any action/intervention/ event that did not help you during the transfer?

Objective 3:

5. **Recommend a set of relevant and feasible transition service guidelines , based on the perspectives of a professional health care providers and informed by the adolescents and their parents experiences.**

Questions that will achieve the objective:

- Considering your experiences , what practices or actions would you recommend to health care professionals that would help your son/daughter to move from one hospital /care setting to another?

Appendix 10: In depth interview Data analysis guide

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Data analysis guide: based on Van Manen Data Analysis strategy (Van Manen, 1990)

1. Transcribe the interviews recordings
2. Study the lived experience description (interview transcription) to achieve familiarization with data.
3. Highlighting the main phrases in the text.
4. Identifying commonalities or possible commonalities between interview texts.
5. Clustering similar codes to each other .
6. Capturing in singular statements or codes the main thrust of the meaning of the themes
7. Identifying categories and subcategories.
8. Comparing categories to each other's and identifying main themes.

Appendix 11: Interview guide for focus group interview

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Focus group interview guide

The focus group interview will be conducted by the researcher and an assistant whose main duty will be to take notes about the interaction between the participants during the interview.

As Voice recording might have effect on the ease of communication and free exchange of data between participants and researcher during the interview, which was noticed during the in-depth face-to-face interviews and the pilot focus group interviews. Some strategies will be employed to overcome this effect, these include:

1. Technology used for recording
    - A highly sensitive recorder with the smallest possible size will be used so that it is unobtrusive during the interview.
    - The interviewer should minimise the visual prompts that indicate the participant is being recorded.
2. Pre-interview
    - The interviewer will arrive earlier to arrange the setting and to fit and check the recording instrument, the computer and the projector ,before the participant arrives, to allow the participant and the researcher to focus on the interview and exchange conversation in a less formal way.

- The setting where the interview is taking place should be chosen so as to achieve the same goal of making the interview look like everyday social conversation.

Objective to be achieved during this focus group interview

1. **Recommend a set of relevant and feasible transition service guidelines , based on the perspectives of professional healthcare providers and informed by the adolescents' and their parents' experiences.**

Introduction

- Introduce yourself and the assistant to the participants.
- Thank the interviewees for their agreement to take part in the study.
- Give a ten-minute presentation about the results of the in-depth interviews with the adolescents/young adults and their parents.
- At this stage the assistant will assign number codes for the participants and start recording the interactions.

Exploratory question

- Tell me what do you think about these finding?
- And how relevant it is to the practice in your hospital?

Theme one : Preparing for transition

Categories and subcategories

1. **sharing knowledge**
   - **a.** information about health-related issues
   - **b.** information about the other hospitals

Questions that will address this theme

- so, thinking about information , in your opinion,
    - what's the best time to provide information ?
    - what's the best way to do that?
    - And How can we assess the child/parents understanding of this information?

2. <u>mitigating the negative psychological effect of transition</u>

a. mitigate concerns
b. empower adolescents

Questions that will address this theme

- Now, if we talk about the psychological effects of transition , what do you think can we do to alleviate adolescents/parents concerns during transition ?
- And how can we empower them during transition?
    - What about the timing and the way , When and how should these interventions been done?
    - And finally, How can we know that these interventions are effective?

<u>Theme two: Amorphous service</u>

Categories and subcategories

1. <u>Structured transition programme</u>

a. no current transition programme which could be of significant help
b. transition preparation that consider developmental stage and carried out in an adolescent friendly environment

Questions that will address this theme:

- In the light of your experience, what elements/components/interventions should a transition programme include?
    - How can these elements be tailored to the adolescents'/young adults' developmental stage?
    - How can the environment be tailored to the adolescents'/young adults' developmental stage?
    - How can we tell if any proposed transition programme is effective?

2. <u>Adolescents and young adults… the need to be involved and listened to</u>

a. Focus on the human side of the service rather than on repetitive paper and clinical tasks.
b. Avoid labelling patients and the use of inappropriate communication styles.

Questions that will address this theme

- Now looking at the current services, how can we modify it to provide a better and more client focused transition service?
- And how can our communication be tailored to be more suitable for adolescents?

3. <u>Service provided on a timely basis</u>

a. Early, planned, transition preparation.

Questions that will address this theme

- In the light of your experience, how can healthcare professionals plan the transition service?
    - What age (s) do you think would be the most suitable to start preparing children/adolescents for the transition?
    - Who should be involved in the planning for the transition?
    - What should be the component of any transition plan?

Appendix 12: Analysis guide for the focus group interview

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Analysis guide for the focus group interview

1. The data is captured and handled by voice recording in addition to the notes taken.
2. Immediately after each focus group, a discussion and debriefing between the moderator and the assistant will take place to capture the first impression from the data. The discussion will include :
    a. What are the most important themes or ideas discussed ?
    b. How did this differ from what we expected ?
    c. What quotes are most important and should be highlighted and remembered?
    d. Should we do anything differently for the next focus group?
3. The tape recording will be listened to and all the relevant conversations will be transcribed.
4. the researcher then will repeatedly go read the transcripts and as s/he comes across idea or phenomena a label is attached
5. When the same idea or phenomena reappear the label is once again attached
6. Similar codes will be gathered and then combined under one heading.
7. Participant verification of data, will be then conducted through the survey in the following phase.

Refernces:

Richard A. Krueger (1998)Analyzing and reporting focus group results, Sage Publication Inc.

Appendix 13: Information sheet for filling out questionnaire....CF patients

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Dear Participant,

Thank you for taking part in this study, your feedback on this survey is very important and much appreciated.

The goal of this survey is to recommend to health care professionals a set of guidelines that help them provide better care for the adolescents during their transition or movement to a new adult setting when they reach the age of transition.

As a young adult or parent for young adult who has gone through this process already, you would be able to tell us what health care intervention would have been important to you and you would like to see included in another adolescents preparation for the movement the adult CF setting, and which intervention would you think is easier to be implemented in that setting

There are (54) items in the survey, collectively the items will guide the care that health care professionals will deliver for you/your child in the future, what you needs to do during this survey is to tell us from your point of view about how important is each item and whether it can be implemented in the CF centres in Ireland or not.

This can be done following this guide :

1. To rate the ***importance*** of each item to be part of the care provided for the adolescents during their movement from children to adult hospital, please choose one of the following answers:

What do you think about the sentence	What answer to choose
if you think that this sentence or guideline of a ***special importance and high benefit to the adolescents and should be included*** in the care when health care professionals are preparing adolescent for transition or movement to the adult hospital.	Choose "**Strongly Agree"** (represented by number 5)
if you think that this ***would be of benefit*** to the adolescents	Choose "**Agree"** (represented by number 4)
If you don't know, or cant decide	Choose "**I don't know"** (represented by number 3)
if you think that this ***would not be of benefit*** to the adolescents .	Choose "**Disagree"** (represented by number 2)
if you think that this guideline ***of no importance and no benefit at all to the adolescents and should not be included***in any transition program	Choose **"Strongly Disagree"** (represented by number 1)

2. To rate the ***feasibility*** of each item to be applied as part of the care provided for the adolescents during their movement from children to adult hospital, please choose one of the following answers

What do you think about the sentence	What answer to choose
. *if you think that this item is* ***highly applicable in any setting and should be applied as basic component*** *of* the care when health care professionals are preparing adolescent for transition or movement to the adult hospital.	Choose "**Highly Feasible"** (represented by number 5)
if you think that this item ***is applicable and can be applied in most settings*** as a component of the transition service.	Choose "**Feasible"** (represented by number 4)
If you don't know, or can't decide	Choose "**I Can't Decide"** (represented by number 3)
if you think that this item ***is not applicable in most settings*** as a component of the transition service.	Choose "**Not Feasible"** (represented by number 2)
if you think that ***this item is not applicable at all in all settings*** *as a component of the transition service.*	Choose **"Not Feasible at All"** (represented by number 1)

Finally, I would like to thank you again for your participation and will be looking forward to receive your completed survey. If you need any help filling out this survey please do not hesitate to contact me on the following email address: **n.al-yateem1@nuigalway.ie**.

Appendix 14: Information sheet for filling out questionnaire....healthcare professionals

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Dear Participant,

Thank you for taking part in this study, your feedback on this survey is very important and much appreciated.

The goal of this survey is to recommend a set of guidelines for best health care practices for transition of adolescents with CF from children to adult health care setting. These guidelines are drawn from focus group interviews held for health care professionals to discuss the reported needs of adolescents and young adults during their transition .

Please note that these are ***guidelines*** for practice and not an exhaustive list of practices and interventions of the transition service, therefore some of the items in the survey might appear as general in nature, but it will be up to the health care professionals in each clinical setting to design specific practices and interventions that achieve these guidelines.

There is (54) items in this survey falling under (6) subsections. Please rate ***all*** the items in the survey following this key :

3. Please rate **ALL** the items in the survey , for your ***agreement***on each item to be included in the guidelines by choosing one of the following answers:

   a. **Strongly agree (5)**, *e.g. if you think that this item of a special importance and high benefit to the adolescents and should be included in any transition program*
   b. **Agree (4),** *e.g. if you think that this would be of benefit to the adolescents*
   c. **Disagree (2),** *e.g. if you think that this would not be of benefit to the adolescents .*
   d. **Strongly Disagree(1),** *e.g. if you think that this item of no importance and no benefit at all to the adolescents and should not be included in any transition program*
4. Please rate **ALL** the items in the survey for it's ***feasibility*** to be applied as part of any transition service by choosing one of the following answers:
   a. **Highly feasible (5)**, *e.g. if you think that this item is highly applicable in any setting and should be applied as basic component of any transition service.*
   b. **Feasible (4),***e.g. if you think that this item is applicable and can be applied in most settings as a component of the transition service.*
   c. **Not Feasible (2),***e.g. if you think that this item is not applicable in most settings as a component of the transition service.*
   d. **Not feasible at all (1),** *e.g. if you think that this item is not applicable at all in most of settings as a component of the transition service.*

Finally, I would like to thank you again for your participation and will be looking forward to receive your completed survey. If have any questions about filling out this survey, please do not hesitate to contact me on the following email address: **n.al-yateem1@nuigalway.ie**.

Nabeel Al-Yateem, RN. MSN. PhD Candidate.

School of Nursing and Midwifery.

National University of Ireland- Galway.

Appendix 15: Content validity tool of the survey questionnaire

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Instrument Content Validity Testing

Dear Sir/Madam,

As an experienced health care professional who are working with patients with CF, you are invited to take part in evaluating the validity of the content of this survey .

This survey is a part of a bigger project that aimed to Develop guidelines for practice for the transition of adolescents with CF from children to adult health care setting .

The survey is intended to elicit transition service stakeholders evaluation of the suggested service guidelines developed after many interview with CF adolescents, their parents and health care professionals.

The survey is composed of 59 items that falls under 6 main headings , I should be very grateful if you rate the relevance of each item to be included in the transition survey, this is done by choosing the number corresponding to the rating you have given in column 2 of the table on next pages of this document using the following key ,

1 = The item is not relevant to be included in the transition survey.

2 = The item needs major revisions to be included in the transition survey.

3 = The item needs minor revisions to be included in the transition survey.
4 = The item is relevant to be included in the transition survey.

Where you rate the item as a 1, 2 or 3, please comment on your reasons for your rating and/or on the revisions required.

Finally, I would like to thank you for your participation and will be looking forward to receive your completed survey. If you need any help filling out this survey please do not hesitate to contact me on the following email address: **n.al-yateem1@nuigalway.ie**.

Nabeel Al-Yateem, RN. MSN. PhD Candidate.

School of Nursing and Midwifery.

National University of Ireland- Galway.

Initial assessment phase:	
6. Healthcare professionals should assess the adolescent's understanding of the timing of the transition	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
7. Healthcare professionals should assess the adolescent's understanding of the adult CF centres which are available for him/her to transfer to	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
8. Healthcare professionals should assess the adolescent's understanding of what is required from him/her during the transition process	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
9. Healthcare professionals should assess the adolescent's understanding of the differences in terms of care between their current setting and the adult setting	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _

10. Healthcare professionals should assess the types of information that the adolescent and their family would like to receive more of during the preparation for the transition, the actual transition and after the transition	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
11. Healthcare professionals should assess the availability of family support for the adolescent during the preparation for transition and the actual transition	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
12. Healthcare professionals should assess the need of adolescents with CF for other resources that aid during the care and transition *(e.g. additional government resources, funds, assistance etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
13. Healthcare professionals should assess the sources of information about CF and CF centres which are available to the adolescent and his/her family during course of treatment and preparation for transition	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
14. Healthcare professionals should assess whether there are possible role models to help the adolescent during the transition process	□ ①**Not relevant** □ ② **Needs major revisions**

	□ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
15. healthcare professionals should assess the impact of developmental transitions taking place *(e.g. from childhood to adolescence, or from adolescence to adulthood)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
16. Healthcare professionals should assess whether other situational transitions are taking place and its impact on preparation for transition *(e.g. starting or finishing college or a course, or being discharged or admitted for treatment)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
17. Healthcare professionals should assess whether other health-related transitions are taking place and its impact on preparation for transition *(e.g. a new diagnosis of another health problem, another complication within the current illness, a change in treatment options, undergoing surgery, etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
18. Healthcare professionals in an adult setting should assess the effects of the change of treatment setting on the young adults *(e.g. their experience of new policies, practices or routines as a result of the move to a new organisation)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant**

	Comments:_ _
19. Healthcare professionals should assess whether there are any specific cultural needs to be considered during the adolescent's preparation for transition	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
20. Healthcare professionals should assess the adolescent's social status, which may impact on the transition or the preparation for the transition *(e.g. separated parents, single parent, guardians, etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
21. Healthcare professionals should assess the economic status of the adolescent's family, as this might affect the transition or the preparation for the transition *(e.g. poor economic background, cannot afford the travel to a particular facility, etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
22. Healthcare professionals should assess whether or not the adolescent has another physical disability that means they require special assistance *(e.g. home visit, available support during visit, etc)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _

23. Healthcare professionals should assess whether long-distance travel is involved that might require a special arrangement with the clinic *(e.g. Early clinic, arranging accommodation, home visits, etc)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
24. Healthcare professionals should assess whether the adolescent has another sibling with cystic Fibrosis which might require a special arrangement with the clinic *(early clinic, same day clinic for both sibling, coordinating appointment date if sibling attending different setting)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
25. Healthcare professionals should assess whether the adolescent has another chronic illness which might mean that they require special assistance *(multi speciality meetings, coordinated tests and clinic dates, etc)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
Planning of care	
26. Healthcare professionals should start planning for the transition when the child is aged around 14 year old	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant**

	Comments:_ _ _ _ _ _ _ __ _
27. Planning the transition is a continuous process and should continue until the transition takes place	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _ _ _ _ _ _ __ _
28. Planning for the transition should involve the adolescent and their family, in addition to the healthcare professionals	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
29. The planning for the transition service should include assigning a key worker for each adolescent in order to facilitate the transition service	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _ _ _ _ _ _ _ __ _
30. Assigning a key worker will help establish a supportive, open relationship with the adolescent and their family	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _ _ _ _ _ _ _ __ _

31. An important role for the key worker is to carry out the initial assessment of care, and afterwards the evaluation of the effectiveness of interventions	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
32. An important role for the key worker is to modify plans or plan any further interventions based on the results of the continuous evaluation of care	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
33. An important role for the key worker is to act as a source of information for the adolescent and their family during the preparation for the transition and the actual transition	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
34. An important role for the key worker is to participate in the process of the handover of care to the adult service	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _

35. The plan for the future should act as the basis for any further healthcare interventions, in order to make these interventions more relevant and more effective	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
36. The plan for the future should incorporate the adolescent's wishes and needs *(e.g. educational needs, possible work, choice of adult care facility , what is important to the adolescent, etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
37. The plan for the future should contain dates and timelines in order to achieve the agreed-upon tasks and activities where possible	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
Continuous evaluation of care:	
38. Healthcare professionals should observe the adolescent's gradual progress in acquiring the communication skills necessary for dealing with healthcare professionals	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _

39. Healthcare professionals should observe the gradual increase in the adolescent's knowledge of CF *(e.g. symptoms, treatment, etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
40. Healthcare professionals should seek feedback from the adolescent, their family and other healthcare professionals about the adolescent/young adult's participation in care	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
41. Healthcare professionals should seek feedback from the adolescent, their family and other healthcare professionals about the adolescent's achievement of the planned objectives	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
42. Healthcare professionals should continuously evaluate the adolescent/young adult's personal development and their capability of dealing with the majority of people in various situations	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _

43. Healthcare professionals should continuously evaluate the adolescent/young adult's abilities to manage his/her own care, and master all that is required from him/her to the level of competent self-care.	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
44. Healthcare professionals in the adult setting should evaluate whether the young adult feels settled in their new adult-focused setting	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
45. Healthcare professionals should evaluate the adolescent/young adult's use of the services and resources available to him/her within this setting (*e.g. contacting staff in the new setting when needed, requesting a particular service, joining a particular support group, etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
46. Healthcare professionals in the adult setting should evaluate whether the young adult is achieving a satisfactory attendance rate at the clinic	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
47. Healthcare professionals in both paediatric and adult settings should arrange an evaluation meeting a few months after the completion of the transfer	□ ①**Not relevant** □ ② **Needs major revisions**

	□ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
Provision of information	
48. Information provided for adolescents should be delivered in information sessions that are held periodically and regularly for this purpose only	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
49. During information sessions, opportunities should be provided for adolescents to ask questions and share their opinions	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
50. Information provided for adolescents during the preparation for transition should be appropriate for their developmental stage	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
51. Information provided during the preparation for transition should be tailored to every individual adolescent's needs	□ ①**Not relevant** □ ② **Needs major revisions**

	□ ③Needs minor revisions □ ④Relevant **Comments:**_ _ _ _ _ _ _ _ _ — _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
52. Information provided for adolescents during the preparation for transition should be delivered using age-appropriate communication techniques	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
53. Information provided for adolescents during the preparation for transition should be provided to both the adolescent and their family	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
54. Helpful written material should be conveyed in a format that is understandable and attractive for both the adolescents and their parents	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _ _ _ _ _ _ _ — _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
An approach that promote independence:	
55. When an adolescent approaches the age of 14, there should be a gradual shift away from child and family centred care towards adolescent orientated care, without ignoring the role of the parents	□ ①**Not relevant** □ ② **Needs major revisions**

	□ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
56. Throughout their time in care, healthcare professionals should empower adolescents and promote their independence using various strategies *(e.g. providing information, considering their opinions)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
57. Throughout the care process and through the time of transition, adolescents should be listened to, involved and encouraged to ask questions, express their opinions and make decisions	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
Environment, gradual and thorough handover to the adult hospital, and training	
58. Transitional care should be provided where possible in dedicated facilities that are suitable for the adolescent/young adult's developmental stage .	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
59. A period of overlap between the paediatric and the adult settings is helpful to adolescents/young adults until they settle into adult care	□ ①**Not relevant** □ ② **Needs major revisions**

	□ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
60. During the period of overlap, adolescents/young adults will practice and develop their independence skills	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
61. Constructive feedback from the adolescent/young adult and their family during this period of overlap should be promoted to help to improve the care provided	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
62. During this time of overlap between the paediatric and the adult settings, maintaining a good standard of communication between the adolescent/young adult, the paediatric team and the adult team is essential to improving the service provided to the adolescent	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _
63. Follow-up mechanisms that are agreed upon between both the children and adult settings should be used to ensure that the adolescent understand the processes in the adult clinic and therefore promote a positive post-transition period	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant**

	Comments:_ _
64. Healthcare professionals who are involved in the care of adolescents should receive training on issues specific to adolescents developmental stages *(e.g. communication skills, developmental needs, care during transitional period, sexual health,etc.)*	□ ①**Not relevant** □ ② **Needs major revisions** □ ③**Needs minor revisions** □ ④**Relevant** **Comments:**_ _

Appendix 16: Invitation for participation in questionnaire - CF patients

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Dear Participant ,

This is an invitation for you to participate in this survey about the transition of adolescents with Cystic Fibrosis (CF) from children to adult health care setting. It will take you approximately 20 minutes to do that.

I would encourage you to take part in this survey as a young adult who has passed already through this experience , Your opinions is very important and will help improve the service provided for other adolescents who did not pass through it yet.

To participate in this survey please click the link blow, this will take you to the survey page where you can find all the necessary information to fill out the survey.

This survey was developed based on data about the transition of adolescent with CF from children to adult healthcare setting, collected from adolescents with CF, their parents and health care professionals working with them, over the last couple of years.

Thank You and looking forward to receive your completed survey.

Nabeel Al-Yateem, RN. MSN. PhD Candidate.

School of Nursing and Midwifery.

National University of Ireland- Galway.

Appendix 17: Invitation for participation in questionnaire-health care professionals

Developing Guidelines for best practices, that address the transition of adolescents with CF from children to adult healthcare setting in Ireland.

Dear Participant ,

This is an invitation for you to participate in this survey about the transition of adolescents with Cystic Fibrosis (CF) from children to adult health care setting. It will take you approximately 20 minutes to do that.

I would encourage you to take part in this survey as a an experienced healthcare professional in this field, Your opinions is very important and will help improve providing the service provided for adolescents with CF during this critical time of their life.

To participate in this survey please complete the attached questionnaire. In the same pack, you will find an instructions on how to do that.

This survey was developed based on data about the transition of adolescent with CF from children to adult healthcare setting, collected from adolescents with CF, their parents and health care professionals working with them, over the last couple of years.

Thank You and looking forward to receive your completed survey.

Nabeel Al-Yateem, RN. MSN. PhD Candidate.

School of Nursing and Midwifery.

National University of Ireland- Galway.

Appendix 18: Survey questionnaire

IMPORTANT NOTE: <u>YOU SHOULD SELECT TWO ANSWERS FOR EACH ITEM.</u> **ONE RATE THE IMPORTANCE OF THE ITEM, AND THE OTHER RATE ITS FEASIBILITY.**								
Key: 4: Strongly agree 3: Mostly agree **2: Mostly disagree 1: Strongly disagree**					**Key: 4: Highly feasible 3: Feasible** **2: Not Feasible 1: Not feasible at all**			
Initial assessment phase								
3. Healthcare professionals should assess the adolescent's understanding of the timing of the transition	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
4. Healthcare professionals should assess the adolescent's understanding of the adult CF centres which are available for him/her to transfer to	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
5. Healthcare professionals should assess the adolescent's understanding of what is required from him/her during the transition process	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
6. Healthcare professionals should assess the adolescent's understanding of the differences in terms of care between their current setting and the adult setting	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
7. Healthcare professionals should assess the types of information that the adolescent and their family would like to receive more of during the preparation for the transition, the actual transition and after the transition	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

8. Healthcare professionals should assess the availability of family support for the adolescent during the preparation for transition and the actual transition	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
9. Healthcare professionals should assess the need of adolescents with CF for other resources that aid during the care and transition *(e.g. additional government resources, funds, assistance etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
10. Healthcare professionals should assess the sources of information about CF and CF centres which are available to the adolescent and his/her family during course of treatment and preparation for transition	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
11. healthcare professionals should assess the impact of adolescent development to adulthood*(e.g. moving to an independent house, starting work, starting relationship, etc)* on the transition to the adult CF hospital.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
12. Healthcare professionals should assess the impact of other major events *(e.g. starting or finishing college or a course, or being discharged or admitted for treatment)* that are taking place on the transition to the adult CF hospital.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
13. Healthcare professionals should assess whether other health-related events *(e.g. a new diagnosis of another health problem, another complication within the current illness, a change in treatment options, undergoing surgery, etc.)* on preparation for transition to the adult CF hospital.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
14. Healthcare professionals in an adult setting should assess the effects of the change of treatment setting on the adolescent *(e.g. their experience of new policies, practices or routines*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

as a result of the move to a new organisation)								
15. Healthcare professionals should assess whether there are any specific cultural needs to be considered during the adolescent's preparation for transition	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
16. Healthcare professionals should assess the adolescent's social status, which may impact on the transition or the preparation for the transition *(e.g. separated parents, single parent, guardians, etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
17. Healthcare professionals should assess the economic status of the adolescent's family, as this might affect the transition or the preparation for the transition *(e.g. poor economic background, cannot afford the travel to a particular facility, etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
18. Healthcare professionals should assess whether or not the adolescent has another physical disability that means they require special assistance *(e.g. home visit, available support during visit, etc)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
19. Healthcare professionals should assess whether the adolescent has another sibling with cystic Fibrosis (CF) which might require a special arrangement with the clinic *(early clinic, same day clinic for both sibling, coordinating appointment date if sibling attending different setting)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
20. Healthcare professionals should assess whether the adolescent has another chronic illness which might mean that they require special assistance *(multi speciality meetings, coordinated tests and clinic dates. Etc)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

Planning of care								
21. Healthcare professionals should start planning for the transition to adult CF hospital when the child is aged around 14 year old	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
22. Planning is a continuous process and should continue until the transition to the adult CF hospital takes place	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
23. Planning for the transition should involve the adolescent and their family, in addition to the healthcare professionals	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
24. The planning for the transition service should include assigning a key worker for each adolescent in order to facilitate the transition service	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
25. During the planning process, the key worker should carry out the initial assessment of care, and afterwards the evaluation of the effectiveness of interventions	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
26. The key worker should modify plans or plan any further interventions based on the results of the continuous evaluation of care	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
27. The key worker will act as a source of information for the adolescent and their family during the preparation for the transition and the actual transition	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
28. The key worker should participate in the process of the handover of care to the adult service	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
29. The plan for the future should guide healthcare interventions, in order to make these interventions more relevant and more effective	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

30. The plan for the future should incorporate the adolescent's wishes and needs *(e.g. educational needs, possible work, choice of adult care facility , what is important to the adolescent, etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
31. Where possible, the plan for the future should contain dates and timelines in order to achieve the agreed-upon tasks and activities	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
Continuous evaluation of care								
32. Healthcare professionals should observe the adolescent's gradual progress in acquiring the communication skills necessary for dealing with healthcare professionals	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
33. Healthcare professionals should observe the gradual increase in the adolescent knowledge of CF *(e.g. symptoms, treatment, etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
34. Healthcare professionals should seek feedback from the adolescent/young adult, their family and other healthcare professionals about the adolescent/young adult's participation in care	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
35. Healthcare professionals should seek feedback from the adolescent/young adult, their family and other healthcare professionals about the adolescent's achievement of the planned objectives	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
36. Healthcare professionals should continuously evaluate the adolescent/young adult's abilities to manage his/her own care, and master all that is required from him/her to the level of competent self-care.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

37. Healthcare professionals in the adult setting should evaluate whether the young adult feels settled in their new adult-focused setting	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
38. Healthcare professionals should evaluate the adolescent/young adult's use of the services and resources available to him/her within this setting (*e.g. contacting staff in the new setting when needed, requesting a particular service, joining a particular support group, etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
39. Healthcare professionals in the adult setting should evaluate whether the young adult is achieving a satisfactory attendance rate at the clinic	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
Provision of information								
40. Information provided for adolescents should be delivered in information sessions that are held periodically and regularly for this purpose only.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
41. During information sessions, opportunities should be provided for adolescents to ask questions and share their opinions	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
42. Information provided for adolescents during the preparation for transition should be appropriate for their developmental stage	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
43. Information provided during the preparation for transition should be tailored to every individual adolescent's needs	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
44. Information provided for adolescents during the preparation for transition should be delivered using age-appropriate	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

communication techniques								
45. Information provided for adolescents during the preparation for transition should be provided to both the adolescent and their family	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
46. Helpful written material should be conveyed in a way that is understandable for both the adolescents and their parents	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
An approach that promotes independence								
47. When an adolescent approaches the age of 14, there should be a gradual shift towards an adolescent orientated care, without ignoring parents.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
48. Throughout their time in care, healthcare professionals should empower adolescents/young adults and promote their independence using various strategies *(e.g. providing information, considering their opinions, etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
49. Throughout the preparation for transition, adolescents should be listened to, involved and encouraged to ask questions, express their opinions and make decisions	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
Environment, gradual and thorough handover to the adult hospital, and training								
50. Where possible, Transitional care should be provided in dedicated facilities that are suitable for the adolescent/young adult's developmental stage .	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
51. A period of overlap, where the care is provided jointly by the children and the adult professionals is helpful to adolescents until they settle into adult care	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

52. During the period of overlap, adolescents will practice and develop their independence skills	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
53. Constructive feedback from the adolescent and their family during this period of overlap should be promoted to help to improve the care provided	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
54. During this time of overlap between the children and the adult settings, maintaining a good communication between teams in both setting is essential to improving the service provided to the adolescent.	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
55. Follow-up mechanisms that are agreed upon between both the children and adult settings should be used to ensure safe post-transition period	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**
56. Healthcare professionals who are involved in the care of adolescents should receive training on issues specific to adolescents developmental stages *(e.g. communication skills, developmental needs, care during transitional period, sexual health, etc.)*	**4**	**3**	**2**	**1**	**4**	**3**	**2**	**1**

Appendix 19: Ethical Approval

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Merlin Park University Hospital
Ospidéal na h-Ollscoile, Páirc Mheirlinne
GALWAY UNIVERSITY HOSPITALS

Clinical Research Ethics Committee
Unit 4
Merlin Park Hospital
Galway.

13th April, 2011.

Mr. Nabeel Al-Yateem
38 Woodstown Way
Knocklyon
Dublin 16.

Ref: C.A. 545 – Patient and Family Needs During Transition from Paediatric to Adult Health Care Services: Patients, Families, and Health Care Professionals Experiences

Dear Mr. Al-Yateem,

I have considered the above project, and I am happy to grant Chairman's approval to proceed.

Yours sincerely,

Dr. Shaun T. O'Keeffe
Chairman Clinical Research Ethics Committee.

Merlin Park University Hospital, Ospidéal na h-Ollscoile, Páirc Mheirlinne,
Galway, Ireland. Tel: 00 353 (0)91 757631

Beaumont Hospital
Ethics (Medical Research) Committee

Chairperson: Professor Gerry McElvaney
Convenor: Professor Alice Stanton

Administrator: Gillian Vale

21st April 2011

Mr. Nabeel Al-Yateem RN, MSN.
PhD Candidate
School of Nursing and Midwifery
National University of Ireland
Galway

Dear Mr. Al-Yateem

11/Oth/12 – Nabeel Al-Yateem (NUI-Galway) – Developing Guidelines for best practice that address adolescent needs during transition from children to adult healthcare setting in Ireland.

- **Phase 2: Distributing a Self-Administered Questionnaire to Healthcare Professionals who are working with patients with Cystic Fibrosis (CF)**

Many thanks for your correspondence dated 5th April 2011, and e-mail correspondence dated 14th and 18th April 2011.

I confirm that Beaumont Hospital Ethics (Medical Research) Committee endorses the decision of Our Lady's Children's Hospital Research Ethics Committee (17th December 2008), St. Vincent's Healthcare Group Research Ethics Committee (25th March 2009) and Adelaide and Meath and National Children's Hospital Ethics Committee (26th January 2011) and that the distribution of self-administered questionnaires to healthcare professionals working with CF patients may proceed as outlined **subject to the agreement of** Dr. Cedric Gunaratnam (Respiratory Consultant, Cystic Fibrosis Unit)

Kind Regards

Professor Gerry McElvaney
Chairperson
Ethics (Medical Research) Committee

c.c.

Dr. Cedric Gunaratnam
Consultant in Respiratory Medicine
Cystic Fibrosis Unit
Beaumont Hospital

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Research Ethics Committee
Sligo General Hospital
The Mall
Sligo
Chairman Dr. John Williams
Adm. Mette Jensen Kavanagh

Nabeel Al-Yateem
38 Woodstown Way
Knocklyon
Dublin 16

May 10th 2011

Re. Research Ethics Application

Dear Mr. Al-Yateem,

The Research Ethics Committee (REC) at Sligo General Hospital has received the submission and amendment of the study "*Developing guidelines for transition service from children to adult health care setting for adolescents with CF*", which is approved by several recognised RECs in Ireland. The REC Chairman has given a **favourable ethical opinion** for the study.

Documents reviewed:
- REC Application Form
- Beaumont Hospital (Medical Research) Ethics Committee

The REC requires that approved studies submit an annual report to the REC. The annual report for the above study is due on May 18 2012

Yours sincerely,

Dr John Williams
Chairman

Ospidéal Mhuire na Leanaí, Cromghlinn
Our Lady's Children's Hospital, Crumlin

ETHICS (MEDICAL RESEARCH) COMMITTEE OFFICE
Tel: (01) 409 6307/6243

Mr Nabeel Al-Yateem
Staff Nurse - Theatre
Our Lady's Children's Hospital
Crumlin
Dublin 12

17th NDecember 2008

REC Reference: GEN/89/08

Re: Patient and Family Needs During Transition from Paediatric to Adult Health Care Services: Patients, Families, and Health Care Professionals Experiences
Chief Investigators: Dr. Gerry Canny, Mr. Nabeel Al-Yateem.

Dear Mr Al-Yateem

Further to our previous correspondence, dated 19th November 2008, in relation to the above project.

I write to advise you that final ethical approval for the above project was given on 17th December 2008, following examination of the altered documentation as requested by the Committee.

Yours sincerely

Claire Rice
Secretary
Research Ethics Committee

CC: Dr Gerry Canny

Email: ethics.committee@olhsc.ie

Elm Park
Dublin 4
Tel: +353 1 221 4000
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Web: www.st-vincents.ie

St. Vincent's University Hospital

Nabeel Al-Yateem
School of Nursing and Midwifery
National University of Ireland – Galway

15 October 2008

Dear Nabeel

Re: Research study "Patient and Family Needs During Transition From Child To Adult Health Care Services: Adolescents, Families and Health Care Professionals experiences."

Following our recent discussions about this Doctoral research study, I am delighted to inform you that the Senior Cystic Fibrosis Social Worker in the Department of Social Work at St Vincent's University Hospital is pleased to provide the necessary counselling support to the research participants (specifically adolescents and family members currently under the care of services at SVUH) in the above mentioned study if the need should arise.

Yours Sincerely

Linda Groenewald
Senior Medical Social Worker
Cystic Fibrosis

St. Vincent's Healthcare GROUP LIMITED

GROUP CHIEF EXECUTIVE: Mr. Nicholas C. Jermyn
BOARD OF DIRECTORS: Chairman: Prof. Noel Whelan, Mr. Edmond J. Bergin, Sr. Eugene Butler, Ms. Louise English, Prof. M. X. FitzGerald, Mr. Nicholas C. Jermyn, Mr. Joe Leyden, Sr. Anne MacEneaney, Ms. Gemma McCrohan, Mr. Patrick Meade, Mr. Michael Meagher, Prof. Diarmuid O'Donoghue, Dr. Risteárd Ó Laoide, Mr. William R. Quinlan, Mr. Conor Sexton, Dr. Michael Somers.

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RE: ethical approval -Nabeel

Wednesday, 26 January, 2011 16:14

From:
"Ursula Ryan" <Ursula.Ryan@amnch.ie>
To:
"Nabeel Al-yateem" <nabeelyateem@yahoo.com>

Hi Nabeel,

Thank you for your submission. I can confirm that the distribution of the self administered questionnaire does not pose any ethical issues of concern.
You may distribute your questionnaire as outlined in your submission.

I will send you a letter confirming this formally if you would please let me know where to send it.

Kind regards

Ursula Ryan
SJH/AMNCH Research Ethics Committee/
Medical Board Secretariat
Ph: 01.4142342
Email: ursula.ryan@amnch.ie

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

Western Area,
Health Service Executive.
Mayo General Hospital,
Castlebar,
Co. Mayo,
Ireland.

Tel: (094) 9042000
Fax: (094) 9021454

KB/MH

15th December 2011

Mr. Nabeel Al-Yateem, RN, MSN,
School of Nursing and Midwifery,
National University of Ireland,
Galway.

Re: Developing guidelines for transition service from children to adult health care setting for adolescents with C.F.

Dear Mr. Al-Yateem,

I am writing in relation to the above study and I am happy to inform you that Ethical Approval has been granted for your proposal to proceed as submitted.

Kind regards.

Yours sincerely,

Mr. Kevin Barry, MD, F.R.C.S.I. (Gen Surg), F.A.C.S.
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