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Abstract

This paper reports on the findings of an interpretive phenomenological study, which explored the experience of seven elderly patients with acute leukaemia receiving chemotherapy. van Manen's approach to data analysis was utilised in interpreting the participants' interview transcripts. Three main themes were interpreted from the study participants' narratives: emotions experienced on diagnosis, the need of support from family, friends, and healthcare professionals and finally, the importance of information. Although some of the findings are similar to those of previous studies examining patients with other cancers, this is the first known study to examine the lived experience of elderly patients receiving chemotherapy for acute leukaemia. All participants experienced shock and fear at diagnosis. Despite their advancing age, all participants expressed the hope that treatments would provide a good quality of life and in some cases even cure. With good support from family, friends and healthcare professionals, participants revealed that they learnt to cope with the diagnosis and its treatments.

Key words: acute, leukaemia, elderly, chemotherapy, phenomenology, cancer.

Introduction

The aim of this study was to explore and interpret the experiences of elderly patients, with limited treatment options, receiving chemotherapy for a life threatening diagnosis of acute leukaemia.

The incidence of cancer due to progressive aging has resulted in increasing numbers of elderly people being treated for cancer (Pasetto et al 2007). The current treatments for acute leukaemia include chemotherapy, radiotherapy and bone marrow transplant. However, these treatments are intensive, with many elderly patients deemed unfit for such therapies.

Although much is written on treating the elderly patient with acute leukaemia (Bolam and Hamblin 1999, Jackson and Taylor 2002, Persson et al 2001, Lang et al 2005), there is a dearth of literature on elderly patients' lived experience of receiving intensive chemotherapies for acute leukaemia. A search of the literature failed to uncover any studies on this topic. The momentum to conduct this study arose from the authors' interest with regard to the impact on elderly patients receiving intensive chemotherapy for acute leukaemia. Knowing this impact will facilitate nurses understanding of patients' experiences leading to improvements in the care they provide.

Background

The literature typically characterizes ‘elderly’ in the context of acute leukaemia as older than sixty or sixty five years of age (Dorcy 2002, Stone et al 2004). Cancer is a common disease of the older adult and unfortunately, due to age, other co-morbidities (such as past medical or surgical histories), limited treatment options, it is associated with high mortality (Balducci et al 2008).

Acute Leukaemia

Acute leukaemia is a clonal haematologic malignancy characterised by proliferation and accumulation of myeloid or lymphoid progenitors within the bone marrow (Balducci et al 2008). Excessive accumulation of either the myeloid (acute myeloid leukaemia) or lymphoid (acute lymphoblastic leukaemia) cells results in overcrowding the bone marrow by immature white cells. This leads to the patient being more prone to infections as these immature white cells fail to function as normal. Additionally other cell lines are unable to develop resulting in anaemia, leading to symptoms such as fatigue and lack of energy, and thrombocytopenia, leading to excessive bruising, bleeding and haemorrhage.

Recent years have expanded our understanding of acute leukaemia in terms of pathophysiology, cytogenetics and classification. Accordingly, new targeted therapies have been discovered and notable advances in supportive care through antibiotics and blood product support are undisputed (Balducci et al 2008). Treatment of acute leukaemia consists of many components such as induction, consolidation/intensification,

maintenance and even central nervous system prophylaxis. Decision on the components used to treat the leukaemia is dependent on the type of leukaemia diagnosed (Pui 2001).

Treating elderly patients with acute leukaemia

There are several options available when treating elderly patients with acute leukaemia which include intensive treatments, less intensive regimes, palliation and supportive care (Jackson and Taylor 2002). However, acute leukaemia remains incurable in the majority of elderly patients. The majority of elderly patients who present with acute leukaemia have many disadvantages such as other co-morbidities, poor tolerance of intensive chemotherapies and poor cytogenetics which results in poor prognosis (Robak 2004). Cytogenetics have increased our understanding of leukaemia and provide us with knowledge of patients that can have successful outcomes with chemotherapy alone and those would need bone marrow transplant. Poor tolerance of chemotherapy regimes are also believed to be caused by reduced drug metabolism and elimination, leading to increased toxicity (Cohen 1986). Additionally, incomplete drug administration and extended intervals between cycles lead to inferior long term results (Robak 2004). Moreover, elderly patients have extra negative prognostic factors such as poor performance status, age, and they normally present with a higher percentage of leukaemia cells on diagnosis (Legrand et al 1997). Nevertheless, Balducci (2007) believes that contrary to this prediction, the majority of older individuals appear to benefit from cancer treatments to an extent comparable to that of younger individuals and only a minority of these patients should be excluded from treatments due to reduced tolerance. In addition, it is reported that older people cope better psychosocially with a diagnosis of cancer and its

management than younger people; probably due to greater life experience which may lead to increased ability to cope with difficult life situations (Thomé et al 2003).

The haematology nurse plays a vital role in managing the care of patients with acute leukaemia by ensuring that their physical, psychosocial, and educational needs are met (Tapin et al 1997). Therefore, understanding the experiences of patients is vital.

Methods

This study adopted an interpretive phenomenological approach, guided by the writing of Heidegger (1927/1996). This approach is a method of seeing the significance and the meaning within the participants' experiences. The interpretive phenomenological approach was considered the most appropriate because the first author, who conducted all the interviews and undertook the analysis of data, was known to all the study participants. Therefore, bracketing, the process of eliminating all pre conceived ideas about the phenomenon being studied, as adopted with descriptive phenomenology (Dowling 2007) was deemed inappropriate.

Purposive sampling was adopted for the study. The sample of 7 participants, four male and three female, (aged between 60-79 years) whose time from initial diagnosis ranged from three months to eight months, were interviewed using a semi-structured interview. All participants were receiving their second cycle of chemotherapy except for one participant who was receiving maintenance chemotherapy for acute lymphoblastic leukaemia due to intolerability of induction chemotherapy. The rationale for interviewing

participants on their second or subsequent treatments was that they had time to come to terms with their diagnosis and were physically in better condition if they had achieved remission.

Ethical approval to undertake the study was obtained through the institution's ethics review board. Prior to being interviewed, the study participants were given both written and verbal information on the study. Chosen pseudonyms were assigned to each participant at their request. While there was no perceived harm anticipated for the participants, it is acknowledged that cancer patients, especially elderly patients are vulnerable (Holloway 2005). The very element of "time" talking to someone has the potential to expose distressing issues unrelated to the topic. This did not occur within this study; however, arrangements were made for follow up with a haematology clinical nurse specialist and a psychotherapist, should support be needed.

van Manen's (1997) steps for data analysis were utilised. Other researchers employing interpretive phenomenology guided by the writing of Heidegger (e.g. Alasad 2002, Smythe 2003, Johnson et al 2006) have also used this method. Utilizing the selected meaning approach, the first author read the text several times with the aim of identifying which statements or phrases seemed particularly revealing about the experience being described. These statements were then highlighted and included aspects such as the importance of information, support of family and friends and many different emotions experienced on hearing a diagnosis and having to commence treatments. The first author then employed the detailed reading approach. This involved the examination of every

single sentence or sentence cluster examining what was being described about the experience.

The first author also kept a reflective diary during the interviewing and analysis phases. In pursuit of enhanced reflexivity, the themes identified and reflective notes were then discussed with the second author who assumed the role of 'critical friend' (Northway 2000).

Methodological limitations

With phenomenological interpretation, there is no clear end-point, and interpretations are always open to re-interpretation. In addition, the sample was specific to one inpatient unit within a large teaching hospital. Inclusion of other inpatient units from other hospitals would have strengthened the findings by providing a broader picture. Moreover, the sample size was small due to the study inclusion criteria of older age, in the early stages of treatment for acute leukaemia.

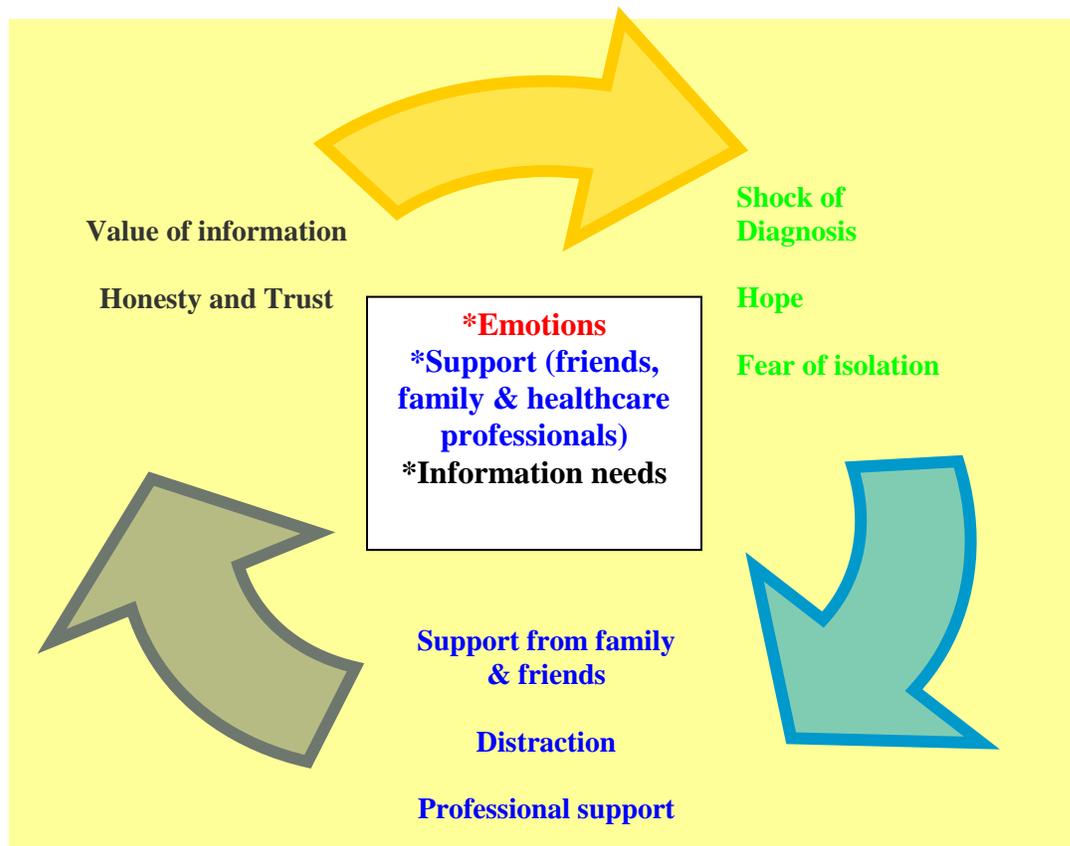
Member-checks of the participants' interview transcripts was not adopted because some of the participants' deteriorating condition. When undertaking research with vulnerable groups, Chouliara et al (2004) advise that the adoption of a patient-centred approach should guide all ethical and methodological choices. Similarly, Koch and Harrington (1998) acknowledge the problems associated with member checking with ill patients. Moreover, participants may forget the information they provide (Sandelowski 1993). However, an additional way of checking data is by requesting a peer familiar with the topic to read the transcripts, and evaluate the researchers' interpretation. This was

performed by an oncology nurse with many years of clinical experience in both haematology and oncology nursing practice and experience of qualitative data analysis. The adoption of member checking by a colleague to help verify a study's results is evidence of a study's trustworthiness (Cutcliffe and McKenna, 1999).

Results

Three main themes were interpreted from the participants' interview transcripts (Figure 1).

Figure 1 Study Findings Themes and Sub themes



Emotions

Emotions highlighted by the participants included shock of diagnosis, hope for the future, and fear of isolation. Both male and female study participants expressed similar emotions, except for the fear of isolation, which was discussed by only one female participant.

Emotions ranged from extreme shock to fear of mortality and some acceptance as treatments and time progressed:

Noel *“So I couldn’t talk for ten seconds I suppose, then I had started to ask maybe a question or two, but I don’t think I wasn’t really with it you know... So I knew I had to confront the notion of mortality or dying even though I am 66 years of age. Prior to this I’d been healthy all my life, I was very healthy,”*

Christina *“Terror is the only word to describe it, I went from a normal day to getting a phone call in the evening, and leaving the house and not coming back for six weeks. It was the suddenness of that; you know it is very hard to deal with, extremely hard to deal with that.”*

Following their initial emotions, many patients considered a diagnosis of leukaemia as a less threatening diagnosis than other forms of cancer.

Seamus *“Leukaemia is leukaemia; sure it’s better than throat cancer or something like that”*

Christina *“I’m going to get better by having leukaemia but if it was in a major organ, I can’t say whether I would or not.”*

All the study participants were hopeful in maintaining remission and as treatments progress there was a feeling of acceptance.

Padraig *“My understanding is that the type of leukaemia that I have is treatable and that I will be o.k. I expect that I will have a remission for whatever period I have. I’m not expecting it to be twenty years or ten years or whatever. It’s just whatever it is, that’s it”.*

Thomas *“Well so far it’s looking good. I’m hopeful, that it’s going to be, well it’s not a cure, but close to it”*

Christina *“Well I hope that at the end of the year, I have to give myself the year anyway, It will probably go into next year as well. I am hoping that I would have a good result that I would have, even if I have a reasonable life”*

Christina expressed the fear associated with isolation:

Christina *“Even though the worst part of all is being in the room, that is absolutely horrific; being put into a room for so long. I had nightmares, I had awful nightmares and even the sound of this...I woke up one night and I didn’t know what it was, it frightened me, I thought it was someone that was in the room. I had awful nightmares...I still have problems sleeping. But I’ve settled down a bit now”*

Additionally, the fear for Christina was not just confined to her room while she was an inpatient. Isolation also led to fear of meeting people once she left the confinements of the isolation room for the first time:

Christina *“You know the first time when I was in it for six weeks, well I was at breaking point when I was told I that, I really was, because the day that the doctor said to me that I could go downstairs and have cup of coffee I was terrified of people. I was absolutely terrified”.*

Support from family and friends and healthcare professionals

All participants expressed the importance of support from family and friends:

Christina *“Apart from my husband, I couldn’t have a better husband. No one on this earth has a better husband than me and you know I have, he has come every single day, driven up every single day to me and stayed as long as I want, you know, if I’m upset”*

Padraig *“...my daughter was a great back up to me because she was a nurse, and she came in, she said to me; “we’ll go through this together”; now I did find that all the way through the last treatment that she was a big help. She came up every opportunity that she got and it was a big help to me to wake up and see her sitting there it helped me to fight it, because, I had support from her and I had the support from the rest of my family as well but more so from her”*

Additionally, Padraig went onto explain that support from friends can lift spirits and reconnect him with his life before his diagnosis of leukaemia.

Padraig *“Another thing I did find, I was just looking at my blood count there and I noticed that there’s two days when my blood count really soars and I put it down to; I had a few friends that came in for two days and we laughed and we talked so much about the past; things we’d done and everything else and them two days were the only two days that I never for one moment thought of what I was in here for.”*

Most patients interviewed identified the satisfaction they experienced from support received from healthcare professionals. Support from health care professionals was provided in many ways, such as spending time with patients, being pleasant, creating a positive working environment and providing a homely atmosphere.

Noel *“Nurses come in and out and they’re smiling as often as anything else, even though they’re just busy people, and by Jesus I can see. I mean it’s grand to see, it just humanises the thing you know”*

Padraig *“I think the nurses are fantastic, the team is fantastic. I find them very nice now and very consoling and help you out in every way...Because, it’s kind of homelike, they come in and have chat. I’d say that they wish they had more time to talk but they have to get on to their next patient as well like”*

Patricia *“The one thing that has made it easier is the staff in general. Particularly when I was up in the other room I wasn’t far from the nurses’ station and I was within earshot of all of the outside activity and I’ve said this to people over and over again, all the banter that I hear from down there; I have never heard a cross word between any two members of staff and that is very encouraging.”*

Christina *“...the nurses and doctors. There’s a few that I would be inclined to become attached too I miss them when they’re not on duty”.*

Noel *“I am very happy that you can be a bit more forward to them [staff] but the willingness of the medical side, medical people side to listen and to tell you more about it, is absolutely amazing. It must be hugely anxiety relieving or anxiety eliminating for a lot of people. I really believe that you know. You are not groping in the dark, wondering the night before, what this stuff does”*

All the study participants viewed information as important. For instance, Noel described how he anticipated the bone marrow biopsy as being a painful experience, but his actual experience of the procedure was quite different:

Noel *“Well he [Doctor] was absolutely, anxiety reducing, eliminating if you like. He sort of spoke at each step of the way during the biopsy, it’s only, as I remember a twenty minute job, but, at every step he took during the biopsy he said; “Noel about to do this now” and I felt no pain. I think once there was an element of a sting or an injection and he told me”*

Honest and trust was also revealed by Christina as important:

Christina *“I like to keep asking questions and I like to be told the truth. I like to keep asking questions and it would be that certain ones that I know tell me the truth...Dr. XXX has never frightened me by anything he has ever said, he always says it’s very positive and has given me a good outlook and he’s never made me nervous. But I am hoping and I know that he’s a man to tell the truth”.*

Discussion

All of the study participants experienced many emotions on receiving their diagnosis of acute leukaemia; mainly shock, fear, and uncertainty about their futures. However, as mentioned earlier, Thomé et al (2003) report that older people cope better psychosocially with the diagnosis of cancer and its management than younger people; a finding also reported earlier by Mor et al (1994). In addition, age affects a person’s perception of their illness (Steverink et al 2001), and longevity appears to help elderly patients prepare for loss in their lives (Boyle and Engelking, 1993). Nevertheless, whilst elderly patients may cope better psychosocially with a diagnosis of cancer, the issue of mortality was difficult for the study participants to contend with, and only two study participants openly talked about his mortality.

Christina was the only study participant to disclose how debilitating isolation felt. Patients with leukaemia are isolated from other patients to minimise the risk of fatal infections. Despite studies examining supports in the form of granulocyte colony stimulating factors among elderly patients with acute leukaemia to reduce the duration of neutropenia and the incidences of fatal infections; no substantial decrease in treatment

related mortality has been reported (Witz et al 1998). Campbell (1999) also reports on patients' experiences of isolation of "being shut in" (p. 441). The role of the nurse as 'professional friend' to support patients in isolation is therefore critical.

Support received from family and friends was viewed as a major influence in helping the study participants cope with their treatment schedule. Cancer patients need strong support from others (Clarke et al 2006). Elderly patients with cancer who remain involved in family decisions experience unique, valuable and crucial feelings of confidence (Thomé et al 2004). In addition, extended family and friends also act as a distraction from the reality of their diagnosis, its treatments and their long term outlook (Thomé *et al* 2004).

The study participants reported the importance of informational support from health care professionals. This is also reported elsewhere where cancer patients report the information helps them adjust to the psychological difficulties associated with the disease (Clarke et al 2006). Having a clear view of diagnosis, test results and the effectiveness of treatments can lead to elderly cancer patients' increased sense of control, security and safety thus leading to an improved quality of life (Thomé et al 2003). However, the understanding that cure is not achievable, due to intolerance of treatments and inability to administer standard treatments due to age and co-morbidities, did not seem apparent among the study participants. This was even despite the time spent by health care professionals discussing diagnosis and long term consequences of leukaemia. Perhaps this finding is related to older people tending to report more optimistic health perceptions about their health than is the reality (Kutner et al 1992). A lack of understanding, however, could lead to patients and families being unprepared for unsuccessful outcomes.

Cancer patients can have trouble in retaining information at diagnosis (Öhrn and Sjöden 2003). When a patient is coming to terms with a cancer diagnosis and pending treatment, their ability to retain information about chemotherapy side effects may be significantly impaired (Sainio and Eriksson 2003).

Conclusion

The number of study participants in this study is small, thus limiting the transferability of the study findings. Nevertheless, the study provides useful findings for haematology nurses on the lived experience of elderly people receiving chemotherapy for acute leukaemia. Knowledge of this study's findings can help nurses frame their discussions with newly diagnosed elderly patients.

Elderly patients who present with acute leukaemia have many disadvantages and while treatments may prolong life for a short period of time, it is important to ensure that patients are aware that a long term survival is not attainable.

The results from this study reveal that all participants experienced emotions such as shock and fear at diagnosis. However, despite their advancing age, all participants expressed the hope that treatments would provide a good quality of life and in some cases even cure. The finding that some participants had hope for a cure is important because all the study participants had been informed by both medical and specialist nursing staff of the reality that cure that was not always achievable.

An encouraging finding was participants' views that good support from family, friends and healthcare professionals, helped them learn to cope with the diagnosis and its treatments. Additionally, the provision of information given honestly and accurately assists the study participants to come to terms with their diagnosis and possible outcomes.

Key phrases

- Acute leukaemia remains difficult to cure and in the majority of elderly patients, there exists the added disadvantage of co-morbidities, and poor tolerance to intensive chemotherapy regimens.
- Elderly patients receiving chemotherapy for acute leukaemia express shock at their diagnosis but also hope for prolonged remission.
- Elderly patients receiving chemotherapy for acute leukaemia express the importance of support from family, friends and health care professionals.
- Elderly patients receiving chemotherapy for acute leukaemia express the importance of health care professionals providing information on their diagnosis and treatment.
- An insight into the lived experience of elderly patients' experiences of receiving treatment for acute leukaemia, can help nurses frame their discussions with newly diagnosed patients.

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