

**CANCER PATIENTS' ILLNESS EXPERIENCES DURING A GROUP INTERVENTION**

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# **CANCER PATIENTS' ILLNESS EXPERIENCES DURING A GROUP INTERVENTION**

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Dissertation (article format) submitted in partial fulfilment of the requirements for the degree of Magister Artium (Clinical Psychology) at the Potchefstroom Campus of the North-West University

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## SUMMARY

### CANCER PATIENTS' ILLNESS EXPERIENCES DURING A GROUP INTERVENTION

**Key words:** cancer patients, experiences, group intervention, narrative therapy, listening group technique, post-modernism

The high incidence of cancer and the accompanying medical and psychological effects thereof make exploring cancer patients' experiences regarding their illness potentially valuable. The aim of this study was to qualitatively explore cancer patients' illness experiences during a listening group intervention. Secondary analysis was done on data previously collected by Strydom (2006), for his study on "Cancer patients' and non-cancer patients' experiences of the listening group technique." The use of this post-modernist approach, in which the individual is seen as the expert in his/her own life, makes the data gathered by Strydom (2006) eminently suitable for gaining a true understanding of cancer patients' illness experiences. Analysis of the data yielded twelve prevalent themes namely, support, perspectives and experiences in medical context, perspectives on life and death, emotional experiences, religion, role of knowledge and information pertaining to cancer, finances, concern for others, loss, desire for survival, humour, and physical symptoms. In an attempt to make sense of these themes a framework suggesting moderating factors that would influence cancer patients' illness experiences and outcomes, is proposed. Due to the rising number of cancer survivors and the fact that finishing the treatment seldom indicates the end of the cancer experience, it is suggested that further research regarding the development of a survivorship care programme within the South African context be undertaken.

## OPSOMMING

### KANKERPASIËNTE SE BELEWENIS VAN HULLE SIEKTE TYDENS 'N GROEPINTERVENSIE

**Sleutelwoorde:** kankerpatiënte, belewenis, groepintervensie, narratiewe terapie, luistergroep-tegniek, postmodernisme

Die hoë voorkoms van kanker en die meegaande mediese en psigologiese effek daarvan maak die verkenning van kankerpatiënte se belewenis van hul siekte potensieel waardevol. Die doel van die studie was om kankerpatiënte se belewenis van hul siekte kwalitatief tydens 'n luistergroepintervensie te ondersoek. Sekondêre analise is uitgevoer op data, wat voorheen ingevorder is deur Strydom (2006), tydens sy studie oor "Kanker- en niekankerpatiënte se belewenis van die luistergroep-tegniek". Die gebruik van dié postmoderne benadering, waartydens die individu beskou word as die ekspert van sy/haar eie lewe, maak die data wat deur Strydom (2006) ingesamel is hoogs gepas om 'n ware begrip van kankerpatiënte se belewenis van hul siekte te bekom. 'n Analise van die data dui op twaalf onmiskenbare temas, naamlik ondersteuning, perspektiewe en belewenisse van die mediese konteks, perspektiewe oor lewe en dood, emosionele ervarings, religie, rol van kennis en inligting oor kanker, finansies, omgee vir ander, verlies, behoefte aan oorlewing, humor en fisieke simptome. In 'n poging om sin te maak van dié temas word 'n raamwerk voorgestel met moontlike modererende faktore wat die belewenis van die kankerpatiënte se siekte en uitkomst kan beïnvloed. Weens die toenemende aantal kankeroorlewendes en die feit dat afgehandelde behandeling selde die einde van die kankerervaring aandui, word daar voorgestel dat verdere navorsing aangaande die ontwikkeling van 'n oorwinnaarskap-sorgprogram binne die Suid-Afrikaanse konteks onderneem word.

## LETTER OF CONSENT

We, the co-authors, hereby give consent that M Venter may submit this article for examination purposes in partial fulfilment of the requirements for the degree Magister Artium in Clinical Psychology and that it may also be submitted to the *Journal for Psychology in Africa* for publication.

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Prof. C.A. Venter

Supervisor

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Prof. K.F.H. Botha

Co-Supervisor

## **INTENDED JOURNAL FOR PUBLICATION AND GUIDELINES FOR AUTHORS**

This dissertation will be submitted to the *Journal for Psychology in Africa* for consideration for publication. The manuscript, as well as the reference list has been styled according to the above journal's specifications. See annexure 2 for a copy of the guidelines for prospective authors as set out by the *Journal for Psychology in Africa*.

MANUSCRIPT

**MANUSCRIPT TITLE, AUTHORS AND ADDRESSES**

**TITLE**

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## **ABSTRACT**

The high incidence of cancer and the accompanying medical and psychological effects thereof make exploring cancer patients' experiences regarding their illness potentially valuable. The aim of this study was to qualitatively explore cancer patients' illness experiences during a listening group intervention by making use of secondary analysis. Analysis of the data yielded twelve prevalent themes namely, support, perspectives and experiences in medical context, perspectives on life and death, emotional experiences, religion, role of knowledge and information pertaining to cancer, finances, concern for others, loss, desire for survival, humour, and physical symptoms. In an attempt to make sense of these themes a framework suggesting moderating factors that would influence cancer patients' illness experiences and outcomes are proposed. Due to the rising number of cancer survivors and the fact that finishing the treatment seldom indicates the end of the cancer experience, it is suggested that further research regarding the development of a survivorship care programme within the South African context be undertaken.

**Key words:** cancer patients, experiences, group intervention, narrative therapy, listening group technique, post-modernism

The high incidence of cancer and the accompanying medical and psychological effects it has on cancer patients make exploring their experiences regarding their illness potentially valuable. According to MedicineNet, Inc. (2004) cancer can be defined as an abnormal growth of cells that tend to proliferate in an uncontrolled way and, in some cases to metastasise. Cancer is not one single disease, but rather an umbrella term for a group of more than a hundred different and distinctive diseases. It can involve any tissue of the body and has many different forms in each body area. Most cancers are named according to the type of cell or organ in which they originate (MedicineNet, Inc., 2004).

According to Parkin, Bray, Ferlay and Pisani (2005) the estimates of the worldwide incidence, mortality and prevalence of 26 different kinds of cancers in the year 2002 were as follows: overall, there were 10.9 million new cases, 6 per cent of which were diagnosed on the African continent; 6.7 million deaths, 7.5 per cent thereof being in Africa, and 24.6 million persons alive with cancer within three years of diagnosis, of which 4.1 per cent were found on the African continent. Although the most commonly diagnosed cancers include lung cancer, breast cancer and colorectal cancer, the most common causes of cancer deaths are lung cancer, stomach cancer and liver cancer (Parkin et al., 2005).

The psychological impact of cancer may include feelings of fear, anger, guilt, and emotional repression which may lead to adjustment disorders, depression and anxiety (Puig, Lee, Goodwin & Sherrard, 2006). According to Fukui, Koike, Ooba, and Uchitomi (2003) several investigators have reported that patients with cancer have numerous concerns, such as intrapsychic (e.g. anger, fear of dying), interpersonal (e.g. loneliness, communication with family and friends), and social concerns (e.g. isolation and stigmatisation).

The initial disruption introduced by chronic illness is often seen in purely negative terms, something has been lost and that loss is something to be coped with and endured. Research on the long-term adaptation to chronic illness revealed that the initial phase of this disruption is often followed by a period of reorganisation and reconstruction of the self and one's place in the world (Mattingly & Garro,

2000). According to Fukui et al. (2003) loneliness is one of the major concerns among patients with cancer.

Group interventions are often seen as being effective in the case of cancer patients as they offer an opportunity for social support, fostering close-knit relationships among the participants, providing a sense of solidarity and commitment amongst them (Adamsen, Rasmussen & Pedersen, 2001). Group interventions also provide cancer patients with an opportunity for helping others, which in turn has a positive effect on their self-esteem (Sheard & Maguire, 1999; Simpson, Carlson & Trew, 2001; Spiegel et al., 1999). Increasing social support and decreasing feelings of loneliness among cancer patients, resulting from psychosocial group interventions, are important for decreasing their mortality rate, as well as reducing depression (Fukui et al., 2003). These findings concurred with Strydom's (2006) study that also found group interventions as having positive results for cancer patients. Strydom (2006) indicated that the listening group technique had beneficial outcomes for the participants as it helped them to develop new perspectives on personal dilemmas, and also stimulated personal growth.

The listening group technique is a specific kind of group intervention which consists of two groups of people participating in the therapeutic process. At the beginning of the process one of the groups, as well as the facilitator/s, sits in a circle in the so-called inner-group. The other group sits in a circle surrounding the inner group and is hence called the outer-group. Members of the inner-group discuss their experiences regarding the problem situation while the outer-group participants observe. The inner- and outer-groups then change positions allowing the outer-group members, now sitting in the middle, to reflect on their experiences based on what they have heard from the inner-group's discussion. The participants then again change their position allowing the inner-group members to reflect on the remarks of the outer-group members. By changing positions the inner-group members' experience goes beyond that of merely being able to tell their stories as it also provides them with an opportunity to receive acknowledgment and feedback. During the last session the two groups unite, forming one large group to discuss the therapeutic process (Carr, 1998; White, 1995).

Strydom (2006) also included cancer patients' supporters in his study on how the listening group technique was experienced. This allowed not only for the perspectives of the cancer patients, but also for those of their supporters. This is of particular importance as cancer is a stressful event that affects all family members and it has even been argued that the partners of cancer patients experience the burden of the disease in much a similar fashion as the patients themselves (Bar-Tal, Barnoy & Zisser, 2005). Based on the working method of the listening group technique, as described above, it clearly ascribes to post-modernist principles.

The objectivity of the modernist worldview often places more emphasis on facts and reproducible procedures than it does on the fundamental significance of the individual (Dueck & Parsons, 2004). The researcher is of opinion that a rich amount of valuable information and a true understanding of the situation can be lost in this way. A post-modernist approach, that views the individual as the expert in his/her own life, is more suitable for gaining a true understanding and making sense of cancer patients' experiences. According to the narrative perspective the intellectual framework used by people to interpret their experiences is called their story (Venter, 2000). Narrative (stories) is defined as discourses with a clear sequential order that connect events in a meaningful way for a definite audience, thus offering insight about the world and/or people's experiences of it (Elliott, 2005).

Over the past two decades, the awareness of the importance of narrative among qualitative researchers has spread through a wide range of different substantive areas. For example, in the sociology of health there has been a focus on lay perspectives of disease and patients' own experiences of ill health. In particular for those suffering from chronic disease, the idea of an "illness career" has been a useful tool and this can be readily expressed in the form of a narrative (Elliott, 2005). This clearly illustrates the usefulness of a narrative approach when analysing cancer patients' experiences of their illness, as it helps the cancer patients to make sense of their illness (Crossley, 2003). Some of the common themes that run through research that pays attention to narrative in respondents' accounts include an interest in people's lived experiences and an appreciation of the secular nature of those

experiences, as well as empowerment of researchers in that the technique allows for them to contribute to determining what the most significant themes in an area of research are (Elliott, 2005).

Cancer is a terrifying, debilitating, depressing and potentially fatal disease (Duncker & Wilson, 1996) for which the appropriate psychological care is often neglected or superficially applied. As a growing population of people with cancer is achieving long-term periods of remission and survival, cancer rehabilitation is becoming more and more important (Holley & Borger, 2001). In light of this the researcher undertook an exploratory study which highlights the experiences and perceptions of cancer patients regarding their illness.

The motivation for this research was that by analysing the cancer patients' experiences of their illness one might be able to understand and identify some of their psychological needs. This can establish the direction for future research and might also lead to the planning of programmes, within the South African context, that can assist them. Therefore, not only leading to a greater understanding of cancer patients' needs, but also to an increased likelihood of being able to meet them.

## **RESEARCH METHOD**

### *Aim*

The aim of the research was to qualitatively explore the experiences and perceptions of cancer patients regarding their illness during a listening group intervention.

### *Design*

A qualitative design was followed as the study was conducted by scrutinising the group discussions of the cancer patients' narratives regarding their illness experiences, and then moving towards identifying more abstract generalisations and ideas concerning the common themes apparent within these discussions. In trying to explain, interpret, and render meaning from the cancer patients' experiences a summative content analysis approach was utilised in an attempt to account for, understand, or "make

sense of” the information presented during the group discussions (Hsieh & Shannon, 2005; Neuman, 2003). This approach allowed the researcher to interpret meaning from the content of the text data and, hence adheres to the naturalistic paradigm (Hsieh & Shannon, 2005). By adhering to the naturalistic paradigm the researcher was able to remain faithful to the evidence of the data and was able to generate themes truly indicative of the cancer patients’ experiences and perceptions regarding their illness.

### *Data gathering methods*

Secondary analysis was done on data previously collected by Strydom (2006), for his study on “Cancer patients’ and non-cancer patients’ experience of the listening group technique.” The researcher therefore did not gather the data herself, but re-examined the data previously collected by Strydom (2006) by asking new questions (Neuman, 2003).

Strydom (2006) gathered data by asking the following questions during the group sessions: “What did you experience when you were first diagnosed with cancer?; How did you handle the situation surrounding your illness?; How do you view the future/plan to proceed from here?; How did cancer impact on the family members/supporters?” Since Strydom focused only on how the listening group was experienced by the participants, by making use of individual interviews after the listening group intervention had been completed, all the data gathered by the above-mentioned questions remained available for further scrutiny. This was then done by asking the following research question: “How do cancer patients experience their illness?”

### *Participants*

Strydom’s (2006) participants included twelve members as part of the inner group. This group consisted of six cancer patients and six supporters, eight of whom were female and four male, ranging from twenty-two to sixty-two years in age. The six cancer patient participants had been diagnosed with different types of cancer and were at various phases in the treatment process. It is for this reason that

they will be referred to as 'patients' during the results discussion. The listening group (outer-group) included nine non-cancer participants consisting of honours and masters psychology students.

Since the study focused on the cancer patients' experiences of their illness the researcher utilised the data provided by the inner group only. The majority of the participants were Afrikaans-speaking and therefore most of the discussions during the group intervention were also conducted in this language. For the purpose of this article quotes used in the results section were translated and verified by the supervisors.

### *Data Analysis*

The researcher analysed the data by making use of qualitative content analysis. Qualitative content analysis can be defined as a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns. The researcher utilised summative content analysis which consisted of identifying and quantifying certain words or content in the text with the purpose of understanding the contextual use of the words or content (Hsieh & Shannon, 2005). Content analysis goes beyond the mere counting of words and includes latent content analysis. Latent content analysis looks for the underlying, implicit meaning within the content of the text (Neuman, 2003). The goal of content analysis is therefore to provide knowledge and understanding of the phenomenon under study, which in this case was that of the cancer patients' narratives (stories) regarding their illness experiences (Hsieh & Shannon, 2005).

The seven steps suggested by Hsieh and Shannon, (2005) were followed. Step one consisted of formulating the research questions to be answered. During this step it was decided that the data collected by Strydom (2006) would be re-examined by shifting the focus of the research question to, "How do cancer patients experience their illness?" During step two the sample to be analysed was selected. Since the research focused on cancer patients' experiences of their illness the data gathered on the inner-group by Strydom (2006) were utilised. Strydom's (2006) group sessions were audio-

taped to ensure that the information provided could be accurately reproduced (Denzin & Lincoln, 1998; Gubrium & Holstein, 2002). The researcher was provided with a CD containing the data, recorded by audiotape, covering all five of the sessions conducted during Strydom's (2006) study for analysing purposes. The data were transcribed to make the content more accessible for the analysing process. Step three involved defining the categories to be applied. No predetermined categories were identified and the data were initially grouped into as many categories as needed from which specific themes were then identified and regrouped.

Step four consisted of the delineation of the coding process and coder training. Open coding involved the process of breaking down, examining, comparing, conceptualising and categorising the data. Next, axial coding, comprised of procedures where the data were put back together by making connections between categories and finally, selective coding, that included the identification of core categories which were then systematically related to one another (De Vos, Strydom, Fouché, & Delport, 2005). The researcher received training in quantitative and qualitative research methods as part of her training and was assisted throughout the coding process by her supervisors, who are both experienced researchers skilled in the coding techniques used. During the fifth step the coding process was implemented. There was continuous collaboration with both supervisors throughout the coding process in an attempt to obtain a more accurate view based on triangulation.

Step six involved establishing trustworthiness. The advantage of using a qualitative approach lies in the fact that it is an unobtrusive and non-reactive way to study the experiences of the cancer patients (Neuman, 2003). It allowed the researcher to use objective and systematic counting and recording procedures to produce a qualitative description of the cancer patients' experiences regarding their illness. The concept and methods employed to ensure trustworthiness will be discussed later in the article. During step seven the results of the coding process were scrutinised and grouped into themes based on regularity. Regularity was determined by the frequency with which specific words or concepts were used. Interpretations based on the underlying meaning of the words or concepts, as well

as alternative terms used, were also taken into account during this categorisation process. Each of these themes will be discussed comprehensively during the results and discussion section of the article.

### *Ethical Concerns*

This study made use of a secondary analysis technique by using data initially collected for a previous study for which approval had been obtained (No. 05k10) from the ethics committee of the North-West University. The participants were informed about the research project, participation was voluntary and informed consent was obtained. Participants were asked to sign release forms for the use of data gathered in Strydom's (2006) and follow-up studies. Permission for the research findings to be published was also obtained. Confidentiality and anonymity of the source material was maintained by ensuring that no identifiable information was made available during reporting of the results.

### *Trustworthiness*

The researcher employed the following provisions suggested by Shenton (2004) in an attempt to meet the criteria for trustworthiness. To ensure credibility the researcher made use of well recognised research methods, developed an early familiarity with the culture of the participating organisations, made use of 'reflective commentary', and also examined previous research to frame findings. Transferability was achieved by providing biographical detail of the participants which established the context of the study. A detailed description of the phenomenon in question, as well as of the research design used is provided for comparative purposes. In an attempt to attain dependability the researcher provided an in-depth methodological description of the study, thus allowing for the replication thereof should the need arise. Confirmability was established by making use of triangulation in an attempt to reduce investigator bias, which in this case was especially important due to the researcher's personal history of familial cancer (grandmother and mother). The researcher collaborated with both of her supervisors continuously throughout the research process to ensure the adequate use of the methods

employed and to confirm and organise findings. Researcher triangulation not only allows for the integration of different viewpoints and therefore a better description of the phenomenon under study, but also reduces the possibility of personal beliefs and assumptions influencing the interpretation of the data. An in-depth methodological description of the study is also provided which allows for the integrity of the research results to be scrutinised. Limitations pertaining to the study's methods will also be discussed later on in the article.

## RESULTS

Each of the themes identified will be discussed. It should, however, be kept in mind that due to the very personal nature of the topic the themes often relate to one or more of the other themes in some way. An effort has been made to highlight this overlap without unnecessary repetition by discussing initial themes quite extensively and then referring to them should a specific aspect become relevant again during subsequent themes.

### *Theme 1: Support*

Support was the most prominent theme identified during the group discussions. Cancer patients experienced support as coming from various sources that included family and friends; the community; medical staff; their congregations as well as other cancer patients. Examples included: "... I know that my parents will be there to look after my child..."; "... friends offered to drive me to Klerksdorp for my treatment..."; "... people in the neighbourhood left an envelope with money at our kitchen door..."; "... there are many fundraising campaigns in the community, like 'CANSAs' for example..."; "... the people at oncology are always very helpful...", and "...the congregation really carried us through...their support really meant much...". The support coming from other patients was deemed particularly helpful as having other cancer patients inform them about their personal experiences managed to alleviate many fears. The following comments were made in this regard: "...we can talk

to each other...we're more or less on the same wavelength..." and "...if you went through it yourself...you know what the other person needs.".

A further distinction was made between practical or tangible support and emotional support. Examples of practical or tangible support included taking the patients books, pills or flowers; going to the hospital with them; taking them for an outing; looking after their children; bringing meals for their family; providing monetary assistance; making their doctors' appointments, and organising the money matters. Remarks included: "...with regard to support...can be very practical, this helps a great deal...bringing meals...this can take away much pressure..." and "...a person needs that kind of help, those basic things...". Examples of emotional support included: talking to them about everyday things; merely sitting with them; inquiring about their test results; doing some research about their type of cancer and its treatment and then sharing this information with them; providing humour, as well as drawing their attention to the number of people who survived. Some patients explained their experience of emotional support as follows: "...having people come and visit you, it's really wonderful..." and "...they're quite pleasant company...with their advice and chitchat...".

Although patients generally experienced the support given to them as being positive they did, however, view the following aspects thereof as being somewhat challenging: not having enough time to spend alone with their families due to the constant flow of supporters, as well as with supporters who sometimes come across as being intrusive, inappropriate and insensitive. Patients described this as follows: "...there were people around constantly...it was an absolutely crazy time...you are often so busy with the supporters that you don't always get around to your family..., but ultimately I really feel that this was what kept us going..." and "...one of my neighbours... came to me with a bowl of dessert, stating that since I'm not going to be with them for much longer she thought that she should bring me some pudding...I was unbelievably upset about this...later I was able to laugh...realised that basically she had meant well...". What was evident from these quotations was that, although not all their

experiences with support could be described as being positive, one thing inevitably remained the same and that was that ultimately they still experienced the support as being helpful.

A few patients also experienced the support given to them within a religious context as being of a negative nature. Some felt that references to “eternal life” and saying that “you just have to believe” were especially cruel since many people still die despite having faith. The fact that people cope with things in different ways was also seen as a source for potential difficulty, especially between spouses. One patient said: “...we both handled this process in our own way...I felt that I was going to die if we didn’t talk about it...and he said that he was going to die if he had to talk about it...”. A few patients also mentioned the problem of actually altogether losing the support of a loved one or friend who perceived himself/herself as being incapable of providing the support that would, according to him/her, be appropriate.

### *Theme 2: Perspectives and experiences in medical context*

A prominent aspect evident about the group discussions pertained to the vast number of medical terms being used by the patients. One of them explained it as follows, “...you get incorporated into the world of cancer...you assimilate to it...you start to learn the terminology...”.

References were often made to the different types of procedures, tests and treatments that had to be endured. One patient described himself as being an “...old customer at the hospital...” due to the frequency of procedures he had to undergo during his treatment process. They also felt that once diagnosed it was like becoming part of the “...medical machine...”, treatments commence almost immediately and procedures follow in quick succession of one another. Comments included: “...it’s like being put on a boat...and being propelled downstream...” and “...the procedures become almost like this systematic thing...it becomes like an ordinary event...”.

Some patients felt that the doctors did not provide them with enough information and that they had not been adequately prepared. One patient explained, “...they speak vaguely about this thing...and you

don't really comprehend...". Most patients did, however, experience the oncology department as being particularly helpful in this regard. The following statement was made: "...you get well informed once you get to the oncology department...".

Differing perspectives and experiences regarding the medical staff were noted. Some patients referred to the medical staff as being insensitive and incompetent. Examples included: "...as I was regaining consciousness I saw the doctor talking to my husband...he had a plastic bag with him which contained that which he had removed...and you get to see this..."; "after being diagnosed with a melanoma the doctor simply said, 'a melanoma takes you to the grave...so what do you now want me to do about it'..."; "...due to neglect an infection had started..." and "...the doctor had failed to send everything away for testing...those that he had sent away didn't show anything...and now they don't know where the primary cause is...something they need to know in order to determine the treatment...".

As discussed in the previous theme some patients did, however, experience the medical staff as being very supportive. Some also felt that they went to much trouble in an attempt to provide them with the best treatment. One patient referred to an incident where he was so upset that "...ultimately the doctor had to take me in her arms in an attempt to console me...". Other examples included: "...he had a stack of notes with him...he had done much research before making the interpretations..." and "...some of the doctors, nurses, and sisters...some of them are the most wonderful people you'll ever find in a hospital... I have a lot of respect for them...".

A few patients referred to the hospital buildings and consultation rooms as morbid. One patient said, "...you would think that it was the most morbid place on earth ...the building is morbid, which makes this kind of morbid impression on you...".

References were made to the importance of having a good medical aid plan. One patient explained her experience as follows: "...I was able to get the best medical treatment, because I had a good

medical aid plan...” while another stated that, “...our medical aid...it places many restrictions on the type of treatments you’re allowed...it prolongs the process...which causes extra stress...”.

A few references were also made to the important role medical science plays in patients’ survival, as well as to cancer research and the funding thereof. Examples of these were: “...science can be applied in such a way that it can assist your healing, it’s remarkable...” and “...there are many fundraising campaigns...if you don’t use the money for research...you won’t be able to help anybody in the end...”.

### *Theme 3: Perspectives on Life and Death*

The following quotes echo most patients’ views on being diagnosed with cancer: “If you have cancer you die” and “...cancer is a death sentence...”. Several references were also made to people who had in fact died of cancer, the experience of coming close to dying themselves, as well as to the fear surrounding death and the unknown. Some of the comments made included: “...seven of the patients who received chemo treatment with me have passed away...”; “...was so close to dying, so many times...” and “...we are all scared of dying...but for the most part it’s the uncertainty thereof with which we struggle...”.

Despite staring death in the face, the development of alternative perspectives on life seemed to be the most prominent. Patients seemed to have differing experiences regarding life and their view of the future. Some patients expressed the desire to live a long life and were readily able to see a future for themselves beyond cancer. One patient expressed this desire as follows: “...I know there is a future for me, I’m still going to see my grandchildren, my child is going to come home...we do plan for our futures, but we also realise our own limitations...”. Others experienced their lives as being “on hold”: “...the world outside seems to stop...you are just busy with this struggle...you only live from day-to-day, from treatment-to-treatment.” Regardless of these differing perspectives with regard to life they all admitted to remaining ever conscious of the fact that death would always remain a possibility and

that relapses, physical symptoms and side-effects, tests, and oncology would always be a part of their future. Some patients rendered descriptions such as: "...and die you can die, because if the chemo doesn't work...this is the reality..."; "...just when you think you're okay...it can start again...", and "... oncology...becomes part of your life ahead...". As discussed in the previous theme the tests and procedures become 'systematic' and a 'natural' part of their lives. One patient stated: "...you learn to live with it...you don't know exactly what is waiting for you in the future, but you know that you'll simply have to deal with it as it comes along...".

For most patients cancer also seemed to bring about personal growth. One patient said: "...I don't think anybody can go through the process of having cancer without changing as a person...". The development of alternative perspectives indicative of growth included coming to appreciate the small things in life, realising the importance of family, coming to realise that many of the things that you once viewed as being important are in actual fact much less important than you thought, learning to appreciate what you have in realising that there are many cancer patients that are worse off, being able to see the positive in situations that are generally viewed as being negative experiences, as well as being more tolerant and less critical of others. The following excerpts describe the unbelievable amount of insight, sensitivity, and understanding that cancer patients develop despite facing incredible odds: "...although it might sound good the problem with using research funds for the direct treatment of cancer patients rather than for cancer research means that in the end they won't be able to help anyone..." and "...when the doctor told me that I would have to resign...started to question if all the things that I felt compelled to be involved in were really worth it...now I have many other things in my life, I now have time to appreciate the things that are really important...".

To most patients changes in lifestyle was another unavoidable consequence of cancer. These changes were either compulsory, due to health or financial issues, or brought about by a new perspective. Compulsory changes included things such as: a more balanced diet, getting regular exercise, job loss, or cutting back on holidays due to financial obligations. Changes based on new

perspectives included aspects such as: spending less time at work and more time reconnecting with family and taking time to engage in activities that they enjoyed but never got around to doing. Some patients explained: "...have to keep in mind, you had cancer...you have to adopt a healthy lifestyle..." and "...when something like this happens it makes you stop...I started to re-assess...where am I now, are all these things really worth it...running the rat race at work...there are other things in life for me now...I spend time with my kids...walk the dog...play golf..."

#### *Theme 4: Emotional experiences*

As one might have expected a wide range of emotional experiences was expressed throughout the group intervention, depending on the patient and his/her unique situation and personality. The most prominent emotions expressed could be grouped into two main categories, i.e. positive emotions and negative emotions.

Positive emotions expressed by the cancer patients included empathy, gratefulness, hope and acceptance. Empathy referred to the concern they expressed for their families, as well as for other cancer patients and their families. This aspect will be discussed later during the theme 'concern for others'. Some patients expressed feeling grateful and having an acute appreciation for the fact that they were still alive and that they had survived cancer, as well as its treatment. One patient explained: "...looking at the photographs and noticing my bald head...I experienced gratefulness...I'm past that phase in my life...I also have pain and side-effects, but...I'm just grateful that I am alive...". As mentioned in the theme perspectives on life and death patients often expressed gratefulness when comparing themselves to other cancer patients they considered to be 'worse off'. One patient said: "...you hear stories...when you compare your own problems with their situation...it's peanuts really...". Surprisingly only a few expressed accompanying positive emotions such as being 'excited', 'happy', or 'glad'. As discussed in the previous theme some patients were able to express feelings of hope with regard to their future and the possibility of survival. Although acceptance was often implied

throughout the group discussions it was explicitly stated only a few times. As highlighted in the previous theme a few patients did, however, mention coming to accept hair loss, having cancer, as well as the accompanying procedures such as the check-ups and tests that go with it.

Negative emotions expressed by the cancer patients included shock, fear and anxiety, anger, depression, shame, as well as experiencing what they described as being an 'emotional block'. Most patients expressed going through a period of shock at various stages of the cancer process. A cancer diagnosis, being told that you are cancer free, hair loss, as well as the realisation of the vast financial implications were all viewed as being the main events eliciting this response. One patient described her experience in the following way: "...I think the first shock is when you hear that you have cancer...the second one is how you feel when your hair starts falling out...". The expression of fear and anxiety centred mainly on dying, suffering and the unknown. Fear of dying and the unknown were discussed in the previous theme, while the following excerpt emphasises the fear of suffering as described by one of the patients, "...I was afraid...of the process that you have to go through...the suffering...the agony that I saw other people going through that had cancer...it was very traumatic...". No clear distinction was, however, made between feelings of fear and anxiety as they were often used interchangeably to describe similar emotional experiences. Anger was mostly experienced during relapse periods, as well as during times that they struggled with issues regarding their faith. One patient explained: "I was so angry with God. Why was He making me go through this process again? I have just gone through this process and now He's sending me down this road again...". Some of the patients expressed feelings of sadness and depression following a cancer diagnosis, during relapses, as well as during the waiting period for test results. Words such as feeling tearful, hopeless, sad, heart sore, emotional pain, and despondent were often used to describe this experience. Some patients expressed their experience as follows: "...you really just couldn't care anymore..."; "...I felt restless...emotional...tearful...", and "...it's depressing...". Feelings of shame and embarrassment were only mentioned twice, i.e. once by a patient who found the experience of having to go to a

government hospital degrading and once by a patient who expressed guilt over questioning God's will as this goes against her religious beliefs. Responses included the following descriptions: "...medical aid wasn't going to cover it...had to go to a government hospital...it was unbelievably demeaning..." and "...I'm ashamed to say that I was defiant ...as Christians we are not supposed to wrestle with God...I'm not supposed to ask Him how dare He bring this on my path...I was taught not to ask questions...I suppose that is why I feel this way..."

A few patients described going through what they called an "emotionless state" or a period during which they felt "emotionally dead". One explained this experience as: "I think you get an emotional block... you are unable to feel anything". Others, however, expressed an unwillingness to admit and/or express their emotions, e.g. "...you block it out because it's simply too painful...and you don't want other people to see your pain, you want to show them that you're strong..."

#### *Theme 5: Religion*

As discussed within the theme 'support', patients experienced the members from their congregations as being an invaluable source of support despite some of the difficulties experienced in this regard.

Another valuable aspect of religion was that most patients referred to their faith as being a resource to be drawn upon in times of stress. Strength was drawn from their connection with God and faith was seen as eliciting positive thoughts which in turn increased their coping ability. The following comment was made in this regard: "...it was very difficult for me...so I went to my room and talked to God, which made me feel better..."

Many patients also used religion as a frame of reference in an attempt to make sense of their experiences. Some described their understanding of the cancer experience as: "...God put me through this process so that I could learn about myself...to make me a better person..."; "...cancer is but one way that He uses to 'recruit' people...His way of preparing you for His kingdom..." and "...God's way of giving you an opportunity to tie up all the loose ends in your life...to get your life in order..."

Most patients felt that going through the process of cancer had furnished them with a deeper spiritual level and that it was because of this growth that they were now able to show more respect and appreciation for denominations that were different from their own.

Only a few patients expressed anger with God and felt abandoned by Him. This was, however, followed by feelings of shame and guilt as discussed in the previous theme.

Despite the interchangeable use of the terms religion and spirituality it was quite evident from their explanations that they defined spirituality as being part of religion and not as a separate or different entity.

#### *Theme 6: Role of knowledge and information pertaining to cancer*

One of the first things that the researcher noticed about the group discussions was that the cancer patients seemed to use every opportunity, even the listening group sessions, to educate other people. As mentioned within the theme 'support', they educated each other on various aspects regarding cancer. Explanations and information pertaining to the following topics were provided: radiation, chemotherapy, white blood cell counts and how these relate to chemotherapy, procedures regarding medical boarding, different types of cancers and their treatment, different "machinery" used during treatment and what one should and should not eat or do. Examples of how some of these aspects were addressed, included: "...the number of white blood cells has to be a certain percentage in relation to your red blood cells...you can't give someone who has a low white blood cell count chemo...because then you are destroying his last defence mechanisms...that is why it is important to go for blood tests first...to check your white blood cell count..." and "...for those of you who didn't know...when you're boarded it means...that they're advising you, based on medical grounds, to take your leave from your current occupation...while retaining your pension and any other compensations...on the condition that you're not allowed to do that kind of work ever again..."

As discussed in the theme 'perspectives and experiences in medical context', most of the patients expressed the need for more information regarding what being diagnosed with cancer actually meant. They expressed a need for information regarding treatment options, as well as what each of these options would entail. There seemed to be some individual differences between what exactly satisfactory information would involve, as well as what the effect thereof would be. The majority of the patients expressed a need for extensive detailed information as it not only alleviated their fears but also increased their coping ability. One patient explained: "...now that I understand why I have to go for radiation...I can cope with it better...and it also makes planning easier...". A few patients did, however, express the need for limited information as they found it upsetting. One patient noted: "...I only want to know the essentials...and that's it, then I want to leave it there...".

The majority of the patients perceived a lack of information as not only maintaining ignorance and sustaining the myths surrounding cancer, but also as underlying the insensitivity discussed in the theme 'support'. One patient mentioned: "...people don't know what to do...they think you are going to die...they don't realise you could still make it...". Based on this perception they then also expressed a need for family members and friends to be informed regarding how to go about supporting cancer patients. The following comment was made: "...there is a lack...everybody focuses on us who had or has cancer...the people who actually also need help are the supporters...they don't know how to approach it...how to express themselves...what to do should the cancer return...what they should do to motivate the person...".

#### *Theme 7: Finances*

Although some patients acknowledged that initially they did not realise the full implication of the financial costs involved in the treatment of cancer there seemed to be a general consensus that it soon become apparent exactly how unbelievably expensive everything was. One patient stated: "...about the financial implications...in the beginning you don't know at all...you don't have the slightest idea of

what hit you in this regard...”. References were made throughout the group discussions to the cost of different procedures and treatments, as well as to the exorbitant amounts charged for doctors’ consultations and hospitalisation. One patient exclaimed: “...treatments are unbelievably expensive...”.

As discussed in the theme ‘perspectives and experiences in medical context’, patients perceived having a good medical aid plan as being important as it not only provided you with the opportunity for the best treatment options, but it also reduced stress as there was no added financial pressure.

Mentioned in the theme ‘perspectives on life and death’ patients were often required to make various lifestyle changes. From a financial point of view these changes included things like having to sell property and policies or cutting back on holidays in order to pay medical bills.

Also discussed in the theme ‘perspectives on life and death’ was the fact that cancer would always be a part of your life as relapses were common and could occur at any time even if the tests proclaimed that you were now cancer free. Some patients expressed the impact this has had on their financial future. One patient explained: “...once you’ve had cancer you get stuck with this profile...now you’re not allowed to take out any policies or annuities...it’s like being boarded, they’re actually discriminating against you...now you have to find some other way to create a type of ‘policy’ for when you get older...”.

One patient also mentioned that although fundraising was regularly being done in the community by organisations like CANSA, the mismanagement of these funds often discouraged the public from wanting to contribute, which means that in the end the patients would suffer the consequences.

#### *Theme 8: Concern for others*

One of the most amazing things was the fact that so many of the patients were able to express concern for others despite their own struggles and often precarious situations. Most patients expressed being concerned about their children, especially the younger children. They also acknowledged the fact that

the children were often the ones who suffered in silence and that there was a tendency to overlook the severity of the impact parental cancer can have on children.

As discussed in earlier themes the cancer patients made various references indicating their concern for supporters. Mentioned in the theme 'the role of knowledge and information pertaining to cancer', this included acknowledging the fact that there was not enough support for the supporters, as well as the fact that there was not enough information made available to them on how to deal with having a family member diagnosed with cancer.

Some patients acknowledged the fact that their having cancer also affected the future of their families, as well as the impact this would have on the people who would stay behind should they pass away. A few patients mentioned the following: "...I think that sometimes it's even more difficult for the people around you...they struggle to see the road ahead even more than you do..." and "...when you pass away...they still have to live with it...". Some also went to great lengths in trying to hide the severity of their illness from their supporters in an effort to protect them. One patient explained: "...it's usually when you have pain that you don't want to come near them...don't want to experience a breakdown in front of them...might upset them...".

Evident in prior themes cancer patients also expressed concern for each other. Not only were they able to understand and appreciate the difficulties that these patients and their families had to go through, but they were also willing to draw on their own experiences and provide support to other cancer patients in an attempt to alleviate their fears and to make the struggle less severe for them.

One patient also expressed concern for people in general who did not invest in a good medical aid plan as he had first hand experience of the problems this could create should one become ill. He said: "...there are many people who disregard medical aids...it's almost the first area people cut back on...this scares me a bit...".

Surprisingly, only one patient explicitly stated spousal concern. She expressed her concern as follows: "...I'm not scared of dying...I'm ready...but I still have children that I love...and a husband that I love...".

#### *Theme 9: Loss*

As discussed in previous themes cancer patients deal with the experience of loss at many different levels. They encounter loss of support, loss of financial security, loss of previous abilities and lifestyle, physical losses such as hair loss or having to go through a mastectomy, and apart from these actual losses they also have to face the accompanying emotional experiences that become part of their lives.

To the majority of the patients the most prominent loss appeared to be the loss of previous abilities and lifestyle. One patient stated "...it sets you back...I don't have the energy to organise a big function every second day anymore...". Even if the lifestyle changes mentioned in the theme 'perspectives on life and death' were voluntarily and were brought about by new life perspectives, the experience of loss was still considered to be acute. References were made to the following losses: not having enough energy to complete everyday tasks, loss of ability to carry out basic self-care, job loss, and being unable to take care of the practical needs of their children. Some of these were expressed as follows: "...I didn't have enough energy to get up..."; "...had to feed me..."; "...at times he had to dress me.."; "...I couldn't brush my own teeth...", and "...I wasn't able to cook for my child...I couldn't cope with taking care of him by myself...".

Mentioned in the theme 'emotional experiences', many of the patients perceived hair loss as being very traumatic. Despite the initial shock this did, however, become a source of amusement and humour for many of them later on in the process. One patient explained: "...used to make the funkiest hairstyles with the wig...if people made a remark...would take it off and ask 'do you want me to look like this, or rather with the wig?...".

As discussed in previous themes, loss of support was only mentioned by a few patients and despite the general consensus regarding the exuberant costs involved in cancer treatment, loss of financial security was also only explicitly mentioned a couple of times.

*Theme 10: Desire for survival*

As discussed in the themes 'perspectives on life and death' and 'emotional experiences' some of the patients expressed a strong desire for survival. This not only included fostering feelings of hope pertaining to their future, but also a willingness to fight for survival no matter what the costs. One patient explained: "...you try your best...once you're in the situation you don't really have a choice...you have to persevere because the alternative is death...so you simply have to carry on...".

Strategies utilised by the cancer patients in an attempt to achieve this included: believing in their own ability to survive, going back to work, keeping busy with activities that they enjoy, surrounding themselves with positive people and taking care of the practical matters surrounding cancer. Some of these strategies were expressed as follows: "...I just thought, this is not so bad...you can do this..."; "...went horseback riding..."; "...I keep myself busy...", and "...after chemo I went directly back to work...this keeps you going...if you sit and brew on it, it will destroy you...".

A few of the patients mentioned what they perceived as being in 'autopilot mode'. One described this as: "...you become numb...you go through everything and you're strong...you do what has to be done and you organise everything...the only problem with this is that later on the reality of it all hits you...". Despite the fact that the patients experienced this 'emotionless state' as being helpful, as it increased their coping ability at the time, one could probably see it as a temporary kind of functional denial.

### *Theme 11: Humour*

Humour was utilised as a coping strategy by many patients. Despite the fact that it was a continuous theme throughout the group discussions it remains difficult to categorise humour as such because it was often revealed in the nuances of the tone of voice or in the sharing of personal anecdotes.

As mentioned in the theme 'support', humour was experienced as being mainly provided by the supporters, especially coming from the children and other cancer patients, as well as being situated in the patients' own ability to detect the humour in difficult situations.

Some of the anecdotes shared by the patients included: "...after having had my mastectomy my son told me that we would now be able to walk around bare-chested together..."; "...I have this friend who constantly tried to lick my bald head..."; "...the people who take blood samples, they're more adamant than the most stubborn mosquito..." and "...you don't have to be scared about receiving radiation, it's actually like the ice-cream of everything...". The following excerpts are also indicative of how humour was used by various individuals as a way of coping: "...glad to be alive...being outside again, even if it happens to be on legs that feel like spaghetti..."; "...chemo literally burns off your hair...even those on your legs...and I don't need any hair there..."; "...it's as if there is this man with an eraser...he erases all the time...I can't remember anything anymore..."; "...nothing to be worried about anymore...but there is always this little man with a little hammer in your head..." and "...I was diagnosed with a melanoma...doctor dismissively said 'melanoma takes you to the grave'...those were his encouraging words...and I just thought '*jou moer my skat[sic]*'\*...".

### *Theme 12: Physical Symptoms*

As one might have expected many references were made pertaining to the physical symptoms and side-effects experienced throughout the cancer process. The most prominent symptoms appeared to be

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\* Afrikaans expression which involves telling somebody in a derogatory way to "go to blazes my darling".

nausea, feeling tired and weak, pain, lack of appetite, and hair loss. Some of these were expressed as follows: "...couldn't eat or drink anything..."; "...have pain, I have pain here where I'm sitting..." and "...you can feel how you're getting weaker...your body gives in...".

As mentioned in the theme 'perspectives on life and death', some of the patients expressed the presence of these physical symptoms as admittedly negative experiences, yet experiences that you had to learn to live with, as they were not going to evaporate into thin air.

A distinction was, however, detected in the way some patients experienced and interpreted these symptoms. While a few patients mentioned using their body as a guide, "...when I start to feel bad...it's my body's way of telling me that there is something that I should take note of..." others felt that they tended to over-interpret these bodily sensations, for example: "...if you have a headache you immediately think, it has spread, now I have brain-cancer or if your back aches then you think, now I have back-cancer...".

## DISCUSSION

Table I proposes a framework for understanding the cancer patients' experiences of their illness as evident from this study. This framework proposes certain moderating factors influencing cancer patients' experiences and illness outcomes.

(Insert table 1 – see annexure 1)

A cancer diagnosis is often associated with loss, as well as with various health-related concerns, such as physical symptoms and psychological distress. As discussed in the theme 'loss', cancer patients have to deal with loss at many different levels, with the loss of previous abilities and lifestyle being the most prominent. This is in accordance with Crossley (2003), who describes the beginning of every serious illness as being a halt, one's normal life ends and another takes its place.

The most prominent physical symptoms reported during this study included nausea, fatigue, pain, lack of appetite and hair loss. According to Porter et al. (2002), as many as eighty per cent of cancer

patients with advanced disease report experiencing significant pain. Cancer patients who are experiencing high levels of pain are also more likely to experience other cancer-related symptoms, such as high levels of depression and anxiety (Porter et al., 2002).

There appears to be an association between the experience of physical symptoms and psychological distress. A terminal or life-limiting diagnosis is extremely stressful to patients and their families and can elicit emotions as varied as fear, anxiety, anger, depression and helplessness (Curtis et al., 2008). Emotional experiences reported during this study included positive emotions such as, empathy, gratefulness, hope, and acceptance, as well as negative emotions such as, shock, fear and anxiety, anger, depression, shame and the experience of an 'emotional block'.

As discussed during the theme 'physical symptoms', some patients were able to use the presence of physical symptoms as a guide indicating a need for concern and intervention, while others catastrophised these bodily sensations as being irrevocable proof of the return or spreading of the cancer. This is in accordance with Lobchuk and Bokhari (2008), who report a relationship between the patient's level of depression and symptom experiences.

According to Gustavsson-Lilius, Julkunen, Keskivaara, and Hietanen (2007), research has shown a marked variability in the psychological reactions of cancer patients. This was then also evident during this study in that individual similarities and differences were evident throughout the majority of the themes discussed. Research suggests that stress may influence health (Ogden, 2004). The relationship between stress and illness is not automatic, and appears to be influenced by factors such as coping style, perceived control over the stressor and social support (Ogden, 2004).

During this study the following factors appeared to act as moderators regarding the patients' illness experiences: perspectives and experiences in medical context, perspectives on life and death, desire for survival, support, information and knowledge pertaining to cancer, finances, religion, and humour. Although it was evident from this study that each of these factors, depending on the cancer patient's

perception, can have a beneficial or adverse effect on his or her illness experiences and coping abilities, the statistical significance of these moderating factors was not tested.

With regard to the perspectives and experiences in medical context, patients' health beliefs can provide some insight regarding their illness experiences. According to Ogden (2004), there appears to be a conditioning effect concerning patients' beliefs regarding the effectiveness of interventions and the competence of health professionals. This was also evident in this study as positive perceptions regarding the medical profession and receiving good treatment appeared to be associated with the report of more positive illness experiences.

Factors such as perspectives on life and death and a desire for survival can also be seen as having a moderating effect on cancer patients' distress levels. Patients' illness cognitions, which refer to the particular beliefs they have about their illness, do influence their illness experiences (Ogden, 2004). Whether an illness is regarded as being temporary or permanent or as incurable or treatable will influence not only the patient's illness experience, but often also the treatment outcomes. During this study some patients reported feelings of hope regarding their futures and a willingness to fight for survival against all odds. This could be seen as relating to a strong sense of coherence, which is assumed to promote and protect health in stressful situations. Positive beliefs are therefore seen as influencing one's appraisal of stressful situations and are thought to moderate the impact of illness-related factors (Gustavsson-Lilius et al., 2007).

Research has indicated that social support influences the health status of an individual. According to Ogden (2004), the term social support can be defined as the perceived comfort, caring, esteem or help one individual receives from others. Lobchuk and Bokhari (2008), state that the relationship between psychological distress and symptom experience is influenced by factors such as social support. The significance of familial and peer support has been emphasised for years, as research suggests that social support is connected to adjustment in disability, quality of life, psychological well-being, treatment compliance, as well as with survival rates among patients with disabilities and chronic illness

(Chronister, Chou, Frain, & Cardoso, 2008). According to Ogden (2004), two theories have been developed to explain the role of social support in patients' health status. The main effect hypothesis proposes that social support itself is beneficial and that the absence of social support is itself stressful, while the stress buffering hypothesis suggests that social support helps individuals to cope with stress by not only buffering the individual from the stressor but also by influencing his or her appraisal of the stressor (Chronister et al., 2008). According to Walsh, Foreman, Curry, O'Driscoll and McCormack (2008), contemporary holistic theorists identified a need to move towards 'normalising' grief, as well as to increasing community education in an attempt to improve the social support systems that people already have. Greater community awareness of grief and bereavement is believed to enhance people's preparation for death, as well as the community's ability to support individuals (Nucleus Group, 2004). This was also highlighted in this study by the comments made by some of the patients as discussed in the themes such as 'support', 'concern for others' and 'the role of knowledge and information pertaining to cancer'.

The role of knowledge and information pertaining to cancer can also be seen as a moderating factor in patients' experiences of their illness. Bertram and Magnussen (2008), suggest that the presence of a knowledge deficit not only has an impact on the patients' ability to cope with their diagnosis, but also reduces the probability of adherence to treatment plans. Most of the cancer patients in this study expressed the need for more information regarding diagnosis and treatment options. Physicians' communications were also often seen as being vague or insensitive. Christakis (1999), proposes that physicians may see their own optimistic presentations of prognosis, as well as the practice of withholding information, as humane ways of sustaining hope in their patients. The differing informational needs reported by the cancer patients in this study are also supported by literature. Curtis et al. (2008), report that while some patients are able to receive information in a straightforward manner, others are unable to cope with such an approach. An individualised approach to communication, matching the needs of each patient and his or her family, is therefore needed. During

this study the role of information on patients' compliance with treatment was also evident. Ogden (2004), states that effective communication between health professionals and patients emphasises the transfer of knowledge from expert to layperson, which in turn increases patients' understanding of their illness and consequently increases the likelihood of treatment compliance.

The staggering financial expenses attached to the treatment of cancer cannot but emerge as a determining factor regarding cancer patients' illness experiences. This is in accordance with Zabora, BrintzenhofeSzoc, Curbow, Hooker, and Piantadosi (2001) who proclaim distress as being inversely related to income. According to Lobchuk and Bokhari (2008), financial status can be seen as being associated with psychological health as patients with cancer who had higher incomes were better adjusted to their disease than those with lower incomes. In this study one of the patients pointed out that a good medical aid plan helped to minimise added financial pressure and that being able to receive proper treatment certainly reduced illness-related stress. It can therefore be assumed that insufficient financial resources would certainly be experienced as a disease-related concern.

Religion was also seen as having an influence on how the cancer patients in this study experienced their illness. Patients reported insensitive referrals to eternal life and experiencing a crisis of faith as having a negative impact on their disease-related experiences, not only in the sense of accompanying feelings of shame and guilt, but also in the sense of decreasing their coping ability. Some patients did, however, view religion as not only being an invaluable source of support but also as providing them with a framework within which to understand their experiences. These findings concur with Ogden (2004), who classifies turning to religion as being one of many coping strategies often used by cancer patients. Seligman (2002) is of opinion that religion provides a coherent belief-system that allows people to find meaning in life and hope for the future. A religious belief system also allows people to make sense of adversities, stresses and inevitable losses (Carr, 2004). Lobchuk and Bokhari (2008) report religious practices as being related to augmented social support and coping skills.

In this study humour was utilised as a coping strategy by many patients. Not only is the use of humour associated with increased efficiency, due to a reduction in stress levels, but it also provides one with a broader perspective. The presence of humour, therefore, not only increases patients' coping abilities but can also be seen as having a positive impact on their illness experiences. According to Ogden (2004), high levels of patient satisfaction are associated with the use of light humour, tension-relieving humour, self-effacing humour, and positive-function humour during consultations.

Outcomes relating to the cancer experience appeared to be centred on personal growth, such as the development of new perspectives, lifestyle changes, and increased spirituality. Crossley (2003), mentions transformation perceptions reported by cancer patients as often being the result of the treatment process. There is an increasing awareness that attitude and perception shape good functioning, particularly in difficult circumstances (Theron, 2008). According to Baumeister and Vohs (2005) and Kaminer (2006), individuals have to revise and make sense of a happening and find potential benefits in that happening in order to facilitate positive perceptions. Puig et al. (2006), report cancer patients' ability to re-frame their cancer experience as providing an opportunity for personal transformation and growth. The personal growth experiences reported by the patients in this study, as discussed within the theme 'perspectives on life and death', adequately reflect this view.

As discussed during the theme 'perspectives on life and death' various lifestyle changes, whether compulsory or brought about by new perspectives, were reported by the cancer patients in this study. According to Ogden (2004), healthy adaptation involves reality orientation, adaptive tasks and constructive coping skills all of which were evident from the reported lifestyle changes mentioned in this study. Most of the patients in this study felt that going through the cancer process has caused them to experience a deeper spiritual level that enabled them to show more respect and appreciation for denominations different from their own. All of the findings mentioned above are in accordance with Ogden (2004), who stated improved self-knowledge, self-change and re-prioritisation as being fairly common outcomes resulting from the cancer experience.

## LIMITATIONS

The following should be taken into consideration when evaluating the results of this study. The listening group sessions conducted by Strydom (2006), consisted of relatively open group discussions during which no effort was made to identify individual speakers. Therefore, identifying different speakers during the transcribing process proved problematic. This had an impact on the data analysis in that selective coding could not be done to the full extent desired. As previously outlined, the categorisation of themes was based on regularity which was determined by the frequency at which specific words, phrases or concepts were used. There was, however, no way to accurately determine whether a particular issue was raised by different group members or whether or not it was merely the same group member repeating his/her viewpoint at a different stage in the discussion.

The secondary analysis method used can be viewed as being either a disadvantage or an advantage. A drawback could be the fact that the researcher was never personally connected to the group, thus creating the possibility of certain nuances and internal emotional experiences, which would have been evident within the group sessions, to be overlooked. However, the fact that the researcher had not been personally involved during the listening group sessions could also be seen as adding to the objectivity with which the data were treated during the analysing process, thus possibly adding to validity.

The fact that cancer is such a common disease and has touched so many people, on either a personal level or through friends and family, inevitably influences one's outlook and attitude. It is then also for this reason that there was continuous corroboration with supervisors, throughout the analysing process, in an attempt to minimise personal bias.

## CONCLUSION, CLINICAL IMPLICATIONS, AND RECOMMENDATIONS

Due to the advances in cancer treatments, early detection, and supportive care, we are left with a rising number of cancer survivors living beyond their initial diagnosis and treatment (Rowland & Yancik, 2006). This rising number of cancer survivors underline the need to concentrate on their unique needs

as ceasing treatment seldom indicates the end of the cancer experience. The cancer diagnosis and side-effects associated with various treatments often create continuous complicated care issues for patients and their families (Aziz, 2006).

The results of this study confirm how stressful and complex living with cancer can be. The problems inherent in adopting an exclusively medical approach to the treatment of cancer patients and their families are also highlighted and thus call for the development of psychologically-based interventions within the South African context. Given that medical doctors are most often the first port of call, it is recommended that a relationship is developed with these professionals. Their attention can be drawn to the role a psychologist could play in helping cancer patients and their families, as well as providing them with a referral base.

Miller (2008) describes a model for a survivorship care plan, which was initially piloted in an out-patient clinical setting in a community hospital for patients with breast cancer in the United States. It was determined later on that this plan could be expanded to include other types of cancer as well. This plan strives to strengthen the care connections and coordination of services for survivors in an attempt to ensure that their needs continue to be monitored and met even after cessation of treatment, thus shifting the paradigm from an acute care medical model to a wellness model for cancer survivors (Miller, 2008).

It is recommended that further research be conducted towards the development of a survivorship care programme in the South African context. It is suggested that the model described by Miller (2008) be used as an outline and that the illness experiences of the cancer patients highlighted in this study be used for adapting this existing care plan to the South African context.

The cancer patients in this study frequently highlighted the benefits, frustrations, and concerns regarding supporters, whether they were family members, colleagues, or friends. In light of the fact that supporters are seen as playing an integral part in patients' illness experiences and coping abilities it is recommended that they also be considered in the survivorship care programme. Supporters' needs

should be taken into account as well. Intervention strategies, such as psýcho-education, support groups, psychotherapy, and respite or adult day care as suggested by Honea et al., (2008), to reduce family caregiver strain and burden should therefore be incorporated into the programme. It is recommended that the programme be based on a systems approach thus providing for the needs of each family member, and not only for the perceived needs of the cancer patient. It is believed that better coping within the family as a whole will ultimately lead to enhanced care, adjustment and coping to the benefit of the cancer patient.

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## ANNEXURE

**ANNEXURE 1**

**TABLE I – THE CANCER EXPERIENCE**

<b>Cancer diagnosis</b>	<b>Moderating factors</b>	<b>Outcomes</b>
<ul style="list-style-type: none"> <li>▪ Loss</li> <li>▪ Health related concerns:               <ul style="list-style-type: none"> <li>▪ Physical symptoms</li> <li>▪ Psychological distress</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▪ Perspectives and experiences in medical context</li> <li>▪ Perspectives on life and death</li> <li>▪ Desire for survival</li> <li>▪ Support</li> <li>▪ Information and knowledge pertaining to cancer</li> <li>▪ Finances</li> <li>▪ Religion</li> <li>▪ Humour</li> </ul>	<ul style="list-style-type: none"> <li>▪ Personal growth:               <ul style="list-style-type: none"> <li>▪ New perspectives</li> <li>▪ Lifestyle changes</li> <li>▪ Increased spirituality</li> </ul> </li> </ul>

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