

THE LIVED EXPERIENCES OF ADOLESCENTS WITH CANCER

ADELE POOLE



A mini-thesis submitted in partial fulfillment of the requirements for the degree of Magister Psychology in the Department of Psychology, Faculty of Community and Health Sciences, University of the Western Cape.

Supervisor: Maria Florence

November 2009

THE LIVED EXPERIENCES OF ADOLESCENTS WITH CANCER

Adele Poole

KEYWORDS

Cancer
Adolescence
Lived experience
Phenomenology
Qualitative Research
Body-image
Self-esteem
Existentials



ABSTRACT

THE LIVED EXPERIENCES OF ADOLESCENTS WITH CANCER

Adele Poole

M.Phil minithesis, Department of Psychology, University of the Western Cape

People often do not want to hear, talk or read about cancer. Cancer is arguably one of the most feared illnesses and maybe rightly so for it is usually associated with pain, fear, uncertainty, anxiety, long uncomfortable treatments and death. To receive a diagnosis of cancer must be absolutely devastating especially when you are in a developmental stage where you are already battling with issues such as self-esteem, body image, independence and career choices. The current study explored the lived experiences of adolescents who have or had cancer and how this experience impacted on their lives. Six adolescent cancer patients from the cancer unit in a public hospital were interviewed. The sample was purposively drawn and the majority of the interviews were conducted at the homes of the participants. Phenomenology was used both as a theoretical framework as well as a means of analysing data. Using the descriptive phenomenological method employed by Giorgi, four essential themes emerged from the data. The themes included (1) Unexpected change of everyday life means experiencing the unfamiliar (2) Experiencing a changed body, (3) Experiencing the support of significant others and (4) Anticipating a future. The themes were explained in terms of the four existentials of Van Manen which is *lived space, lived body, lived other* and *lived time*. The study revealed that although the initial diagnosis of cancer came as a shock to the participants and their families, they were able to deal with the

inevitable changes that accompanied the diagnosis mainly as a result of the support they received from family and friends. Their initial fear of death were replaced with an ardent pursue of their dreams for the future.

November 2009



DECLARATION

I declare that *The lived experiences of adolescents with cancer* is my own work, that it has not been submitted before for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged as complete references.

Name: Adele Poole

Date: November 2009

Signed:.....



Dedication

This thesis is dedicated to:

Ralphina Poole, who died of Osteosarcoma at the tender age of nine.

and

My parents, Pieter and Gladys van Wyk, words are not enough.

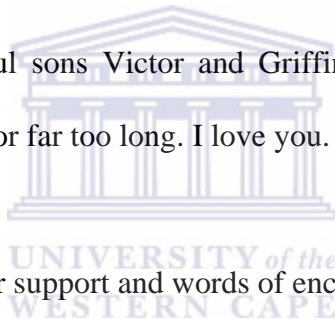


ACKNOWLEDGEMENTS

My praises go to Almighty God for enabling me to complete this project.

My sincere gratitude goes to my husband, Victor, for all the support during this period in my life. Thank you for accepting the role as main caregiver when I was busy with the thesis. Your endless patience and willingness to give and not expect anything in return is much appreciated.

Thanks to my two wonderful sons Victor and Griffin who had to share their mothers' attention with the computer for far too long. I love you.



Thanks to my friends for their support and words of encouragement when I needed it most.

Maria Florence, my supervisor. Thank you for your patience, guidance, encouragement and support throughout this period.

Thanks to Sandra James and Clive le Roux who were always there to assist in searching for books and journal articles in the library.

Thank you to the cancer survivors who participated in this study. You are truly brave and your courage is remarkable. You are in my thoughts.

Table of Contents

	Page
Keywords	ii
Abstract	iii
Declaration	v
Dedication	vi
Acknowledgements	vii
Appendices	x
List of Tables and Figures	xi
List of Acronyms	xii

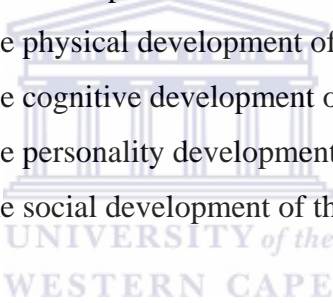
Chapter 1 Introduction to the study

1.1	Introduction	1
1.2	Rationale of the study	4
1.3	Theoretical framework of the study	4
1.4	Aims of the study	6
1.5	Research methodology	7
1.6	Outline of the study	8



Chapter 2 Literature Review

2.1	Introduction	9
2.2	Theoretical framework	9
2.2.1	Intentionality	10
2.2.2	Noema and Noesis	11
2.2.3	Life-world	13
2.2.4	Epoché	15
2.2.5	Reduction	16
2.2.6	Essence	17

2.3	Adolescence	
2.3.1	Definition of adolescence	18
2.3.2	Adolescence as a developmental stage	20
2.3.3	Adolescence and health	22
2.4	Cancer	
2.4.1	Definition of cancer	24
2.4.2	Classification of cancer	24
2.4.3	Treatment of cancer	25
2.5	Cancer in adolescence	
2.5.1	Medical and psychological impact of cancer on adolescents	27
2.5.2	Most common adolescent cancers	28
2.5.3	Impact of cancer on the development of the adolescent	29
2.5.3.1	Impact of cancer on the physical development of the adolescent	29
2.5.3.2	Impact of cancer on the cognitive development of the adolescent	31
2.5.3.3	Impact of cancer on the personality development of the adolescent	32
2.5.3.4	Impact of cancer on the social development of the adolescent	34
2.6	Conclusion	36
		
Chapter 3	Methodology	
3.1	Introduction	37
3.2	Research design	37
3.2.1	Phenomenology as a research method	38
3.2.2	Phenomenology as a data analytical tool	40
3.3	Participants	42
3.4	Procedure	45
3.5	Ethical considerations	47
3.6	Reflexivity	47

Chapter 4	Data Analysis	
4.1	Introduction	50
4.2	Background to the themes	50
4.3	Essential themes	51
4.3.1	Unexpected change of everyday life means experiencing the unfamiliar	52
4.3.2	Experiencing a changed body	58
4.3.3	Experiencing the support of significant others	64
4.3.4	Anticipating a future	68
4.4	Conclusion	71

Chapter 5	Summary	
5.1	Conclusion	72
5.2	Limitations	74
5.3	Recommendations	75



References

APPENDICES

Appendix 1:	Summary of the cancer incidence of adolescents	85
Appendix 2:	Letter outlining the detail of the study issued to the Social Work Department of the hospital.	87
Appendix 3	Information regarding the study issued to parents	88
Appendix 4:	Informed consent form issued to parents	91
Appendix 5	Interview guide	93

List of Tables

Table 3.1: Demographic details of participants

44



List of Acronyms

ALL: Acute Lymphoblastic Leukemia

CNS: Central Nervous System

CANSA: Cancer Association of South Africa

WHO: World Health Organisation

NCR: National Cancer Registry



CHAPTER ONE

INTRODUCTION TO THE STUDY

1.1 INTRODUCTION

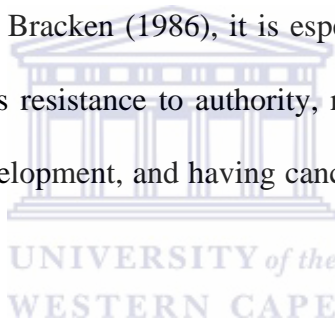
Adolescence is a flexible concept involving specific developmental tasks but broadly encompassing individuals in their early teens and early twenties (Lewis, 1996). Personal experience taught the researcher that adolescents sometimes have difficulty dealing with life situations. To some being an adolescent can be quite confusing and relatively tolerable to others. Adolescents rarely fall ill.(McIntyre & Williams, 2002). In general research done on adolescents' health includes risk behaviour such as smoking. The untimely death of a family member at the age of nine after being diagnosed with bone cancer initiated the idea in exploring how children (specifically adolescents) are able to deal with an illness such as cancer and how it impacts on their lives. Rollins (1990) wrote that:

“The diagnosis of cancer in any family member can be a devastating experience for all family members. Nonetheless, when the family member is a child, the experience seems even more traumatic. This announcement changes our view of the natural order of life where typically it is the elderly that suffer and die and the young who carry on with the work of life” (cited in Murray, 1998:pp 218).

When someone is diagnosed with cancer, the almost immediate response is a mental image of baldness, nausea, vomiting, pain, fear and anxiety. The ultimate image of cancer

diagnosis for anyone is death or a process of dying, but a certainty that death is inevitable. The disease, in as sense, could be uncontrollable.

When children enter the developmental phase of adolescence they have a tendency to be 'uncontrollable' too, as they experience this phase to be an age of 'storm and stress' as stated by G. Stanley Hall (Sigelman, 1999). It is a time when they struggle with issues such as self-esteem, body image, independence from their parents, forming close relationships with the opposite sex and thinking about a career. Having to deal with a developmental period such as adolescence is in itself stressful and adding a diagnosis of cancer to this can be devastating. According to Bracken (1986), it is especially hard for adolescents to cope with a diagnosis of cancer as resistance to authority, rebellion and rule breaking become common in this phase of development, and having cancer is likely to accentuate 'negative' behaviour.



Cancer treatment means that patients are subjected to losing their hair, having a pale skin, losing a limb, even losing an eye and adolescents are normally very conscious of their body image and having to lose any part of their physical appearance could possibly result in adolescents experiencing feelings of distress and withdrawal from others. The overall experience of having cancer as adolescent is 'negative'.

According to the World Health Organization (WHO, 2004), cancer is one of the leading causes of death in the world, particularly in developing countries. In 2005, 7.6 million people died of cancer out of the 58 million deaths worldwide. Based on projections, cancer

deaths will continue to rise with an estimated 9 million people dying from cancer in 2015, and 11.4 million dying in 2030 (WHO, 2004).

In South Africa cancer killed approximately 41,000 people in 2005 of which 27,000 of those people were under the age of 70. Cancer of the cervix uteri was the leading cause of cancer deaths in women whereas cancer in the trachea, bronchus and lungs were the leading causes of cancer deaths in men (WHO, 2004).

The most recent full report (1998-1999) of the National Cancer Registry (2004) states that South African men have a lifetime risk of 1 in 4 of developing cancer, while South African females have a lifetime risk of 1 in 6 of developing cancer. This report further confirms that childhood cancers comprised on average 1 per cent of all female cancers and 2 per cent of all cancers in males reported in 1998 and 1999. The top four common childhood cancers in males aged 0-14 years in order, were leukemia, brain, kidney and non-Hodgkin lymphoma, constituting 53 per cent of all male childhood cancers. In females aged 0-14 years in order, were leukemia and cancers of the kidney, brain and bone, constituting 55 per cent of all female childhood cancers. The biographical distribution of age in the National Cancer Registry (2004) is 0-14, 15-29, 30-54, 55-64 and 65+. This makes it difficult to single out the cancer statistics for adolescents who are defined in South Africa as an individual from age 11 to 21 (Louw, *et al.*, 1998).

In a study done in Canada by Larouche and Chin-Peuckert (2006) concerning the changes of body image experienced by adolescents with cancer, one of the recommendations that emerged from the conclusion of the study was that there is a “[need for] future qualitative

research to understand the lived experiences of adolescents with cancer”. The researcher found that limited research projects are conducted on the lived experiences of adolescents who have cancer, especially in South African.

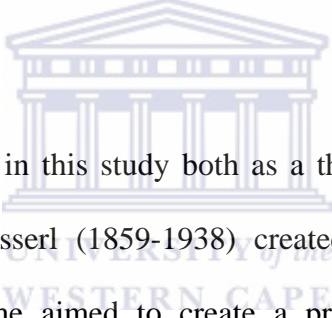
1.2 RATIONAL OF THE STUDY

The rationale of this study is that there exists a definite need for research in this particular field especially in South Africa. My personal interest in this area was to gain insight and understanding of how adolescents personally and emotionally integrated this experience into their lives and relationships and what their sense of the future was at the time of their illness. In addition the study examined how adolescents made sense of looking ‘not normal’, how they dealt with their changing body image when they had cancer. Questions around their lives before, during and after the cancer experience were focused upon. The overall intend of this study was to explore the lived experiences of adolescents with cancer by allowing the participants to talk about the impact this illness has had on their lives and listening to them without any personal preconceived ideas of such an experience.

1.3 THEORETICAL FRAMEWORK OF STUDY

The study locates itself in a descriptive phenomenological context as described and used by Amedo Giorgi (2003). This approach, also known as the Duquesne School is the oldest and most established form of phenomenological psychology (Langdrige, 2007). Descriptive phenomenology is concerned with describing phenomena rather than explaining it. No attempt is made to find the underlying causes of the phenomenon; the main aim is to simply describe the phenomenon as it appears or as it is experienced (Langdrige, 2007).

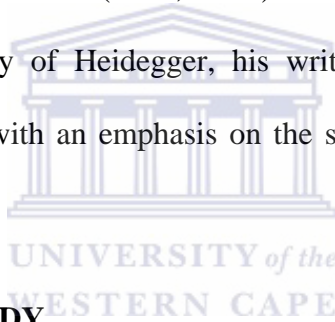
Therefore, phenomenological research aims to clarify situations lived through by persons in everyday life (Giorgi & Giorgi, 2003). Within this study, having cancer during your adolescent years, a situation is sought in which individuals have first hand experiences that they can describe as they actually took place in their life. The aim is to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place (Giorgi & Giorgi, 2003). The participants in the study were allowed to talk about the experience of having cancer as an adolescent, how they coped with looking different from their peers, the importance of support they received from family and friends and whether or not this experience impacted on career goals they have set for themselves.



Phenomenology was utilised in this study both as a theoretical framework and as a data analytical tool. Edmund Husserl (1859-1938) created phenomenology as a school of thought. As a philosopher he aimed to create a pre-suppositionless philosophy by a reduction and epoche or bracketing of all received ideas. The objective is to find the essence, which are the primary truths of the mind. This is a search for truth through direct introspection of lived experience (Bazier, 1991). A phenomenological theory is a philosophical approach which seeks to go into the frame of reference of the participant and values the participant's phenomenal world without any prejudgments and preconceived ideas of the particular phenomenon (Bazier, 1991).

Phenomenology also offers the possibility of studying human experience in the context of the life-world (Madjar & Walton, 1999). The Canadian phenomenologist Max van Manen (1990) writes extensively on the life-world. To gain greater understanding on the lived

experiences of adolescents with cancer Husserl's descriptive phenomenology as portrayed by Giorgi as well as van Manen's four existentials were used. Descriptive research usually refers to all those enquiries whose goal is to give a natural, close and thorough account of the topic that is investigated (Valle & Halling, 1989). According to van Manen (1990), phenomenology attempts to clarify the meanings as we live them in our everyday existence, our life-world. Van Manen (1990) claims that phenomenology is the study of the life-world, the world as we immediately experience it pre-reflectively rather than as we conceptualise, categorise or reflect on it (Husserl, 1970 as cited in van Manen, 1990). Even though the writings of van Manen (1990; 1998) are mostly associated with that of the interpretative phenomenology of Heidegger, his writings also combine the descriptive phenomenology of Husserl with an emphasis on the study of the world before reflection (Dowling, 2005).



1.4 AIMS OF THE STUDY

Based on the limited literature found on the lived experiences of adolescent with cancer especially in South Africa, the focus of the current study was guided by the following questions: How do adolescents experience cancer and how are they able to deal with their changing body image when they have cancer, the influence of the support of family and friends and effect the cancer experience had on career goals. The research questions subsequently resulted in the formulation of the aims of the study which is exploring the lived experiences of adolescents with cancer. A secondary aim was exploring the impact the cancer diagnosis had on their lives of the adolescents.

1.5 RESEARCH METHODOLOGY

Six adolescents, three male and three female, whom have or had been diagnosed with cancer, were interviewed for this study. They were either in remission or in an advanced stage of receiving treatment. Semi-structured interviews were used for gathering data. The majority of the interviews were conducted at the participants' homes. One interview was conducted at the hospital as the participant was receiving chemotherapy at the time.

A phenomenological method of analysis was used. This approach is primarily concerned with lived experience (Langdrige, 2007). According to Moustakas (1994), all psychological phenomenologists employ a similar series of steps. The transcribed interviews are divided into statements or horizontalization. Then the units are transformed into clusters of meanings expressed in psychological and phenomenological concepts. Finally these transformations are tied together to make a general description of the experience, the textual description of what was experienced and the structural description of how it was experienced (Creswell, 1998). From the individual textual-structural descriptions, a composite description of the meanings and essence of the experience will be developed, representing the group as a whole (Moustakas, 1994).

1.6 OUTLINE OF THE STUDY

Chapter one has briefly described the rationale and aims of the current study, chapter two will provide a more detailed overview of phenomenology, adolescence and cancer. Chapter three details the research procedure which includes research design, participants, procedure, reflexivity and ethical considerations. Chapter four provides a discussion of the results in which themes are identified and ends with a summary of the results. Chapter five deals with the discussion of the limitations of the study and concludes with recommendations for future research.

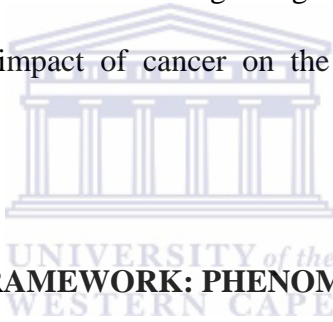


CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

The aim of the study is to explore the lived experiences of adolescents with cancer and the impact this experience had on their lives. This chapter commences with a description of the theoretical framework which justifies this aim and which guides the research approach, namely phenomenology. Previous research regarding adolescents and cancer are discussed which mainly involves the impact of cancer on the different developmental stages of adolescence.



2.2 THEORETICAL FRAMEWORK: PHENOMENOLOGY

Edmund Husserl (1859-1938) is regarded as the founder of the branch of philosophy known as phenomenology. For Husserl phenomenology meant the rigorous and unbiased study of things as they appear, so that one might come to an essential understanding of human consciousness and experience (Valle & Halling, 1989). Consciousness in this sense can also be referred to as an awareness of something. The word 'thing' is a term coined by phenomenologists to represent phenomena. These objects include experiences, memories and so on. Precedence is given to the phenomenon of consciousness and in its broadest sense it refers to the totality of lived experiences that belong to a single person (Giorgi, 1997). Consequently phenomenology is a way of viewing ourselves, of viewing others and of viewing all else that comes into contact with our lives (Wagner, 1983). Giorgi, (1997)

states that the focus is on people's perceptions of the world or according to Husserl, their perception of the 'things in their appearing'. The 'things in their appearing' for adolescents would be the experience of having cancer as an adolescent.. According to Langdrige (2007) a phenomenon in terms of phenomenology means the presence of any given precisely as it is given or experienced. Husserl identified several fundamental concepts to describe the human experience of the world. These concepts are briefly discussed.

2.2.1 Intentionality

Intentionality was regarded by Husserl as an essential feature of consciousness. In phenomenology intentionality means that whenever we are conscious (or aware or perceptive), it is always to be conscious of something. There is always an *object* of consciousness (Langdrige, 2007). The reality of an object is inseparably related to one's consciousness of it. Reality, according to Husserl, is not divided into subjects and objects. This shifts the Cartesian duality to the meaning of an object that appears to consciousness (Creswell, 1998). There are not two separate entities, objects and subjects, existing in themselves which later will get to relate to each other, but the very meaning of subject means a relationship to an object, and to be an object fundamentally implies being related to subjectivity (Giorgi, 1997). The focus is on the way consciousness is turned out on to the world, the relationship between the person's consciousness and the world which is also known as the public realm of experience (Langdrige, 2007). In relation to the current study, cancer is the object of consciousness; which is the consciousness of the adolescents. The experience of having cancer as an adolescent is a subjective experience adolescents are

aware of, each cancer experience being different for each individual adolescent. Each individual adolescent experiencing cancer relates to their subjective experience of cancer.

Phenomenology is particularly concerned with anything that presents itself to consciousness, whether the object is real or imagined, empirically measurable or subjectively felt. Our consciousness is the only access human beings have to the world (van Manen, 1990). An important aspect of phenomenology is understanding experience and the way in which the person perceives the world he or she inhabit (Langdridge, 2007). Because of our consciousness we are related to the world. Therefore, all we can ever know presents itself to consciousness. Anything which falls outside of consciousness falls outside the bounds of possible lived experience (van Manen, 1990). Creswell (1998) states that the reality of an object is only perceived within the meaning of the experience of an individual and humans have the capability to reflect on it. A person cannot reflect on lived experience while living through the experience. Phenomenological reflection is not introspective but rather retrospective. Reflection on lived experience is always recollective, it is reflection on experience that is already passed or lived through (van Manen, 1990).

Giorgi and Giorgi (2003) explain that descriptions of how people live through and interpret situations are retrospective and this feature is a key aspect in phenomenology. In this study, adolescents were able to recollect and therefore reflect on their experiences with cancer.

2.2.2 Noema and Noesis

Intentionality furthermore indicates the indivisible relation of human beings to the world (van Manen, 1990). To further clarify intentionality, Husserl argued that all experience is experience of something. Within the experience of a thing there is the transformation of the

distinction between subjects and objects. Intentionality is the relationship between *what* is experienced (the object) which is known as noema and the *way* it is experienced (subject), known as the noesis. (Langdrige, 2007). Noesis constitutes the mind and spirit and awakens us to the meaning or sense of whatever is in perception, memory, judgment, thinking and feeling. Noema is its perceptual meaning, the remembering. Noema is that which is experienced, the *what* of the experience, the object part of the relationship. Noesis is the *way* in which the *what* is experienced, the experiencing or act of experiencing, the subject part of the relationship. (Moustakas, 1994). The relationship between the noesis and noema is intentionality; those things of experience (noema) that *are* present to me and the *way* in *which* these things are present to me (noesis) can thus be reflexively detected (Langdrige, 2007). The focus is on the experience of the world as it is lived by the participants through their own perceptions of the world and through this, come to understand the person in the act or perceiving (Langdrige, 2007).

Language cannot be separated from consciousness, and least of all from the conscious activity that we are thinking (Wagner, 1983). According to Giorgi (1997) one gives linguistic expression to an object when describing any given act precisely as it appears within that act. In other words, through the medium of language one is able to communicate to others the objects of consciousness to which one is present, precisely as they are presented. Thus, in this study adolescents used language to describe their experience of cancer (the noema) and the way in which cancer was experienced (noesis). The reality of having adolescent cancer can only be perceived by the participants within the meaning of

the experience of the adolescent. . They are able to reflect on it through recollection because they have passed through the experience of having cancer as an adolescent.

2.2.3 Life-world

The life-world is another key aspect in phenomenological research which was introduced by Husserl whose concern was on the uninterpreted world of everyday experience as expressed in everyday language; with the world as given in direct and immediate experience. The life-world is the world as lived by the person and not the external entity separate from or independent of of the person. (Valle & King, 1978). The life-world can be described as the background on which all things appear as themselves and as meaningful. The life-world is a dynamic sphere in which we live and nothing can appear in our life-world except as lived (van Manen, 1990). Our lived experiences and the structures of meanings in terms of which these lived experiences can be described and interpreted constitute the life-world. Our lived experiences, the description and the interpretation thereof and the structures of meaning in terms of which these lived experiences can be described and interpreted, make up the vast complexity of the life-world (van Manen, 1990).

In an attempt to explore the lived experiences of adolescents with cancer, the current study is investigated the life-worlds of adolescents' at the most basic and general structure.

Van Manen (1990) identified four existential themes of the life-world. The existentials will be explored as guides for reflection in the current research process. The four existentials include: lived space (spatiality), lived body (corporeality), lived time (temporality) and

lived human relation (relationality or communality). These themes can be seen as a way in which all human beings experience the world because the life-world comprises the world of objects around us as we perceive them and our experience of our self, body and relationships (Finlay, 2008).

- *Lived space (spatiality)*

Lived space signifies felt space. Lived space is mainly pre-verbal for we do not normally reflect on it even though we know that the space in which we find ourselves affect the way we feel (van Manen, 1990). Benner (1994) notes that the most fundamental aspect of the life world is spatiality which she refers to as that things are close or remote. According to van Manen (1990), we become the space we are in.

- *Lived body (Corporeality)*

Lived body refers to the phenomenological fact that we are always bodily in the world (van Manen, 1990). The reality of being tangible, our physical body reveals and conceal something about ourselves. The lived body speaks directly to the perception an individual has of his/her body image(or body concept). The image of the body is defined as the subjective image one has of one's own body, specifically with respect to evaluative judgments about how one is perceived by others and how well one is adjusted to these perceptions (Reber, 1985).

- *Lived time (Temporality)*

Lived time refers to subjective time as apposed to objective time (clock time). Lived time is the time that appears to speed up when we are having fun and slow down when

we are not. Lived time is also our temporal way of being in the world (van Manen 1990).

- *Lived other (Relationality)*

Lived other refers to the lived relation we have with others in the interpersonal space we share with them. In a larger existential sense human beings have searched in this experience of the other, the communal, the sense of purpose in life, meaningfulness, grounds for living, as in the religious experience of the absolute Other, God (van Manen, 1990).

Effective understanding of the existentials involves the process of epoché (bracketing) and reduction. These processes have to be applied by the researcher. The application of epoché and reduction will result in the identification of the essence of the study; themes that will be identified after applying the process of analysing the data using phenomenology as a data analytical tool. The terms epoché, reduction and essence will be described briefly.

2.2.4 Epoché

Epoché is a term used by Husserl which denotes the process by which we make an effort to abstain from presuppositions, those preconceived ideas we may have about the things that we are investigating; this is also sometimes referred to as bracketing (Husserl used the term 'natural attitude' which basically means our most basic way of experiencing the world, including all our taken-for-granted assumptions (Langdrige 2007). According to Moran (2000) epoché means the suspension of the natural attitude which involves setting aside all scientific, philosophical, cultural and everyday assumptions. Bracketing results in

the researcher attempting to meet the phenomenon as free and as unprejudiced as possible in order that the phenomenon present itself as free and unprejudiced way as possible so that it can be precisely described and understood (Dowling, 2005). Bracketing off one's preconceptions about a phenomenon being investigated and being open to the participants' experience, allows the 'returning to things themselves' in their appearing to the consciousness. In an attempt to exercise bracketing, the researcher was constantly aware of her preconceived ideas of cancer and the adolescent. It was a constant reminder that the researcher need to listen to the participants with an open and receptive mind. The researcher did this by asking them on elaborating on answers that were not clear; The reseacher made an attempt not to assume anything.

2.2.5 Reduction

A procedure that is initiated by epoché and follows up on it is the process of phenomenological reduction. This involves treating data from participants with equal value. All detail must be described, regardless of how ordinary it seems, and no particular perception should be privileged during phenomenological reduction (Langdridge, 2007). Giorgi (1997) states that phenomenological reduction is a methodological devise invented by Husserl in order to help make research findings more precise. Langdridge (2007) states that one should examine minute details and then the whole; doing this helps to identify the essence of the phenomenon. In an attempt to exercise reduction during the interviews the researcher listened to each participant with equal enthusiasm trying at all times to listen to their experience as if for the first time, therefore trying to treat them as equal.

2.2.6 Essence

The term essence signifies the inner fundamental nature of a thing; it is what makes a thing what it is and without which it would not be what it is (van Manen, 1990). Essence, as Husserl uses the concept, means that which is common or universal, the condition or quality without which a thing would not be what it is (Moustakas, 1994). Identifying the essence in phenomenology represents a move from description of individual experiences to investigation of the structure underlying such experience. Husserl believed that it was possible on the basis of a single experience to identify the universal structures (essences) underlying the experience (Langdrige, 2007). That is the fundamental goal of phenomenology is to reduce the textural (what) and structural (how) of experiences to a brief description that typifies the experience of all the participants in a study. All the individuals' experiences are reduced to the 'essentials' of the experiences (Moustakas, 1994). Essence does not emerge through some sense of inner intuition but through rigorous examination and reflection on experience itself as given to consciousness among the participants and the researcher. Epoché and phenomenological reduction provide the method for identifying essences (Langdrige, 2007).

The goal of the phenomenological analysis is reducing the experiences of the individuals and describing the experience of all the participants as a whole. Through the process of epoché/bracketing and reduction, the essence or real meaning of being an adolescent with cancer is revealed. The challenge during the interviews was to receive information from the participants, not because they were reluctant to share information as such, but the researcher found that the participants had difficulty voicing their experience. The following

section deals with adolescence as a developmental stage, the explanation of adolescence by theorists Erik Erikson and Jean-Pierre Piaget. A brief discussion on adolescence and health will follow.

2.3 Adolescence

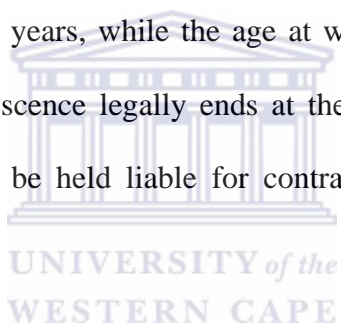
Adolescence is defined as the period of transition from childhood to adulthood. This period is probably the most challenging and complicated period of life to describe, to study or to experience (Berger, 2000). Literature not only explores the developmental milestones during adolescence, but also includes an exploration of sexual abuse, alcohol, tobacco and drug abuse during adolescence. This section will briefly discuss the definition of adolescents and the theoretical perspectives of Erik Erikson and Jean Piaget regarding this particular developmental stage.

2.3.1 Definition of adolescence/adolescents

Adolescence is a flexible concept reflecting specific developmental tasks but broadly encompassing individuals in their teens and early twenties. Adolescence can be viewed as a period of life where tasks such as establishing personal identity, establishing independence, making occupational choices and making philosophical choices are initiated, although these tasks continue throughout life. Lewis (1996) believes that contrasting to the widely recognised view of adolescence as time apart somewhere between childhood and

adulthood, it should be viewed as containing elements of both. Adolescents can be seen as both adults and children

According to Sigelman (1999) adolescence is the developmental stage between childhood and adulthood, ages 12 through 19. The term *adolescence*, means to grow to adulthood. Since adolescence is seen as a growth process toward adulthood, and adulthood is seen in all cultures as the ultimate goal in human development, the term can be applied to all cultures (Louw *et al.* 1998). Depending on biological and socio-cultural factors, as well as individual differences, the age at which adolescence as a separate developmental stage begins, varies from 11 to 13 years, while the age at which it ends is between 17 and 21 years. In South Africa adolescence legally ends at the age of 18 when parental consent expires and the person may be held liable for contractual obligations (Louw & Louw, 2007).



Reber (1985) defines adolescence as the period of development marked at the beginning by the onset of puberty and at the end by the attainment of physiological and psychological maturity. The WHO (2004) defines adolescents as young people aged 10-19 years. There are about 1.2 billion adolescents comprising a fifth of the world's population and adolescents' numbers are still increasing. Four out of five adolescents live in developing countries (McIntyre & Williams, 2002). In the current study adolescents are viewed as youth aged from 10-19 years old.

2.3.2 Adolescence as a developmental stage

Adolescence can be subdivided into three phases. Early adolescence, ages (10-13) is characterised by a spurt of growth and the beginnings of sexual maturation. Young people start to think abstractly. In mid-adolescence (14-15) the main physical changes are completed. However, during mid-adolescence the individual develops a stronger sense of identity and relates more strongly to his or her peer group, although families usually remain important. The process of thinking becomes more reflective. In later adolescence (16-19) the body fills out and takes its adult form, while the individual now has a distinct identity and more settled ideas and opinions. Each phase is characterised by specific developmental tasks and associated psychosocial processes. According to the WHO (2004) each stage of adolescence is experienced differently and different meanings are attached to these experiences in the stages of adolescence. When studying adolescence, it is important to be reminded of the complexity and diversity of adolescents' physical and sexual development, the development of their thinking, feelings, personal relationships, behaviour and identity.

Erik Erikson and Jean-Pierre Piaget are two prominent developmental theorists who respectively wrote extensively regarding the psychosocial - and cognitive development of adolescents. Piaget labels the cognitive developmental stage of adolescents as the formal operational period. During the formal operational period, adolescents develop the ability to perform formal operations. This means that they learn to think in an abstract and logical way. They can think deductively as well as inductively. Formal operational thought is not tied to concrete objects, but can deal with abstract things, possibilities and hypotheses. Formal operations consist of 'thought thinking about itself' (Louw, *et al.*, (1998).

Erikson is best known for characterising adolescence as a time of ‘identity crisis’ a critical period in the life long process of forming one’s identity as a person. During this psychosocial stage of identity versus role confusion, adolescents attempt to define who they are (in terms of career, religion, sexual identity, and so on) where they are heading and where they fit into society (Sigelman, 1999). Erikson was primarily concerned with the way in which psychosocial forces influence a person’s development. In his theory he describes a series of life crises or turning points that occur in response to demands that society place on the developing individual; that is demands to conform to adult expectations about self expression and self-reliance. He stressed the importance of cultural traditions and values on the way in which children are reared and on the quality of social interactions that affect personality development (Gormly, 1997).

In the light of the abovementioned views it is reasonable to deduct that adolescents have the ability to reflect and describe their experiences having cancer. They have the cognitive ability to make deductions and reason in an abstract manner. Apart from this they are able to realise the enormity of the experience as well as anticipate how this could impact on their future. A secondary aim of the current research is to explore the impact of cancer on the image that the adolescent have of him/ herself. Body image is a term which may refer to our perceptions of our own physical appearance, or our internal sense of having a body which is constructed by the brain.. Essentially a person’s body image is how they perceive their exterior to look, and in many cases this can be remarkably different to how they actually appear to others. Adolescents in most countries are very aware of their body shape

and appearance. Because of their desire to be accepted in their peer group, it becomes very important for them to fit in their group (Louw & Louw, 2007).

2.3.3 Adolescence and health

According to McIntyre and Williams (2002) adolescents are subject to most of the same illness as other age groups within a given population. They are, however, much less likely to recognise symptoms and much more likely to underestimate the importance of the symptoms. In addition, they usually do not know where to go for help and this often results in them being the least likely section of the population to go for early treatment when they are ill. They may leave diseases untreated because they are afraid of the outcome of the diagnosis and worried about the stigma attached to having a particular disease.

In addition, adolescents are most likely to engage in health-risk behaviours such as smoking and having unprotected sex. In a study done by Biglan (1990) cited in Brannon & Feist, (2000) found that adolescents engaging in one type of high risk behaviour such as smoking were more likely to engage in other high risk behaviours. For example adolescents who had sex with multiple partners whom they did not know very well were also not likely to use condoms.

Younger adolescents often do not take responsibility for their own health, because they do not properly understand the changes in and to their bodies. Girls may be embarrassed about growing breast, or embarrassed that they are late developers. Boys too become very anxious about the changes in their bodies. Such concerns are generally brief but some

young people develop low self-esteem due to this phenomenon (McIntyre & Williams, 2002).

In a study done by Suris *et al.*, (1996) on the investigation of emotional distress and suicidal ideation among adolescents with and without chronic illnesses it was found that chronic illnesses were associated with substantive emotional distress and suicide ideation in females but not in males. Females with chronic conditions did not, however, seek medical health services more often than their non-chronically ill counterpart. This finding suggests serious shortcomings in identification of 'at risk' youth and effective outreach to the adolescent population.

In a phenomenological study of the experiences of physically disabled children done by Mulerij (1996) the highlighted importance of early stimulation of positive feelings about the body and physical competence and physical competence instead of emphasizing learned helplessness. The importance of contact with peers and the stimulation of social competence were also emphasised.

In general, studies regarding healthy adolescents show that they are prone to engage in risky behaviours and are not likely not to take responsibility for their health. On the other hand adolescents with a chronic illness are associated with depression, including emotional distress and at times suicidal tendencies. A diagnosis of cancer is most likely to evoke pessimistic behaviour such as depression and anxiety mainly because you are never really 'cured' of the disease. Cancer has the unique ability to 'come back', you are never sure of

your status of being cancer-free and for how long. A discussion on cancer, the treatment thereof and the impact of cancer on developmental milestones of adolescents will follow.

2.4 Cancer

2.4.1 Definition of cancer

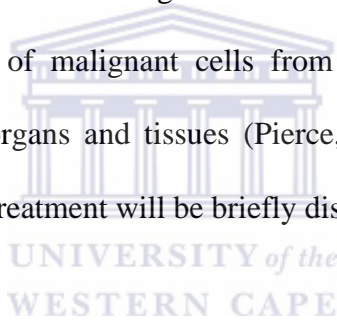
The word cancer is derived from the Latin meaning 'crab'. The word cancer also means any dangerous and spreading evil – presumably linked to early concepts of the crab's shape and movement (Ireland & Ireland, 1993). Although many people think of cancer as being a single disease, it is in fact a term used to describe over 200 different diseases. However, all types of cancer have one characteristic in common – the uncontrollable growth and accumulation of abnormal cells (Nezu, *et al.*, 1998).

Many cancers take the form of tumors, however, other cancers, such as leukemia, affect the blood, resulting in complications across numerous organs. Cancer is believed to be caused by both genetic and environmental factors with at least 5 per cent to 10 per cent of cancers being hereditary in nature (American Cancer Society, 2003, cited in Cruce and Stinnett, 2006). In addition cancer may be a result of contacts with chemicals, infectious diseases or radiation exposure as well (Phelps, 2006).

2.4.2 Classification of cancer

Cancer can be classified according to tumour grades, staging and the Tumour, Nodes and Metastasis system, also called the TMN system (Nezu, *et al.*, 1998). Tumour grades are classified in terms of their differentiation. Tumour cells are said to be differential if they

closely resemble their normal, healthy counterparts. Cancer cells that are dissimilar are called undifferentiated or anaplastic. The degree of cell differentiation plays an important role in making treatment decisions. In staging cancer, classification is according to the stages as a means of determining how far a cancer has progressed and according to whether and where it has spread. The TMN system classifies cancer in terms of three cancer variables: tumour (T), nodes (N) and metastasis (M). The T relates to the size of the primary tumour, and whether it has invaded nearby tissues and structures. The N involves the degree to which lymph nodes have been affected by the primary tumour. M refers to whether the cancer has spread to other organs and the degree to which it has metastasized. Metastasis is the spreading of malignant cells from a primary tumor with growth of secondary tumors in other organs and tissues (Pierce, *et al.*, 1978). The tumors can be treated in several ways. The treatment will be briefly discussed.



2.4.3 Treatment of cancer

Cancer treatment generally falls into four major categories. Surgery is the oldest form of cancer treatment. It used to support other treatment modalities such as chemotherapy or radiation. Chemotherapy is used for haematological tumours and for solid tumours that have metastasized to another area. Radiation, another form of cancer treatment, is used on tumours such as Hodgkin's disease, malignant skin tumours, cervical and early stage testicular cancers. These cancer types are curable today with the use of radiation therapy. Immunotherapy uses biological response modifiers (BRMs) to treat cancer. It is a newer

cancer modality that uses the individual's own immune system to fight the tumour cells in order to engender the therapeutic response (Nezu *et al.*, 1998). Cancer is a tremendous mental and physical challenge, and when experienced during adolescence, it could not be easier to handle than at an older more mature developmental stage.

2.5 Cancer in adolescence

In South Africa the biographical distribution of age in the National Cancer registry is 0-14, 15-29, 30-54, 55-64 and 65+. This makes it difficult to single out the cancer statistics for adolescents who are defined in South Africa as an individual from age 11 to 21 (Louw, *et al.*, 1998). Given that adolescents fall in both the 0-14 and the 15-29 age group, when considering statistics, both these age groups will be taken into consideration. This implies that a portion of the statistical information excludes adolescents (22-29), even though in countries such as England, adolescence ranges from ages 10-25 (Lewis, 1996). Appendix 1, Tables 1 and 2 depicts is a summary of the cancer incidence of adolescence in age group 0-14 years and 15-25 years according to the National Cancer Registry Report (2004).

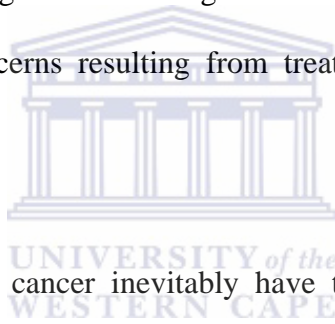
There were 60 172 new cancer cases reported to the cancer registry in 1998 and 60 343 new cases in 1999. Children (0-14 years) comprised 1 per cent of all female cancer cases, whilst young women aged between 15 and 29 years comprised 4 per cent of the total female cancer cases in 1998 and 1999 (National Cancer Registry Report, 2004).

It is interesting to note that the six most common cancers in age group 0-14 years for both male and female are similar, differing only in percentage. Leukemia is the leading cancer type in both male and female in the age group 0-14 years. Refer to Table 1 in Appendix 1.

This is different for the age group 15-29 age group. In this group leukemia is still the prevalent cancer type in males, but does not appear in females in the 6 most common cancer types for females. Cervical cancer is more common in females in the age group 15-29 years. Refer to Table 2 in Appendix 1 (National Cancer Registry Report, 2004).

2.5.1 Medical and psychological impact of cancer on adolescents

Uncertainty in illness may be more difficult for an adolescent who is experiencing rapid developmental changes than for an adult who has obtained a relatively stable lifestyle. While numerous bodily changes occur during adolescence, the adolescent with cancer has many additional bodily concerns resulting from treatment and /or the illness (Neville, 2005).



Adolescents diagnosed with cancer inevitably have to deal with medical interventions which include chemotherapy, radiation therapy, immunotherapy and surgery. These interventions have damaging effects both physically and emotionally. These side effects include changes in body image, loss of hair, nausea, fatigue and sterility (Brannon & Feist, 2000). Phelps (2005) reports that according to the American Cancer Association, many children report fatigue, nausea, and vomiting after treatment sessions and children may have an increased chance of infections or temporary hair loss after treatment. Another side effect that is common when exposed to radio active materials is a sunburn-type skin condition at the site of exposure. However, the effects vary according to the cancer type.

2.5.2 Most common adolescent cancers

- **Leukemia**

Leukemia is a cancer of the blood, forming cells. Leukemia is a general term used to describe four different disease types, one of which is called acute lymphocytic leukemia (ALL). Each year, 35 people in every million learn that they have leukemia, of which 5 will be children. ALL is the most common form of leukemia in children (CANSA, 2008).

- **Osteosarcoma**

Among the several cancers that affect teenagers, osteosarcoma comes nearest to being a characteristic cancer of adolescence (Whelan, 2005). Osteosarcoma is the most common type of bone cancer. In adolescents it can sometimes appear during their growth spurts. Osteosarcoma affects twice as many boys as girls and tends to appear in people who are taller than average. The most common site for osteosarcoma to develop is around the knee and almost half of all tumors will be in the distal femur (Grimer, 2005).

- **Brain cancer**

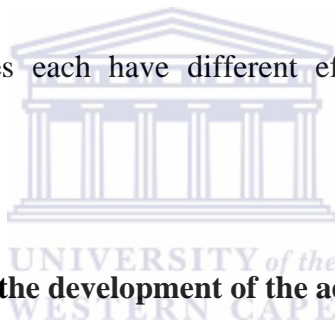
Brain cancers are usually discussed in the literature as part of the central nervous system tumors (CNS tumors). CNS tumors are the second most common type of cancer in children, consisting of approximately 20 per cent of childhood cancers and occurring most frequently in people less than 10 years of age (Cruce & Stinnett, 2003). The term 'brain cancer' is commonly used, but it can be a confusing term as it represent all brain cancers sound like one type of cancer. Brain cancer as a term actually encompasses a

variety of cancers. There can be actual brain tumors which arise from the brain itself, known as primary brain cancers and there are brain metastases which represent the spread of other cancers, such as lung or breast, to the brain (Dolinsky, 2006).

- **Lymphoma**

Lymphomas are divided into two major categories: Hodgkin's lymphoma and non-Hodgkin lymphoma (CANSa, 2008). Hodgkin's lymphoma usually occurs in adolescents and young adults. Incidence rates are higher in adolescents and young adults and long term survival rates are more than 86 per cent.

These common cancer types each have different effects on the lives of people and especially adolescents.



2.5.3 Impact of cancer on the development of the adolescent

2.5.3.1 Impact of cancer on physical development of the adolescent

Physical development in adolescents is characterised by a dramatic growth spurt and the attainment of sexual maturity. During this time the adolescent also experiences improved physical functioning and is very concerned with body image (Sigelman, 1999). According to Louw *et al.*, (1998), adolescents are acutely aware of the physical changes they experience and an important developmental task during adolescence is the acceptance of a changed physical appearance.

Girls typically become concerned about appearances and worry about how others will respond to them. In contrast boys' body image are more positive, and they are more likely to welcome weight gain that come along with puberty, for they hope to be tall, hairy and handsome. Boys may become pre-occupied with their physical and athletic ability (Sigelman, 1999). A cancer diagnoses can have a negative effect on the body image of an adolescent because 'fitting in' and 'looking normal' are sometimes all that matter.

In a study done by Wallace *et al.*, (2007) on managing appearance changes resulting from cancer treatment in adolescent girls it was found that there were definite concerns around their altered appearance especially during treatment. However, since treatment participants expressed a shift in views and expectations of their appearance as well as the value placed on it. They expressed increased satisfaction with their own appearance and a decrease in its importance.

However, in a study done by Larouche and Chin-Peuckert (2006), which explored the effects of cancer and cancer treatment on adolescents' (both males and females) perception of body image, adolescents reported having noticeable physical changes that modified the way they perceived their body image; they found that they looked different than other adolescents, at times, even abnormal or strange. Adolescents attributed their body image perceptions as not looking normal to different physical factors such as hair loss, presence of an implanted subcutaneous central venous catheter (CVC), scars and pale skin complexion.

It would seem that the impact of cancer on the physical development of adolescents is subjective. Some may find it difficult to deal with during the whole process and even

afterwards as well while others is able to deal with it more constructively. Because adolescents are normally conscious of how they look and more important, what others think of their look, the effects of chemotherapy can impact on the view adolescents have themselves during a time where body-image plays a pivotal role in the life of an adolescent. The manner in which they deal with their changing body-image has in part to do with their way of thinking and reasoning. The manner in which they make sense of the temporary changes in their physical look is important in their overall coping with impact of cancer and its treatment.

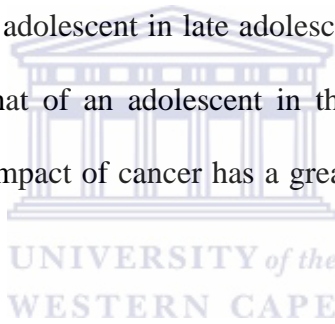
2.5.3.2 Impact of cancer on the cognitive development of the adolescent

In contrast to physical changes that are noticeable and occur universally, cognitive changes are less obvious and more variant. Cognitive changes during adolescence result in changing the child's concrete thinking ability to a comprehensive, more advanced ability that can analyse and reason logically about concrete as well as abstract concepts (Louw *et al.*, 1998). Adolescents are in the formal operations stage of development and therefore concrete operations are possible at this stage. They have the ability to mentally juggle and think logically about ideas and deal with possibilities, including those that contradict known reality (Sigelman, 1999).

A study done by Yeh (2002) on the life experience of Taiwanese adolescents with cancer revealed that the perception of illness varied in accord with their disease progress. At the beginning of the illness, participants held positive attitudes about the illness, such as, '*I will be cured and get back to school.*' Participants were angry at comments by others which

were different from their own perception. Participants gradually learned however that they had little control over their illness and the necessary treatments. From this particular study also emerged a need for an instrument which is specific to the culturally sensitive framework of the life experiences of adolescents with cancer which needs to be developed to specify their experiences with cancer.

Because adolescents have an advanced ability of thinking that enables them to analyse and reason logically about concrete and abstract concepts, they are able to rationalise that the effects of the cancer treatment are of a temporary nature. The level of reasoning depends of the stage of adolescence. An adolescent in late adolescence are generally able to deal with the effects of cancer than that of an adolescent in the early stages of adolescents. The researcher believes that the impact of cancer has a great deal to do with the personality of the adolescent



2.5.3.3 Impact of cancer on personality development of the adolescent

Personality development involves the development of a unique identity, one's self concept as well as self-esteem. Adolescence is the period in which the development of the self is most important. Adolescence is the time for 'finding oneself' which involves the formation of a positive or negative self-esteem.

Identity development implies that adolescents need to define who they are, what is important to them and what directions they want to take in life. Erikson referred to this identity development as an identity crisis- a temporary period of confusion, during which adolescents explore, question existing values and experiment with alternative roles in order

to develop an own set of values and goals (Louw *et al.*, 1998). Erikson believed that one of the reasons adolescents experience an identity crises is due to the fact that their bodies change and they must therefore revise their body image (part of their self-concept) and become accustomed to being sexual beings (Sigelman, 1999). In order to develop an own identity, Erikson believed that adolescents have to form a continuous, integrated, unified image of the self (ego-synthesis). This means that regardless of the course of time and the accompanied changes, a person should feel that he or she is still the same person (Louw *et al.*, 1999). In a study done by Woods and Shearer (2005), an adolescent girl who was diagnosed with cancer stated that she had come to terms with the illness and the altered body image and she has accepted herself.

In a study conducted by Ritchie (2002) on self-esteem and hopefulness in adolescents with cancer, it was found that poor self-esteem and hopelessness are not necessarily associated with the experience of cancer in the adolescence. However, a relationship between psychosocial development and coping, in the form of self-esteem and hopefulness, does exist but requires further exploration.

In a qualitative study done by Adamson *et al.*, (1998) on adolescent identity, it was found that the respondents were frequently occupied with controlling, or trying to control, their own behaviours and interactions with other people. Adolescents needed to possess both an experiencing and an introspecting self-concept dimension, as well as to be able to relate to other without losing her/his autonomy. Hence, identity development can be viewed as a process of balancing between intra- and interpersonal parts of the identity.

2.5.3.4 Impact of cancer on the social development of the adolescent

All aspects of adolescent development occur within a social context. During adolescents this social context is formed amongst others, by parents and peers (Louw *et al.*, 1998). Adolescents experiences various strong cognitive and physical changes, for the first time in their lives and therefore they may start to view friends, their peer group as more important than their parents/guardians. However, attachment to parents remains highly important during adolescence. Adolescents who enjoy secure attachments with their parents seem to have a stronger sense of identity, higher self-esteem, greater social competence and better social adjustments. When parents provide emotional support and a secure base for exploration but also encourage autonomy, their adolescents seem to thrive (Sigelman, 1999). A good and healthy relationship with parents could only benefit the adolescent with cancer. Even though adolescents strive for more independence from their parents, they tend to draw closer to parents and siblings during this time of cancer.

Adolescents have an intense desire to belong. Their social development is therefore characterised by an increasing interest in and involvement with friends and the peer group (Louw *et al.*, 1998). Struggles with adolescent identity and depression usually set in when an adolescent experiences a loss (includes loss of health). Relationships with family and friends change. Family means a great deal and they find it hard to come to terms with the illness and how it impacts on the adolescents' life. But through all of this the relationship with family and siblings tend to grow stronger.

Adolescents may also experience strife in their relationships with friends (Williams & Savage, 2007). Most adolescents judge their value in terms of others' reaction to themselves and are dependent on their peers' approval, support and acceptance for healthy psychological development (Louw *et al.*, 1998). Friends are an important part of adolescence. They provide social support and true friends are accepting of faults, differences and challenges.

In a study done by Adamson *et al.*, (1998) on adolescent identity it was found that adolescents generally perceive contact with parents and close family as warm and positive. It has also been established that adolescents are at a transitional and emotionally turbulent life stage and that families managing any illness diagnosed in adolescents will encounter significant problems. Given that a diagnosis of cancer among any age group carries its own significant psychosocial impact, when these factors are combined the result is likely to produce considerable problems for the family's management of the illness (Grinyer, 2002).

Yeh (2002) found that there was a strong desire by adolescents with cancer to be isolated from peers, and their empathy was with other sufferers and an extended dependency on their mother in particular. Repeated hospitalisation made access to their peers difficult. These adolescents did one of two things; they either kept it from their friends or openly informed them in his/her own way.

2.6 Conclusion

According to the literature cancer has a significant effect on the physical, cognitive, personality and social development of the adolescent. It is also true that the intensity of the impact of the cancer has a great deal to do with other factors such as support, resilience, and so forth. It is apparent from the literature the frequent question asked is how adolescents experienced cancer in terms of their lived body (corporeality), lived space (spatiality), lived time (temporality) and live other (rationality). This phenomenon will be dealt with in chapter 4.



CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

This chapter describes the research methodology used throughout the thesis with particular reference to phenomenology as a methodology as well as a data analytical tool. From this the reader will come to understand why phenomenology was chosen to reach the aims and objectives of the thesis. The procedures for data collection and analysis will be explained after which reflexivity issues will be addressed.

3.2 RESEARCH DESIGN

This study was conducted within a qualitative research framework since it is aimed at exploring and understanding the lived experiences of adolescents with cancer and how it impacts on their view of themselves, it will be undertaken within a qualitative research framework. This framework is concerned with exploring, describing and understanding human behaviour in its natural setting. The motive behind using a qualitative rather than a quantitative research approach for this particular study was due to the latter approach's emphasis is on the quantification of constructs. The quantitative researcher believes that the best, or only, way of measuring the properties of phenomena is through assigning numbers to the perceived qualities of things (Babbie & Mouton, 2001). Qualitative research is an exploratory process of understanding based on distinct methodological traditions of enquiry

that explore a social or human problem. The researcher builds a complex, holistic picture, analyses words, reports detailed views of informants, and conducts the study in a natural setting (Creswell, 1998). Rather than using a measurement scale as an instrument of observation, in qualitative research the researcher is the instrument of observation (Terre Blanche & Durrheim, 1999).

3.2.1 Phenomenology as a research method

As a research method, phenomenology is the scientific study of the appearance of phenomena as they appear to us in consciousness. Husserl claims that the aim of phenomenology is the meticulous and impartial study of things as they appear in order to arrive at an essential understanding of human consciousness and experience (Valle & Halling, 1989). Phenomenology thematises the phenomenon of consciousness, and in its most complete sense, it refers to the totality of lived experiences that belongs to a single person (Giorgi, 1997). Therefore phenomenological research aims to clarify situations lived through by persons in everyday life (Giorgi & Giorgi, 2003). According to Merriam and Associates (2002) a phenomenological study focuses on the essence or structure of an experience. The interest is in showing how complex meanings are built out of simple units of direct experience. It is therefore also an attempt to deal with inner experiences of everyday life. This means that to study a particular phenomenon of having cancer during your adolescent years, a situation is sought in which individuals have first hand experiences that they can describe as these actually took place in their lives. The aim is to capture as closely as possible the way in which the phenomenon is experienced within the context in which the experience takes place (Giorgi & Giorgi, 2003). At the heart of phenomenology

is the aim of insightful understanding and description of the phenomena of human experience (van Manen, 1990).

Phenomenology as a method encompasses three interlocking steps: (1) the phenomenological reduction, (2) description, and (3) search for essence (Giorgi, 1997). Phenomenological reduction essentially means to bracket past knowledge about a phenomenon in order to encounter it freshly and describe it precisely as it is experienced. It is important to consider what is given precisely as it is given, as presence, or phenomenon (Giorgi, 1997). Description is the use of language to convey the objects of consciousness. Through the medium of language one is able to communicate to others the objects of consciousness to which one is present, precisely as they are presented (Giorgi, 1997). According to Langdridge (2007) identifying essences in phenomenology represents a move from describing from individual experience to exploring the structure underlying the experience. Essences emerge not through some sense of inner intuition but through rigorous examination and reflection on experience itself as given to consciousness among the participants in the investigation.

Phenomenology is not only a research method as employed frequently by qualitative researchers, it is also a philosophy. There are many styles of phenomenology and hence a number of schools of phenomenology even though they all have some commonalities (Dowling, 2005). The phenomenological method employed in the current study is that of the phenomenological psychologist Giorgi Amedeo. His human science approach to phenomenology follows a rigorous program of Husserl's writings and maintains that the object of phenomenological description is achieved solely through a direct grasping

(intuiting) of the essential structure of phenomena as they show in consciousness (van Manen, 1990).

In conjunction with the work of Giorgi (2003), the current study employs the methodological and analytical approach of Max van Manen. The writings of van Manen (1990) combine the descriptive phenomenology of Husserl with an emphasis on the study of the world before reflection and argues that it is also scientific and, at the same time, emphasises that it involves interpretation (Dowling, 2005). The researcher is of the believe that in combining the two methods the data collected from the participants can be explained in a more comprehensive manner.

Lived experiences' is a central issue for it presents the interpretative approach that will be used as a means of understanding the phenomenon from within its context, in an empathic manner. The focus of the study is on two phenomena. The phenomenon of being an adolescent with cancer and the phenomenon of lived experience. This focus revolves around the 'insider' or 'first person' perspective and involves adopting and representing the perspective of the person or group having the experience (Kelly, 2005).

3.2.2 Phenomenology as a data analytical tool

Phenomenological method of analysis is concerned primarily with lived experience, whether it is the experience of being a victim of crime (Langdrige, 2007) or the experience of being an adolescent with cancer. When engaging with the literature in order to carry out a phenomenological analysis the researcher must assume a psychological perspective to get within the attitude of the scientific phenomenological reduction and be mindful of the

phenomenon being studied (in this case the experience of being an adolescent with cancer). There are four stages to a descriptive phenomenological analysis (Giorgi & Giorgi, 2003). The specific steps in data analysis use are (1) The researcher first reads all descriptions in their entirety, (2) the researcher then extracts significant statements from each description, (3) these statements are formulated into meanings, and these meanings are clustered into themes and (4) the researcher integrates these themes into a narrative description (Creswell, 1998). The first stage involves reading the text for overall meaning. This is to try and grasp an overall sense of the meaning of the text. The second stage is the identification of meaning units. This is an attempt to separate discrete meaning units and at the same time adopt a psychological attitude towards the text. The researcher should become aware of emotions, beliefs or behaviours. Giorgi and Giorgi (2003) claims that the meaning units are formed by careful rereading of the description and every time the researcher experiences a transition in meaning a slash must be placed in the text. It is important to note that meaning units should be understood as constituents rather than elements of a whole for a constituent can only be understood in context whereas a element can be understood independent of the context (Langdridge, 2007). The third step involves assessing meaning units for their psychological significance. In this step there is a move from the idiosyncratic (individual) detail to a more general meaning. The forth (last) step involves the production of individual structural descriptions and then one general description. This process involves identifying the key elements for the phenomenon being described (Langdridge, 2007). In the analysis process van Manen's use of phenomenology was considered as well. For a complete holistic view, van Manen (1990) suggests analysis following the lived existentials. These four lived experiences of body, space, time and other connect and

interact to describe the lived experience of adolescence with cancer. A brief discussion of the four existentials is found in chapter 2.

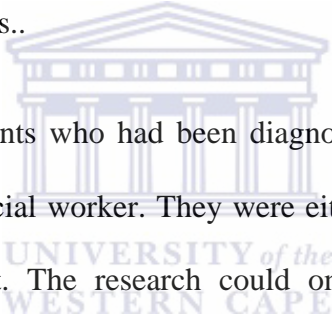
3.3 PARTICIPANTS

The recruitment of the eight participants for the study was a great challenge. Due to the sensitive nature of the topic, the standard process of approaching prospective participants was omitted. As a means of recruiting participants for the study, criterion sampling was used. Creswell (1998) suggests this type of sampling to be best when doing a phenomenological study. According to Miles and Huberman (1994:28) criterion sampling works when all the cases meet some criterion; useful for quality assurance. This type of sampling is ideal when all the individuals studied represent people who have experienced the phenomenon (cited in Creswell 1998).

The participants were purposively drawn from the cancer unit at a public hospital. In a phenomenological study, according to Creswell (1998), participants may be located at a single site, although this may not be necessarily be the case. More importantly, they must be individuals who have experienced the phenomenon being explored and can articulate their conscious experiences. A letter outlining the details of the study was issued to the Social Work Department of the hospital. (see attached as Appendix 2). This department acted as a liaison between the researcher and the participants. This hospital is affiliated with a local university. The Committee for Human Research of the Faculty of Health Science granted permission for names to be given to the researcher after more than a year of the

initial meeting. While waiting for permission, the researcher attempted to recruit participants through the education department for there are special schools who have chronically ill children. Permission was granted almost immediately granted, but unfortunately the school which was contacted in this regard did not have children in the required age group.

Due to sensitive nature of the research topic a large number of participants were not required. It was the aim of the researcher to include participants from a variety of backgrounds and from all cultures represented in South Africa, but was unsuccessful in securing respected participants..



The names of eight adolescents who had been diagnosed with cancer were given to the researcher by the hospital social worker. They were either in remission or in an advanced stage of receiving treatment. The research could only be conducted with six of the participants. One participant passed away during the time of the interviews and another participant has relocated which made it impossible for the researcher to make contact with the participant. . All the participants were from the 'Coloured' community and, except for one, came from a low socio- economic background. Participants were both males and females. Criteria for participant selection included willingness to participate in a tape recorded interview, the use of English or Afrikaans as primary language and the ability to articulate the lived experiences of being an adolescent with cancer. Participants voluntarily participated in the interviews with informed consent from parents or guardian for those if under the age of 18. Participants also provided informed assent for their participation in the study. Participants were not paid for any part of their involvement in the research.

The participants' ages varied between 13 – 19 years. Fifty per cent of the participants were male and fifty percent were female. Two participants were diagnosed with Osteosarcoma. One is female and the other one male. The female happened to be the oldest in the group of six participants and the male the youngest in the group. Both of them had a leg amputation. The other participants' diagnoses were Rhapdo, Hodgekins, Bone cancer, a brain tumour and ALL.

TABLE 3.1 Demographic details of participants

Participants	Age	Gender	Home Language	Diagnosis	School Grade	Age when diagnosed
1	13	Male	Afrikaans	Leukemia	7	11
2	13	Male	Afrikaans	Osteosarcoma	6	13
3	19	Female	Afrikaans	Osteosarcoma	12	12
4	15	Female	English	Rhapdo	10	14
5	16	Female	Afrikaans	Brain tumor	10	11
6	15	Male	Afrikaans	Hodgekins (lymph)	10	12

Source: Compiled by author, 2009

The study required that the participants be verbally fluent in English or Afrikaans and have the ability to communicate their feelings, thoughts and perception in relation to the phenomenon being researched. All the participants, except for one, were fluent in Afrikaans

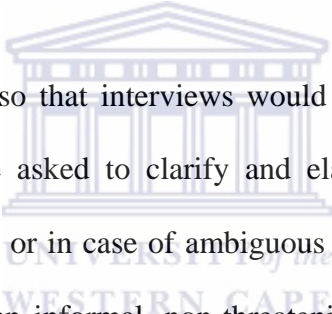
and the researcher felt it best to conduct the interview in their home language for it is believed that they would be more capable of being expressive and articulate. The participants were assigned numbers to distinguish between them in an attempt to ensure confidentiality.

3.4 PROCEDURE

The researcher deemed it important to meet with the parents and participants who were under 18 prior to the interview. This initial meeting took place at the homes of four of parents, and a telephonic conversation was held with the other two. This was an opportunity to inform the parents what the study is all about (attached as Appendix 2), the consent form (attached as Appendix 4) was discussed and signed as well as the questionnaire were presented to the parents. This presented an opportunity for them to pose questions or express any uncertainty. All the parents encouraged the opportunity for their children to talk about their experience. One mother in particular expressed her appreciation that her child who does not want to talk to her about his experience will be provided with an opportunity to do so.

The interviews were conducted in a setting in which the participants felt comfortable. To ensure a comfortable rapport and facilitate the development of trust, all the participants, except for two, were interviewed in their homes. One participant preferred to be interviewed at his school and the other, because he was receiving chemotherapy at the time, was interviewed at the hospital.

Conducting an interview is a more natural form of interacting with people and therefore fits well with the qualitative approach to research. It offers an opportunity to get to know people quite intimately, so that the researcher can fully understand how the participants think and feel (Terre Blanche, & Durrheim, 2002). Semi-structured interviews were used for gathering data. In semi-structured interviews, the researcher has a list of themes and questions to be covered, although these may vary from one interview to the next. Instead of an interview schedule, interview guides are used in semi-structured interviews (Welman *et al.*, 2005). The interview guide was drawn from Murray and Chamberlain (1999) and is attached as Appendix 5.



Adequate time was allowed so that interviews would not be constrained by an imposed time limit. Participants were asked to clarify and elaborate on phrases and words the researcher did not understand or in case of ambiguous statements. Attempts were made to conduct these interviews in an informal, non-threatening manner thus allowing for more flexibility in the interviews where the participants' understanding of their experience could be explored. In spite of this, participants' were somewhat reluctant to elaborate comprehensively and significantly. The researcher used the experience as a high school educator to talk 'their language' at times when probing for answers, but even this did not have the desired effect. It proves to be true that in phenomenological interviews, asking appropriate questions and relying on informants to discuss the meaning of their experiences require patience and skill on the part of the researcher (Creswell, 1998). However, further discussion of this aspect will be discussed in the results chapter.

3.5 ETHICAL CONSIDERATIONS

Ethical aspects such as: obtaining informed consent from the parents of the participants as well as the relevant authorities at a public hospital. The researcher obtained permission from the participants to audio tape the interviews and confidentiality regarding the information was given to the participants. The participants were informed that the audiotapes were at their disposal at any time. The researcher displayed respect towards participants by ensuring a sense of caring and understanding; assuring confidentiality and anonymity; adhering to an agreement that participants can withdraw at any stage. In order to guard against misrepresentation of data the researcher suggested providing feedback regarding research findings at the participants' request. Due to the sensitive nature of the study, care and support for the participants was made available within the Social Work Department at a public hospital. Attached as Appendix 5, is an informed consent form issued by the hospital.

3.6 REFLEXIVITY

According to Creswell (2003) during reflexivity, the researcher systematically reflects on who he/she is in the enquiry and is sensitive to his/her personal biography and how it shapes the study. Langdridge (2007) further notes that in the process of reflection, the researcher should always be conscious about the ways in which their questions, methods and their subjective position might impact on the psychological knowledge in the research study for the role of the researcher is co-producing psychological knowledge either as an

insider or and outsider. As the researcher does not have the 2007). personal experience of being an adolescent with cancer, it makes the research , in the process of reflexivity, an outsider. Langdrige (2007) guards against this as he states that reflexivity becomes particularly important when a researcher seeks to study vulnerable people especially if the researcher has not experienced the issue thus cannot identify with the cancer patient. The danger exist that as an outsider there is the likelihood of misinterpreting the participants to the point where the participants no longer recognise themselves.

In an attempt to guard against misinterpretations by the researcher, the researcher has to assume a phenomenological attitude (Willig & Stainton-Rogers,, 2008). To assume the phenomenological attitude means two things. In the first place the researcher must bracket all past knowledge about the phenomenon being researched so that he/she can be freshly present to the current instance of it. Bracketing the knowledge as a researcher regarding cancer and adolescents was not difficult for the concept was initially new. The researchers' interest in the topic was originally initiated when information was received of the death of a young family member who died of Osteosarcoma. Although the research was never acquainted with the deceased all the information about the illness and subsequent death was learned via relatives. The researcher was then intrigued by wanting to know more about the experiences of children (specifically adolescents) with cancer. As cancer is a hereditary disease the researcher wanted to be informed and be knowledgable about this subject.

Secondly the researcher does not speculate the phenomenon he/she is experiencing to be real (even if it is) but merely considers it to be a presence to the experiencing person. Strictly speaking it is a phenomenon for the experiencer, but not necessarily a reality in the

world. Consequently all the epistemological claims made by the researcher relate to the experiential realm of the experiencer and not the reality aspect of the given (Willig & Stainton-Rogers, 2008). Cancer, unfortunately is a crude reality in the world but having said this, the lived experience of each participant was exactly that; a subjective experience, a presence to the experiencing person. The researcher handled the information as such, and regarded each participants experience as truth and respected it for itself.

Phenomenological research also emphasises the lived experience not only of the research participants, but also that of the researcher (Merriam & Associates, 2002). Due to the sensitivity of the phenomenon the researcher guarded against getting too emotionally involved. It was therefore of utmost importance that the researcher was psychologically prepared to listen to responses that could be emotionally devastating, without the threat of showing too much emotion. Thus an attempt of the researcher to conduct the interviews as professional as possible. Although not an easy process, it was certainly rewarding. The attitude the participants displayed towards the researcher and hearing such a personal experience with a stranger, was a humbling experience.

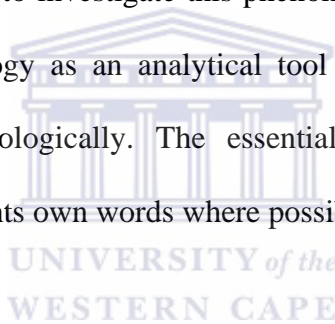
CHAPTER 4

DATA ANALYSIS

“Humans can fulfill the meaning of their lives not only by achieving and experiencing but also by suffering” (Frankl, 1959).

4.1 INTRODUCTION

The current study aimed to explore the phenomenon of adolescents’ experiences that have/had cancer and the impact this experiences had on their lives. In the study phenomenology was utilised to investigate this phenomenon. The chapter will start with a background of phenomenology as an analytical tool with the intention to describe the essential themes phenomenologically. The essential themes are then presented and described using the participants own words where possible.



4.2 BACKGROUND TO THE THEMES

According to Giorgi and Giorgi (2003) it is essential that individuals, who have personal experience of a phenomenon, are able to describe the phenomenon as it actually occurred in their life. The participants were able to describe the experience of having cancer as an adolescent because this phenomenon appeared to their consciousness; they all have/had the experience of being an adolescent with cancer. Giorgi (1997) further notes that ‘nothing could be spoken about or witnessed if it did not come through someone’s consciousnesses.

Van Manen (1990) states that consciousness is the only access human beings have to the world; the phenomenon of being an adolescent with cancer was part of the participants’

life-world. The life-world is described by Husserl as the ‘world of immediate experiences’ or the world as ‘already there’ (van Manen, 1990). The participants’ individual experience enabled them to reflect on *the what* of experience (having cancer as an adolescent); also known as the noema. *The way* in which they experienced the phenomenon, known as the noesis, was reflected upon too.

The objective of the analysis is to arrive at the essence of the experience for the participants. Van Manen (1990) describes phenomenology as the study of essences. In this study essence is understood as a description of a phenomenon. The researcher strove to investigate how the lived experience showed itself in each interview; portraying the essence of the experience for each participant and ultimately the essence of the experience as a group. Attributes of the phenomenon were written as essential themes and described using the participant’s own words wherever possible to explain the real meaning of being an adolescent living or who lived with cancer. The findings were presented across all interviews as a whole by four key essential themes in the six interviews. Together they present the participants’ joint unique lived experience having cancer as an adolescent.

4.3 ESSENTIAL THEMES

1. Unexpected change of everyday life means experiencing the unfamiliar
2. Experiencing a changed body
3. Experiencing the support of significant others
4. Anticipating a future

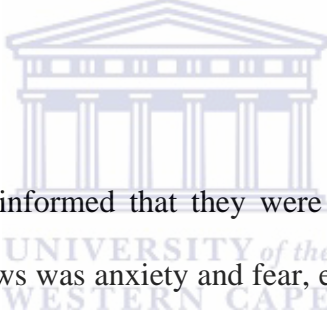
4.3.1 Unexpected change of everyday life means experiencing the unfamiliar

According to a study done by Gormly (1997) adolescents do not see themselves less vulnerable than adults. This statement, to an extent, contradicts the early beliefs of theorists who considered adolescence to be a period characterised by major rebellious behaviour especially towards grown-ups. Apart from the occasional misunderstandings that take place between siblings and parents, the participants have a good relationship with their parents and siblings. The majority of participants were in the stage of early adolescence when they were diagnosed with cancer. Participants described their lives preceding cancer as joyful and pleasant. They were in good health, carefree and the most part of their days were spent being with friends and enjoying family life. They were energetic and took part in extra-mural activities at school. Being diagnosed with cancer was a shock to all the participants. McIntyre and Williams (2002) states that adolescents generally do not expect to fall ill for they are much less likely than older people to recognise symptoms and more likely to underestimate the importance of the symptoms.

The symptoms of the illness experienced by the participants were diverse for five different types of cancer diagnoses were amongst the six participants. For instance the participant with the brain tumor experienced extreme headaches when she fell ill whereas the participant with Osteosarcoma experienced a limp in the leg. A number of the early symptoms of all the participants were the same. They experienced pain, discomfort and fatigue. Fatigue was one of the symptoms that was prominent; which is also one of the earliest signs of the cancer. This supports previous research by Gibson *et al.*, (2005) who found that fatigue was overwhelming affecting the adolescent cancer patient physically and mentally. In a study done by Ramani (2008) on adaptation of adolescents with cancer, it

was found that some of the most frequent experiences with cancer were weakness, extreme fatigue and pain. The cancer presented itself as a body that did not function as it usually did. Van Manen (1998) explains that a broken and disrupted relation with the body is characteristic of all experiences of illnesses.

As the participants were generally healthy children their parents did not suspect anything serious when they first mentioned that they felt unwell. The parents initially dealt with the symptoms as slight. The parents assumed that the symptoms would disappear within a day or two. Even at the clinics, some of the participants were misdiagnosed and was sent home with painkillers.



When the participants were informed that they were diagnosed with cancer, the almost immediate response to the news was anxiety and fear, especially fear of the unknown and a fear of dying. The participants received the news from their parents and medical staff. Ironically, despite the fear they experienced, the majority of them were unaware of what cancer was about. Carr-Gregg & White (1987) notes that it is important that adolescents be informed extensively about their illness, what is to follow and they must be urged to ask any questions about the illness and fears that they may have. The result of insufficient information about the illness can have devastating consequences for diagnostic tests and often invasive treatments force adolescents into the role of being the passive recipients of foreign, and at times painful and frightening procedures. The response to this confinement may be anger, frustration and depression. Knowledge of cancer has been positively related

to self-image and it has been suggested that increased knowledge may help with adjustment (Lewis, 1996).

Even though all the participants said that the information they received regarding their diagnosis was sufficient, but fearing death still persisted. Fear of the unknown territory they found themselves in. was overwhelming. Difficulty was also encountered in terms of dealing with the diagnosis and also dealing and managing the emotions of family members.

Prior to falling ill, the participants were active and enjoyed a healthy and contented life with their parents and siblings. The lived experience of being an adolescent with cancer manifested itself as a sudden change in their lives that was caused by the illness and them being subjected to foreign spaces and procedures. The normal routine of their lives were disrupted by hospitals, and the question of death were always there.

The following statements of the participants is presented individually for the reader to come to get to know the participant with regards to the type of cancer he/she had as well as their lived experience of their initial symptoms.

Participant 1 - Boy – 13 years old - Grade 7 (Leukemia)

I was very playful. We (my friends and I) played ball games in the street. (at school in athletics) I did sprinting, long jump, high jump, long distance... (When I fell ill) I did not play as much as I used to, I was just tired and felt exhausted. I could not do anything. Initially I was afraid....the needles...when they inserted the catheter I was not afraid anymore.... I did not know what cancer was then I asked my mother. My mother told me (he

had cancer). I was very scared; I didn't want to be sick. I was very scared. I was afraid that I was going to die, and then my mother told me that I am not going to die.

Participant 2 - Boy 13 year old – Grade 6 (Osteosarcoma)

I told my mother some time ago but she did not acknowledge it. It was only when I started limping and could no longer step on the leg that they took me to the clinic. His mother took him to the local clinic who, at the time, only supplied him with painkillers. Subsequent to the second visit, the staff at the clinic referred them to hospital. My knee was barely visible that is when they sent us here (the hospital.). The doctors(informed him). They explained to me that I have cancer and that they will have to amputate my leg.....and that I would get a prosthetic limb. I was sad and cried.

Participant 3 - Girl -19 years old - Grade 12 (Osteosarcoma)

I was very good at sport. I was in the gym, stuff like that...I was an athlete and so on.... My leg got swollen before I was diagnosed. Sometimes I thought....every time my leg would give way and swell even more. I took part in sport. On one occasion it happened that while I was running my leg would give way. And then....even while I was walking my leg would for no reason give way. Only when the swelling of my leg got worse, I was taken to the doctor. I didn't know what cancer was. My mother had to explain to me and the doctor. My first question was whether I was going to die. Many a times then one asks "Why me, what have I done?...."

Participant 4 - Girl - 15 year old – Grade 10 (Soft tissue cancer in the ear)

I was very happy, I did netball.....I got a pain in my ear and my face started getting skewer.... I went to the doctor and so they got into my ear and they took a piece and the ...at the laboratory..... Well, at the beginning I was afraid.....(but later) I felt a bit better. At that moment (when receiving the diagnosis), I didn't actually feel anything because it was a shock..... They (the doctors) told my mother who then told me. It was actually on Valentines Day that I heard.

Participant 5 - Girl - 16 year old - Grade 10 (Brain Tumour)

This participant was initially misdiagnosed. Her recollection of the experience was vague and it was difficult for the researcher to obtain information from the participant. Her Grandmother and twin sister remembered details of her illness, but this information is invalid for it was not the experience of the participant herself. She could remember the following:

I remember that I cried. I had a lot of headaches and I told my mother about it. That is when my mother took me to the hospital and they diagnosed me with meningitis.

I was not afraid; I did not know what was going on. It was a few days after the operation that they told me what was wrong with me...but I...I always thought what was cancer?... I did not know what cancer is.

Participant 6 - Boy - 15 year old – Grade 11 (Hodgkins disease)

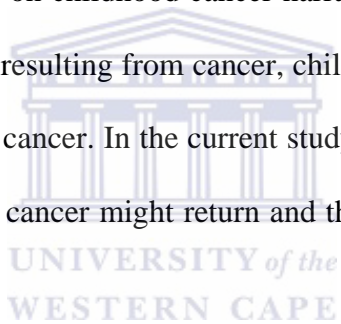
This participant experienced his symptoms virtually painless and he had no discomfort. His sister noticed that his neck was swollen. His mother took him to the doctor who immediately noticed that something was terribly wrong.

I did not complain (of any pain).....One night we sat in the pool room and my sister noticed that my neck was swollen. We went to the doctor who referred us to the local hospital. My mother (told him he had cancer). I felt down....I thought I was going to die and so... and why did it happen to me.

The participants were in an unknown space. Their familiar space or lived space was unexpectedly threatened. Van Manen (1990) refers to lived space as space that are being felt or sensed and the space in which we find ourselves affects the way we feel. The unfamiliar lived space in this study was an area where procedures were done that were invasive; not only the body but the person too. One particular participant said that he was initially afraid of the needles. It rendered the participants feeling anxious, afraid, shocked and questioning their mortality. In a study conducted by Thomé *et al.*, (2004) on the meaning of having to live with cancer in old age it was found that lived space meant an involuntarily expanded lived space owing to treatments requiring quite a number of journeys and residing away from home.

Upon hearing the diagnosis of cancer the majority of participants reported that they feared that they were going to die. Having cancer meant a sudden awareness of the finiteness of life. The experience of lived time for the participants in this study was threatened because

of their fear of death. The lived experience made thoughts of death inevitable. Van Manen (1990) states that lived time is our temporal way of being in the world, like a young person oriented to an open and beckoning future, or as an elderly person recollecting the past. When they heard they were diagnosed with cancer, they lost view of the youth; the future that was supposed to be promising was now obscured with a cancer diagnosis. Roberts *et al.*, (1998) claims that adolescents with cancer are shoved into a premature confrontation with death and an accompanying fear of the recurrence and death. Parents tend to avoid discussions about death due to their own anxiety about their child's well-being. In a study done by Woodgate (2006a/b) on childhood cancer narratives, it was found that besides the emotional and physical scars resulting from cancer, children and their families always have the fear the recurrence of the cancer. In the current study two of the participants mentioned that they were afraid that the cancer might return and that they chose not to share this fear with their parents.



4.3.2 Experiencing a changed body

Physical appearances are important to adolescents. Adolescents are concerned about their appearances primarily because they experience significant physical changes in their bodies during puberty. They are therefore likely to experience highly dynamic perceptions of body image. Furthermore, body image is influenced strongly by self-esteem and self-evaluation, more so than by external evaluation by others (Croll, 2005).

All the participants in the current study reflected on the negative feelings they had to deal with when they received treatment. Treatment was often in the form of chemotherapy and often the consequences had an effect on the body image and self-esteem of the participants.

Body image (or body concept) is defined as the subjective image one has of one's own body, specifically with respect to evaluative judgments about how one is perceived by others and how well one adjusts to these perceptions. Self-esteem is defined as the degree to which one values oneself (Reber, 1985). In a study conducted by Dusek and Flaherty (1981) it was found that self-esteem normally fluctuates but self-concept remains reasonably stable. They found very little evidence that adolescent self-concept undergoes dramatic changes. This was confirmed in a study by Savin-Williams (1984) on stability and self concept in adolescents, who found that adolescents generally maintained a stable and slightly positive sense of themselves as cited in Gormly, (1997).

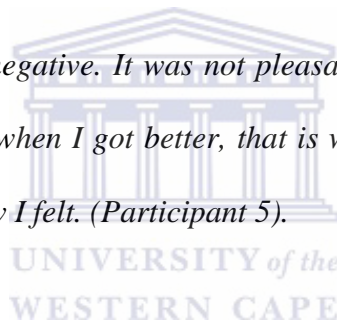
During the treatment of cancer it is highly likely that certain bodily changes occur.

Depending on the type of cancer, different parts of the body are affected, for example hair falling out, losing a limb (leg), losing an eye, paleness of the skin, loss or gain of body weight, permanent scarring, etc. According to Thompson (1996) the effects of the chemotherapy treatment included hair loss or weight loss, weight gain from steroids, scarring from surgery, skin effects and growth disorders from radiotherapy, and this influences the individual's identity and self-esteem (as cited in Lewis, 1996).

In the current study the most prevalent side effect of chemotherapy received by the participants was that of bodily hair loss. The hair loss was particularly difficult for them to deal with and it left them feeling self-conscious, embarrassed and humiliated. In a psychological overview on adolescents and cancer Carr-Gregg and White (1987) notes that hair loss is the most pervasive of the changes that takes place during chemotherapy and is

thought to be particularly devastating to the adolescent who are typically preoccupied with their physical appearance. Both male and female participant was conscious of their hair loss. The participants described their self-esteem and the image of themselves as positive before the cancer diagnosis. Since most of them were involved in sports, they were generally in good health which impacted positively on their self confidence. However, when they received chemotherapy to treat the cancer, the majority reported that their hair fell out and that it impacted negatively on their self esteem. This 15 year old participant commented:

My (self image) was really negative. It was not pleasant. My hair fell out. I was very shy and did not like myself. But when I got better, that is when I started to like myself. I'm so glad it is all over. That is how I felt. (Participant 5).



One of the participants mentioned that her hair loss were more traumatic than the cancer diagnosis. She felt that her hair loss was difficult to deal with initially, but realised that it would grow back. She reported that her self-esteem changed for the better after the cancer ordeal, noted in the following remark:

...the fact that I was sick was not such a big deal but the fact that my hair was going to fall out....that was strange. I have never been, it has never been the case that I don't have hair... I was very shy, I didn't really talk...but now I do. I would say that I have more self confidence now. I wasn't such a positive person, I was....I used to...always more negatively inclined. I would say I have more of a self image...a better self-image. (Participant 3)

This is supported in a study which explored the lived experience of chemotherapy-induced alopecia (hair loss) for women with breast cancer it was found that chemotherapy-induced hair loss is more traumatic for some women with breast cancer than the loss of a breast or the treatment itself. It was found that many of the women surveyed felt psychologically lower after losing their hair than when going through the chemotherapy treatment (Power, 2007). Overall the participants were conscious and shy and felt awkward when people stared at them. It was the girls in particular who felt extremely conscious of their bald head. Fortunately they realised that it would grow back when the chemotherapy treatment was completed. This is supported by a study conducted by Roberts, et al., (1998) who stated that hair loss is a major issue for children receiving treatment for cancer and that loss of hair was extremely distressing especially among females. However, it was found that when patients were informed of the temporary nature of the side effects the adolescent separated the experience from who they are from how they look.

In spite of this the participants described their self-esteem to have suffered dramatically. The majority believed that the image of themselves to have been negative at the time of bodily changes. One of the participants mentioned that he refused to look at himself in the mirror. He finds himself repulsive, 'ugly' to look at. He had difficulty dealing with both an amputated leg as well as hair loss.

.....afterward they found out that it was cancer and that they can't do anything for me, they have to amputate my leg. I can't handle it...I don't want to talk to anyone. I can't look in the mirror...I just can't. (Participant 2)

This is supported in a study conducted by Elkateb *et al.*, (2002) on the quality of life of adolescent cancer patients as perceived by patients, nurses and mothers, it was found that alteration in body image occurs when changes in appearance, function and control result in a conflict between the image that has been established over time and the current reality. Negative adjustments are much more likely when significant physical changes result from the disease or treatment. A 13-year old participant was too shy to talk about his self-esteem and how it was affected during the cancer treatment. The researcher was informed by his mother that short pants and bear feet was a favourite prior the diagnoses. During treatment he lost all bodily and facial hair. This resulted in being self conscious and made no eye contact with visitors; he would lie with his back towards them. Stretch marks are visible on his legs and feet as a result of swelling resulting from the treatment. After his recovery he chooses to wear only long pants and would not go without shoes of fear that the stretch marks will be noticed in public.

One of the participants had soft tissue cancer of the ear which caused her face to draw skew/disfigure. This resulted in extremely shyness and dreaded the stares of people and dealt with it by praying to God for strength. She commented:

When my face got skew, so I didn't really feel....and...my hair, I'm wearing a wig. People treat me differently like they felt sorry for me... I'm ok. But sometimes it just gets a bit weird, but it's fine. It's just that everybody is looking at me....I just pray... I just pray to be myself and just not worry about them. (Participant 4)

During the interviews the research found that the younger participants did not cope as well with the bodily changes as the older ones. Richie (2002) notes that adolescents with cancer or a chronic disease relationships' with other people and their perceptions of themselves can change as they go through treatment and experience hospitalisation. Changes in body image, disruptions of normal activities because of the disease and reactions of prescribed therapies can all have effects on the adolescents' self image. This rapid change in self-esteem can then confuse and impair the adolescent's perception of him or herself and lower his or her self-esteem. The body image of participants in the current study was negatively affected by the consequences of the chemotherapy. It was found in this study that even though the participants were concerned about the physical changes as a result of the chemotherapy, they realised that they will, in time, be better again. Their reasoning behind the rational thinking could be attributed to adolescents are in a time of formal operational thinking, allowing them to think abstractly and enabling them to tests hypothesis and reason about hypothetical and ideal situations (Gormly, 1997).

The participants experienced the lived body as vulnerable, unruly, unreliable and unfamiliar. The vulnerability of the body was revealed in their awareness that the body was not as reliable as it used to be. Van Manen (1990) describes the lived body in a phenomenological sense as being bodily in the world. The body' ability was not as it

usually was and this was the first indication to the participants that something was wrong. In a study conducted by Woodgate, (2005) on adolescents' experience with cancer it was found that adolescent with cancer not only experienced a lived body but also were aware of their lived bodies which in turn influenced their self understanding. It was through their body that acquired information about themselves and their health status. The participants in the study were enjoying good health prior to the cancer diagnosis; they were not so much aware of the functioning of their body as when they became ill. Van Manen (1998) states that "serious illness like cancer changes everything; at the moment when our wellness is disturbed, then we discover, as it were, our own body".

4.3.3 Experiencing the support of significant others

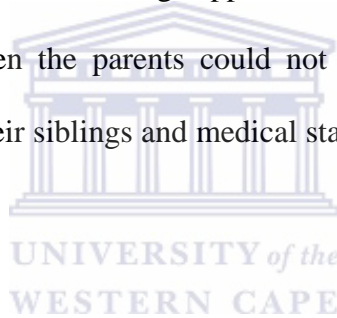
All the participants reported that they received great support from their parents, siblings, grandparents, friends, medical staff and even strangers. Support, in this regard can be viewed as the furnishing of comfort, recognition, approval, encouragement, etc. to another person (Reber, 1985). Woodgate (2006b) emphasises the reality that adolescents with cancer are confronted with many challenges and the extent to which they are able to deal with such challenges appears to be partly dependent on a strong positive support system. According to Brannon and Feist (2000) strong, emotional support, the joining support groups or attending group psychotherapy sessions can affect the survival time of cancer patients.

In the current study it was clear that the relationship the participants maintained with their families, friends and health care members helped them cope and deal with the cancer diagnosis and the effects of the chemotherapy. It was the mothers in particular who played

a major role in supporting the adolescent with cancer. Constantly research highlights that family members, especially mothers, are identified as the major source of support (Woodgate, 2006b). This is manifested in the following comments:

My mother was with me every day. She didn't want to go home. My mother helped me to bathe myself, and when I felt like playing, she played with me. If my mother wasn't there I would not have been able to do anything. (Participant 1)

The participants mentioned the comforting support of their siblings and medical staff while they were hospitalised. When the parents could not be there for the participants, they welcomed the presence of their siblings and medical staff as reinforced by comments of the following participants.



My sisters came to visit me almost every day. My brothers....one,...sometimes my brothers took turns to spend the night by me. (Participant 1)

.....and when my mother went home, my grandma and grandpa would come..... ...(the medical staff) ...was very nice. They tried to make you feel at home. They would come and sit with me...it was sometimes the case that when my mother leaves, my grandparents could not come immediately. They would then sit and spend some time with me. (Participant 3)

The protective nature of the relationship between the participants and their family members was of consolation to the researcher. Reynolds (1998) claims that the parent-adolescent

relationships are typically supportive during adolescence which fortunate since family connections underlie psychological functioning (cited in Berger, 2000). Even the adolescent who seem most at risk due poverty, family structure, war, violence and life-threatening illnesses are often able to function well if their families are supportive and protective

Friends play a crucial supporting role as well. During adolescents friends' acknowledgement and approval are very valuable. The majority of the participants received a great deal of support from friends. The friends visited regularly and the sick adolescent welcomed this and took pleasure in the fact that their friends were not ashamed of them. Gormly (1997) found that peer relationships become more important during adolescents, but are not significantly different from the adult culture. Adolescent friendships are based on intimate relationships and supplement the support adolescents receive from their families. It was important to the participants that their friends treat them as they did before the cancer diagnosis. This helped them to cope and experience a sense of normalcy/normality in their lives as depicted in the following comments:

...(my friends)...they are normal with me....They (her friends) were ok with it (the cancer diagnosis)...because we have known each other for so long, they got used to it. It was not a case of them not knowing how to react towards me, everything was alright (Participant 3)

In the current study the friends of the participants made it relatively easier for them to cope and adjust to the change in their lives brought about by the cancer diagnosis.

In a study done by Elkateb *et al.*, (2002) on the quality of life of adolescents' cancer patients as perceived by patients, nurses and mothers, it was found that half of the patients were socially adjusted. The relationships with family, siblings, and schoolmates comprise the primary social sphere of the adolescent with cancer.

Although the family is usually the primary source of support, it may also be a major source of anxiety. Roberts (1998) found that adolescents friend's reactions to cancer and the side effects of chemotherapy were varied. In a study conducted by Heiney (1989) that 61.5 per cent of adolescent cancer amputees reported that friends drifted away after the initial crisis of the cancer diagnosis. This was supported in a finding in the current study where one of the participants had the experience of his mother and friends being a source of angst rather than a source of support. His father and maternal grandmother were his primary source of support. His mother became involved with drugs and did not show the necessary compassion and support. His friends felt awkward in his presence for he was an amputee. He could no longer play with them and this placed strain on their friendship.

His comments:

When I am home I see my friends and I can't play with them. I sit outside and watch them play. My friends used to laugh and make jokes with me, but now....they are quiet when they come to me. My mother allows other people into our house and then they use drugs in the house, my mother also uses drugs in the house.(Participant 2)

Fortunately the majority of the participants in the study experienced the support of family and friends as comforting and this support added to them being able to cope with the cancer experience. The participants' interpersonal relationship with family and friends enabled them to cope and despite the initial fear of death, they anticipate a future involving a career, a home and a family of their own. Van Manen (1990) defines lived human relations as 'the lived relation we maintain with others in the interpersonal space we share with them' and refers to it as lived others. The experience of the lived other revealed itself in the support and care that the participants received from family and friends. The presence of the lived other enabled them to deal and cope with the cancer diagnosis and subsequent treatments.

4.3.4 Anticipating a future

All of the participants foresaw a positive future. Some of the participants stated that the experience of having cancer impacted upon them more positive than negative. The participants claimed that they have better relationships with significant others and they appreciate what they have, especially their health. Despite the changes and uncertainty of what was wrong with their bodies and the subsequent cancer diagnosis, the participants managed to cope. Coping strategies can be seen as conscious, rational ways of dealing with the anxieties of life (Reber, 1985). As an adolescent this could also be explained in terms of their cognitive ability at this stage of their lives. The experience of living with cancer for all the participants were associated with anxiety, fear, despair but also courage, hope, and even views for the future and despite their initial fear of death, they anticipate a future involving a career, a home and a family of their own.. One participant said that her illness drew her nearer to God.

I see my futurego to college, and then having my own house and my own family...and working. ...(our family)...we are closer. My spiritualis better, like I believe more in God and I am closer to my family and I...(Participant 4)

Another participant felt that he tend to respect his mother more than before his illness. He would normally argue with his mother to the point where unnecessary hurtful things were said. But after his illness he would think twice before losing his temper and show more respect towards his mother.

(What have changed significantly after the illness was)...I think my manners and so (has changed the most)...rudeness and so with my mother (and sister).Usually when things went wrong in the house my mother and I would yell at each other...(but now) sometimes (we would still yell at each other)..but now it is much less. (Participant 6)

According to Gormly (1997), choosing a career is a process that develops over time but had its roots in adolescence. All participants knew what they want to do when they finished school is an indication of positive thinking. All participants had a clear vision in terms of career paths which is a good indication of positive thinking. Although confronted by the idea of death/dying, courage was displayed dually the support by family and friends. Although they had the initial fear of dying and the unpleasant experience of chemotherapy, they kept on hoping and displayed courage mainly due to the support of family and friends. This hopefulness prevailed throughout the study, the participants tried to stay positive in

difficult times and this allowed them to anticipate a future where they would be independent; much like a 'normal' adolescent.

.....I would like to work for at least three years and then go on tour. I want to do interior decorating, houses...inside and outside. (Participant 3)

I actually want to be a soccer player (for 2010).... (Participant 6)

However, according to Carr-Gregg and White (1987) the possibility of future dreams realising is slim, and therefore reports that the nature of an adolescent's interest and goals before diagnosis will play a central role in determining how these patients will view their future. Those whose plans focused on physical activity, for example a physical sporting career may find their future to be restricted than those whose ambitions were more sedentary.

One of the participants who had a leg amputation during treatment had a dream of becoming a body builder when leaving school. He realised that the possibility of this dream realising was unlikely.

Lived time was experienced as more or less unsettled. Van Manen (1990) refers to lived time as our corporeal way of being in the world. The temporal aspects of the past, present and future constitute a person's temporal outlook on life. In the current study the participants feared their mortality upon receiving a cancer diagnosis. With the progression

of the illness the thought of death made way for the realisation that they can maintain their dreams they had before they were diagnosed with cancer.

4.4 Conclusion

The participants' subjective experiences have been described and presented as four essential themes namely: the unexpected change of everyday life means experiencing the unfamiliar, experiencing a changed body, experiencing the support of significant others and anticipating a future.

These themes were chosen because it describe the essential meanings shared by the participants. Direct quotes from the participants' account were incorporated to provide qualitative descriptions of the themes. Themes were compared to previous research amongst them employing phenomenology as a data analytical tool and it was found to substantiate the majority of the previous research findings. The following chapter summarises the key findings of this study. It addresses the limitations of the research and recommendations for further research.

CHAPTER 5

SUMMARY

5.1 CONCLUSION

The current study aimed to explore the lived experiences of adolescents with cancer and the impact these experiences had on their lives. Four essential themes emerged from the participants' experiences: Unexpected change of everyday life means experiencing the unfamiliar, experiencing a changed body, and experiencing the support of significant others and anticipating a future. In addition, the meaning of living with cancer as an adolescent could be said to correspond with the four existentials described by van Manen (1990) as seeping into the lives of all human beings: lived space, lived body, lived other and lived relations. According to van Manen (1990) the four existentials can be differentiated but not separated for all form an 'intricate unity which we call the life-world; our lived world'. Wurhnow (1984) states that phenomenology offers the possibility of studying human experience in the context of the life-world and this context not only includes the physical and social environment, but also one's history, concerns and aspirations (cited in Madjar, 1999). Phenomenological inquiry is able to take into account not only individual meanings of a situation, but also the intersubjectivity of human experience, the shared meanings that act as a basis for social interaction.

The unexpected change of everyday life means experiencing the unfamiliar can be linked to the fact that prior to the cancer diagnosis the participants were healthy individuals and enjoyed an active life. Serious illness and death were not part of their day to day encounters

mainly because they were young for it is generally believed that adolescents are healthy. The diagnosis of cancer was devastating to all the participants and their families; they unexpectedly found themselves in a space that was new to them. Hospitals, procedures, staff and medical terminology added to their initial shock and fear of death. Knowledge of cancer was poor, and was only understood as a deadly disease. With the cancer diagnosis they experienced their lived space to be unknown and frightening.

The feelings of uncertainty and shock intensified with the chemotherapy treatment which left them bald headed and looking, to an extent, abnormal. They experiencing a changed body; the participants' self-esteem was lowered due to this experience. However, when the parents and medical staff explained the procedures and possible effects of the treatment to the participants, their fear subsided to an extent and they dealt with it in a more realistic, adult way.

The researcher gathered that with the support of significant others in the lives of the participants, it contributed significantly in the way the participants dealt with the cancer diagnosis. . This finding is supported by Carr-Gregg and White (1987) who stated that when discussing the impact of the diagnosis of cancer on adolescent, most writers agree that successful adjustment is determined by a variety of interrelated factors. These include the age of onset, the visibility of the condition, the degree of functional impairment, the cause of the illness, the patient's premorbid emotional functioning, their ethnic background and the availability of family support. Kellerman (1980) notes that in spite of the many obstacles that a diagnosis of cancer poses to normal psychological development in the

adolescent, some studies show them to be functioning surprisingly well (cited in Carr-Gregg, 1987). Gormly (1997) states that stressors adolescents experience are the result of simultaneous demands by the social, family, and school context. Adolescents' self-esteem is influenced by their ability to cope with the changes and expectations they encounter.

A universal experience of adolescents in the study was with the support of family and friends they could attempt to lead normal lives despite their diagnosis. This is consistent with previous research that stressed the importance of maintaining a sense of normality and resilience to develop into a well-adjusted individual. Similar to previous work, the current study reveals that a chronic illness such as cancer determines, in part, how adolescents choose to live their lives, integrating their illness experience into their lives and coping in the face of significant adversity. Despite their initial shock and fear of death they managed to envision a future they have dreamt of prior the cancer diagnosis.

5.2 LIMITATIONS

There are a number of shortcomings in this study. Foremost is that the findings are derived from a small number of adolescents and therefore future research is required to confirm the lived experience of adolescents with cancer especially within a South African context. The current study was undertaken within a qualitative research methodology. A suggestion would be that the lived experiences of adolescents with cancer be undertaken within a mixed methods methodology. The researcher believes if both quantitative and qualitative methods are employed, a more generalised outcome would be possible. Lack of cultural diversity in the sample is another shortcoming that warrants future work involving

adolescents from different cultures. All the participants were from the 'Coloured' community, of the Christian faith and residing in a low economic (except for one participant who lives in a high socio-economic area) area within the same province in South Africa. Because different cultures necessarily have different belief systems, it could be that the outcome will differ considerably.

Despite the fact that the researcher met with the majority of the participants and their parents a week prior to the interviews (the interviews were conducted in their homes (except for one participant). The researcher found that the participants had difficulty verbalising their experience. A follow-up interview would have made them more relaxed and this may have impacted on the findings.

Despite the limitations the researcher tend to agree with Neville (2005) who claims that 'more adolescents lives longer and are surviving cancer, therefore there is an increased need to gain a better understanding of what the experience means and how that experience impacts on their lives and that of their families, not just during their treatment but for long periods of time thereafter'.

5.3 RECOMMENDATIONS

Although the study's findings require further confirmation before they can be generalised to other adolescents with cancer, the knowledge gained from this study may help to guide nurses in their assessment and applications of interventions directed at assisting the adolescent cancer patient taking into account their developmental stage especially in terms

of their body image and giving as much information as possible in order to lift the burden of cancer a little.

When consent were asked from the parents of the participants who were under 18 years old, the parents were particularly willing for the participants to partake in the study. Feedback from parents indicated that the participants were reluctant to talk to them about their experience; they therefore appreciated the opportunity for their children to talk about their experience. It is therefore a recommendation that further research be done on the lived experiences of adolescents with cancer taken into account that adolescents are a vulnerable group and often do not want to talk about their feelings.



REFERENCES

Adamson, L., Hartman, S.G. & Lyxell, B. (1998). Adolescent identity – a qualitative approach: self concept, existential questions and adult contacts. *Scandinavian Journal of Psychology*, (40), 21-31.

Babbie, E. & Mouton, J. (2001). *The practice of social research*. Cape Town: Oxford University Press.

Bazier, D.D. (1991). *Phenomenology in counseling and psychotherapy*. [Online] Available at: http://www.amidatrust.com/article_phen.html.

Benner, P. (1994). *Interpretive phenomenology. Embodiment, caring, and ethics in health and illness*. Thousand Oaks, London, New Delhi: Sage Publications

Berger, K.S. (2000). *The developing person through childhood and adolescence*. New York: Worth Publishers

Bracken, J.M. (1986). *Children with cancer. A comprehensive reference guide for parents*. New York: Oxford University Press.

Brannon, L. & Feist, J. (2000). *Health psychology. An introduction to behavior and Health*. 4th ed. Australia: Wadsworths.

Carr-Gregg, M. & White, L. (1987). The adolescent with cancer: a psychological overview. *The Medical Journal of Australia*. 146, 496-502.

Creswell, J.W. (1998). *Qualitative inquiry and research design. Choosing among five traditions*. Thousand Oaks, California: Sage Publications.

Creswell, J.W. (2003). *Research design. Qualitative, quantitative, and mixed methods approaches. 2nd ed.* Thousand Oaks , California: Sage Publications..

Croll, J. (2005). Body image and adolescents. In Stang, J & Story, M (eds). *Guidelines for adolescent nutrition services.* Minneapolis: Center for Leadership, Education and training in Maternal and Child Nutrition, School of Public Health, University of Minnesota.

Cruse, M.K. & Stinnett, T.A. (2006). Children with cancer. In Phelps, L. (2006). *Chronic health-related disorders in children: Collaborative medical and psychoeducational interventions.* Washington, DC: American Psychological Association.

Dolinsky, C. (2006). *Brain cancer. The basics.* The Abrahams Cancer Centre of the University of Pennsylvania.. [Online] Available at: <http://www.oncolink.org/types/article.cfm?c=2&id=9534&s=4&ss=25>.

Dowling, M. (2005). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44, 131-142.

Elkateb, N., Ibrahim, A.S. & Riad, S. (2002). Quality of life of adolescent cancer patients as perceived by patients, nurses and mothers. *Journal of the Egyptian National Cancer Institute*, 14 (4), 343-348.

Finlay, L. (2008) *Introducing phenomenological research.* [Online] Available at: www.lindafinlay.co.uk/An%20introduction%20to%20phenomenology%202008.do

Frankle, V. E. (1959). Man's search for meaning. The classic tribute to hope from the holocaust. London, Sydney, Auckland, Johannesburg: Rider Books

Gibson, F., Mulhall, A.B., Edwards, J.L., Ream, E. & Sepion, B.J. (2005). A phenomenological study of fatigue in adolescents receiving treatment for cancer. *Oncology Nursing Forum*, 32 (3), 651-660.

Giorgi, A. (1997). The theory, practice, and evaluation of the phenomenological method as a qualitative research procedure. *Journal of phenomenological psychology*, 28 (2), 235-260.

Giorgi, A. & Giorgi, B. (2003). Phenomenology. In Smith, J.A. (ed), *Qualitative psychology. A practical guide to research methods*. London: Sage Publications.

Gormly, A.V. (1997). *Lifespan human development (6nd ed.)*. Fort Worth: Hartcourt Brace College Publishers.

Grimer, R.J. (2005). Osteosarcoma and surgery. In Eden, T.O.B., Barr, R.D., Bleyer, A. & Whiteson, M. *Cancer and the adolescent*. Malden Massachusetts: Blackwell Publishing.

Grinyer, A. (2002). *Cancer in young adults: through parents' eyes*. Philadelphia: Open University Press.

Heiney, S.P. (1998). Adolescents with cancer sexual and reproductive issues. In Roberts, C.L., Turney, M.E. & Knowles, A.M. Psychosocial issues of adolescents with cancer. *Social Work in Health Care*, 27 (4), 3-16.

Ireland, J. & Ireland, J. (1993). *Beating breast cancer: life saving choices for South African women*. Cape Town: Oxford University Press.

Kelly, K. (2006). Lived experience and interpretation: the balancing act in qualitative analysis. In M. Terre Blanche, K. Durrheim & D. Painter (eds), *Research in practice: applied methods for the social sciences. (2nd ed)*. Cape Town: UCT Press.

Langdrigde, D. (2007). *Phenomenological psychology. Theory, Research and Method.* Harlow: UK: Pearson Education Limited.

Larouche, S.S. & Chin-Peuckert, L. (2006). Changes in body image experienced by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 23(4), 200-210.

Lewis, I.J. (1996). Cancer in adolescence. *British Medical Bulletin*, 52 (4), 887-897.

Louw, D.A. & Louw, A.E. (2007). *Child and adolescent development.* Bloemfontein: Psychology Publications.

Louw, D.A., van Ede, D.M. & Louw, A.E. (1998). *Human development. (2nd ed).* Cape Town: Kagiso Tertiary.

Madjar, I. & Walton, J. (1999). *Nursing and the experience of illness: phenomenology in practice.* London & New York: Routledge.

Marks, D.F., Murray, M., Evans, B., Willig, C., Woodall, C. & Sykes, C.M. (2005). *Health psychology. Theory, research & practice.* Thousand Oaks: Sage Publications.

McLoughlin, A. (1989). *The information needs of cancer in the Republic of South Africa.* South Africa: UNISA.

McIntyre, P. & Williams, A. (2002). *Adolescent friendly health services – an agenda for Change.* United Kingdom: Oxford.

Merriam, S.B. & Associates. (2002). *Qualitative research in practice. Examples for discussion and analysis.* New York: John Wiley & Sons, Inc.

Miles M. B. & Huberman, A.M. (1998). *Qualitative data analysis: A sourcebook of new methods* (2nd ed.) In Creswell, J.W. *Qualitative inquiry and research design. Choosing among five traditions*. Thousand Oaks, California: Sage Publications.

Moran, D. (2000). *Introduction to phenomenology*. New York: Routledge.

Moustakas, C. (1994). *Phenomenological research methods*. California: Sage Publications.

Mqoqi, N., Kellett, P., Sitas, F. & Jula, M. (2004). *Incidence of histologically diagnosed cancer in South Africa, 1998-1999. National Cancer Registry of South Africa*, Johannesburg: National Cancer Registry of South Africa, National Health Laboratory Service.

Mulderij, K.J. (1996). Research into the life-world of physically disabled children. *Child care, health and development*, 22 (5), 311-322.

Murray, M. & Chamberlain, K. (1999). *Qualitative Health Psychology. Theories and methods*. London: Sage Publications.

Neville, K.L. (2005). The impact of cancer on adolescents and their families. In Eden, T.O.B., Barr, R.D., Bleyer, A. & Whiteson, M. *Cancer and the adolescent*. Malden, Massachusetts: Blackwell Publishing.

Nezu, A.M., Nezu, C.M., Friedman, S.H., Faddis, S. & Houts, P.S. (1998). *Helping cancer patients cope. A problem-solving approach*. Washington DC: American Psychological Association.

Phelps, L. (ed.) (2006). *Chronic health-related disorders in children: collaborative medical and psychoeducational interventions*. Washington DC: American Psychological Association.

Pierce, G.B., Shikes, R. & Fink, L.M. (1978). *Cancer. A problem of developmental biology*. New Jersey: Prentice-Hall

Power, T.J. 2006. Collaborative practices for managing children's chronic health needs. In Phelps, L. (ed.). *Chronic health-related disorders in children: collaborative medical and psychoeducational interventions*. Washington DC: American Psychological Association.

Ramani, S.K. (2008). Embracing changes: adaptation by adolescents with cancer. *Pediatric Nursing*, Jan-Feb. 2008.

Reber, A.S. (1985). *Dictionary of Psychology*. London: Penguin Books.

Richie, M.A. (2002). Self-esteem and hopefulness in adolescents with cancer. *Journal of Pediatric Nursing*, 16 (1), 35-42.

Roberts, C.L., Turney, M.E. & Knowles, A.M. (1998). Psychosocial issues of adolescents with cancer. *Social Work in Health Care*, 27 (4), 3-16.

Rollis, J. (1998). Childhood cancer: Siblings draw and tell. In Murray, J.S. (1998). The lived experience of childhood cancer: one sibling's perspective. *Issues in Comprehensive Pediatric Nursing*, 21:217-227

Sigelman, C.K. (1999). *Life-span human development. (2nd ed)*. Washington: Brooks/Cole Publishing Company.

Sitas, F. (1992). Report on cancer incidence in South Africa. *The South African Journal of Epidemiology and Infection*, 7(1), 2-3.

Smith, J.A. (ed.) 2003. *Qualitative psychology: a practical guide to research methods*. London: Sage Publications.

Suris, J., Parera, N. & Puig, C. (1996). Chronic illness and emotional distress in adolescence. *Journal of Adolescent Health*, 19 (2), 153-156.

Terre Blanche, M. & Durrheim, K. (1999). *Research in practice. Applied methods for the social sciences*. Rondebosch: University of Cape Town Press.

Thomé, B., Esbensen, B.A., Dykes, A.K. & Hallenberg, I.R. (2004). The meaning of having to live with cancer in old age. *European Journal of Cancer Care*, 13, 399-408.

Valle, R.S. & Halling, S. (1989). *Existential – phenomenological perspectives in psychology*. New York & London: Plenum Press.

Valle, R.S. & King, M. (1978). *Existential – phenomenological alternatives for psychology*. New York. Oxford University Press.

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. London: Althouse Press.

Van Manen, M. (1998). Modalities of body experience in illness and health. *Qualitative health research*, 8 (1), 7-24.

Wagner, H.R. (1983). *Phenomenology of consciousness and sociology of the life-world: an introductory study*. Edmonton, Alta: The University of Alberta Press.

Wallace, M.L. Harcourt, D., Rumsey, N. & Foot, A. (2007). Managing appearance changes resulting from cancer treatment: resilience in adolescent females. *Psycho-oncology* 16, 1019-1027.

Welman, C., Kruger, F. & Mitchell, B. (2005). *Research methodology (3rd ed)*. Oxford: Oxford University Press.

Whelan, J. (2005). Advances in osteosarcoma. In Eden, T.O.B., Barr, R.D., Bleyer, A. & Whiteson, M. (2005). *Cancer and the adolescent*. Malden: Massachusetts: Blackwell Publishing.

Willig, C. & Stainton-Rogers, W. (eds.) (2008). *The SAGE handbook of qualitative research in psychology*. Los Angeles: Sage Publications.

Woodgate, R.L. (2005). A different way of being: Adolescents' experience with cancer. *Cancer Nursing*, 28 (1), 8-15.

Woodgate, R.L. (2006a). Life is never the same: childhood cancer narratives. *European Journal of Cancer Care*, 15, 8-18.

Woodgate, R.L. (2006b). The importance of being there: perspectives of social support by adolescents with cancer. *Journal of Pediatric Oncology Nursing*, 23(3), 122-138

Woods, M. & Shearer, L. (2005). Body image. In Eden, T.O.B., Barr, R.D., Bleyer, A. & Whiteson, M. *Cancer and the adolescent*. Malden: Massachusetts: Blackwell Publishing.

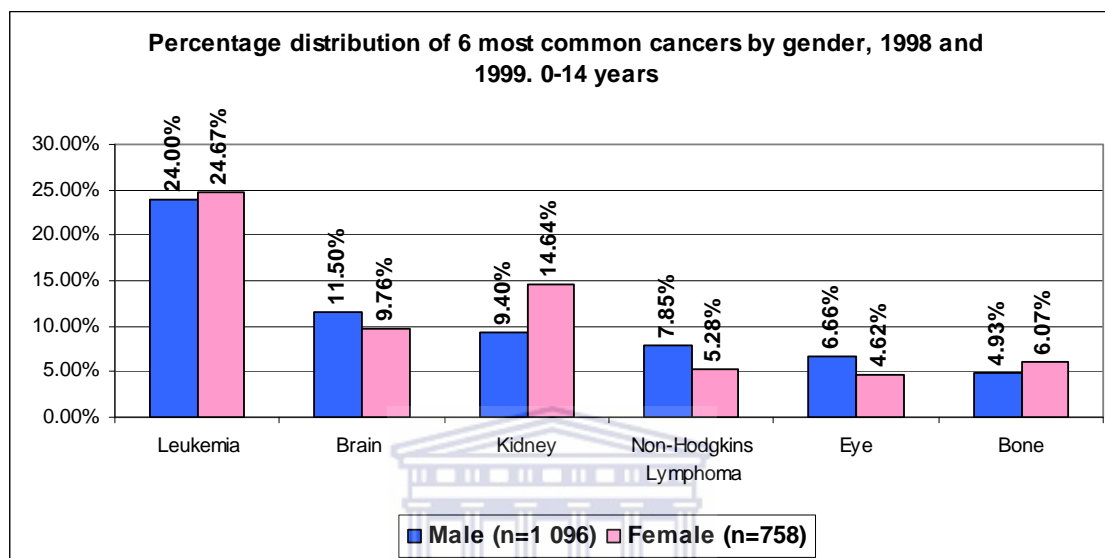
www.WHO.com. (2004)

www.CANSA.com. (2008)

Yeh, C. (2002). Life experience of Taiwanese adolescents with cancer. *Scandinavian Journal of Caring Science*, (16), 232-239.

APPENDIX 1: Summary of the cancer incidence of adolescents

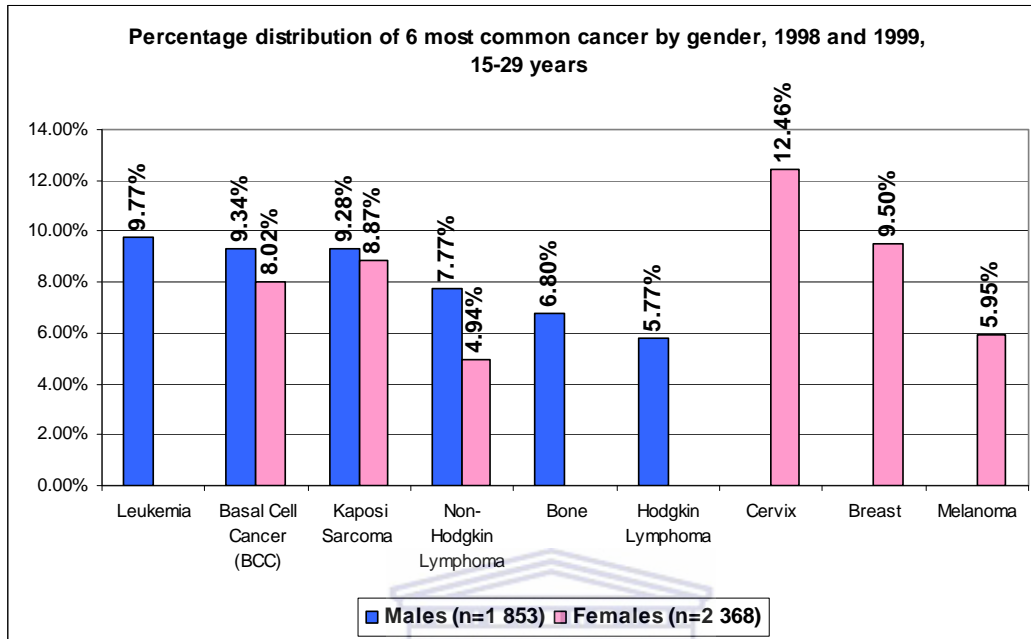
TABLE 1: Cancer incidence of adolescence in age group 0-14 years



Source: National Cancer Registry of South Africa, December 2004 as cited in McIntyre, P. & Williams, A. (2002).

It is interesting to note that the six most common cancers in age group 0-14 years for both genders are the similar, it differs only in percentage. Leukemia is the leading cancer type in both genders in the age group 0-14 years

TABLE 2: Cancer incidence of adolescence in age group 15-29 years.



Source: National Cancer Registry of South Africa, December 2004 as cited in McIntyre, P. & Williams, A. (2002).

There is a clear change in the types of cancer that occur in the 15-29 years age group. Leukemia is still the prevalent cancer type in males in this age group, but it does not at all appear in females in the 6 most common cancer types. Cervical cancer is more common in females in the age group 15-29 years.

APPENDIX 2: Letter outlining the detail of the study issued to the Social Work Department of the hospital.



UNIVERSITY of the WESTERN CAPE

Private Bag X17 Bellville 7535 South Africa Telephone: UNIBELL
Tel.: (27.21) 959-2948, 959-2949 Fax: (27.21) 959-3170

The Dean's Office:
DEPARTMENT OF RESEARCH DEVELOPMENT

E-Mail:
RCHRISTIE@UWC.AC.ZA
GADAVIDS@UWC.AC.ZA
PSYSTER@UWC.AC.ZA

24 November 2006

To Whom It May Concern

I hereby certify that the Senate Research Committee together with the Human Subjects Ethics Committee of the University of the Western Cape has approved the methodology and the ethics of the following project by Ms. A Pool:

Research Project: "The lived experiences of adolescents with cancer"

Registration no. 06/9/21

Yours Sincerely

Peter Syster
Research Development
University of the Western Cape

Ek verklaar dat hierdie dokument 'n ware afskrif is van die oorspronklike dokument en dat ek my waarnemings, die oorspronklike nie op enige wyse verander het.
I hereby certify that this document is a true reproduction/copy of the original which was examined by me and that, from my observations, the original has not been altered in any manner.

Ex Officio: Kommissaris van Ede
Ex Officio: Commissioner of Oaths

Ampt(Rang) LIAISON RELATIONS OFFICER
Designation (Rank) PAWK: DIREKTORAAT ADMINISTRASIE
PAWC: DIRECTORATE ADMINISTRATION

Adres: 17 Bellville

Telefoon: 021 959 2948

APPENDIX 3: Information regarding the study issued to parents



UNIVERSITY *of the* WESTERN CAPE

DEPARTMENT OF PSYCHOLOGY

Private Bag X 17, Bellville 7535, South Africa, Telephone: (021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

Informed consent form

The lived experiences of adolescents with cancer

Dear Participant

I would like to request your participation in a research study examining the lived experiences of adolescents who have cancer.

If you are willing to participate in this study, I would like to conduct a face-to-face interview with you, which would take approximately one hour. With your permission this interview will be video-recorded. I am currently a Masters student in Research Psychology at the UWC and will be conducting the interview myself. The interview will take place at the Tygerberg Hospital in the Social Work Department and the time will be arranged at your convenience well in advance.

In the interview, questions will be asked about your experience of being an adolescent with a life threatening disease such as cancer and how it impact on your view of yourself, especially with regards to the physical and psychological changes it brought about. Some of these questions will be personal and may bring back difficult memories and feelings. However, please be assured that you may stop the interview at any time or that you can refuse to answer specific questions during it. You are also free to discontinue participation at any time and this will not affect your ongoing treatment at the hospital.

Should you choose to discontinue participation you can request that all the data collected about you, including tapes and transcription of tapes, be destroyed and they will be.

Should you find questions asked in the course of the research interview to bring back painful or difficult memories and you would like to talk to someone about your feelings, the services of a psychologist will be made available to you free of charge.

To ensure confidentiality of the research material real names and true identities will not be revealed. All data collected will be stored in a locked box and only the researchers and supervisor will have access to this information. Thus all information will be kept confidential. Reports about the study, including articles will not mention any real names. Descriptions of any individuals will be disguised, so that they will not be recognizable to anyone else reading the study. Thus, there will be no way to tie in any piece of information collected by the study with any specific individual or family. On completion of the study all tapes and transcripts will be destroyed.

If you participate in the study and would like to receive a copy of the final study, please note this on the informed consent form below.

If you are interested in participating in this study, please read the following statement and sign below.

I understand that participation in this study is voluntary and am aware of the risks, benefits and possible inconveniences associated with my participation. I recognize that I am free to ask questions, to refuse to answer questions, and to terminate the session at any time.

I also understand that if I do have any questions or problems concerning this research that I should contact the researcher, Adele Poole at 082 878 3490.

.....

.....

Signature of Participant

Date

.....

.....

Signature of Participant

Date

..... Yes, I would like to receive a report of the study's findings.

Address:

.....



UNIVERSITY *of the*
WESTERN CAPE

APPENDIX 4: Informed consent form issued to parents



UNIVERSITY of the WESTERN CAPE

DEPARTMENT OF PSYCHOLOGY

Private Bag X 17, Bellville 7535, South Africa, Telephone: (021) 959-2283/2453
Fax: (021) 959-3515 Telex: 52 6661

Consent form of parent/guardian

Title of the research project

The lived experiences of adolescents with cancer

Principal researcher: Adele Poole

Address: 187 Altenaway
Strand
7140

Contact numbers: Cell no.: 082 878 3490
Home no.: 021-853 2673
Work no.: 021-483 9545

.....
Name of child
(To be written by the child if possible)

.....
Independent witness

Declaration of parent/guardian

By signing below, I (*name of parent/guardian*)agree to
allow my child (*name of child*).....who is currently

years old, to take part in a research study entitled

The lived experiences of adolescents with cancer

I declare that:

Signed at (*place*).....on (*date*).....2007.

.....
Signature of parent/guardian

.....
Signature of witness

Declaration by investigator

I (*name*).....declare that:

I explained the information in this document to

I encouraged him/her to ask questions and answered them to the best of my ability

I am satisfied that he/she adequately understands all aspects of the research as discussed.

I did not use a translator.

Signed at (*place*).....on (*date*).....2007.



UNIVERSITY of the
WESTERN CAPE

.....
Signature of investigator

.....
Signature of witness

APPENDIX 5: Interview guide

A Sample of a Semi-structured Interview

1. Please think back to the 6 months preceding your diagnosis. How would you describe those months?
2. Describe to me what you recall thinking at the time of the initial diagnosis.
3. I would like you to summarise the course of your disease for me thus far. For example, can you tell me about your treatment? How would you describe your 'normal week'? Describe to me what will happen in terms of your next course of treatment.
4. Do you think you have received/are receiving adequate information from health care professionals?
5. What things are different about your life now than before you had cancer?
6. How have people responded to your cancer? What have they said, or done, which was helpful, or not helpful? (a) spouse, (b) family, (c) close friends, (d) other friends, (e) co-workers, (f) health care professionals, and/or (g) anyone else? Did any of these things change the way you thought about yourself or about having cancer?
7. What is different about yourself since your diagnosis? In other words, is the way you see yourself now different from the way you saw yourself in the past?
8. What is different about your body since your diagnosis?
9. Since your diagnosis, has your relationship changed with your (a) partner, (b) family/children, and/or (c) friends?

10. What do you think caused your cancer?
11. What does the term the 'future' mean to you right now? What are your feelings about your life expectancy?
12. Do you feel your cancer is/can be cured?
13. Is there anything else that I have failed to ask you in this interview which is important for me to know?
14. Looking over your whole cancer experience, what is the most significant change in your life that has taken place as a result of the diagnosis?

Source: Mathieson and Stam, 1995: 291 as cited in Chamberlain & Murray (1999)

