

**THE PSYCHOSOCIAL EXPERIENCES OF PATIENTS DIAGNOSED WITH
ACUTE LEUKAEMIA DURING HOSPITALIZATION**

by

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I declare that

The psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references.



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Thank you Almighty God.

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Laetitia

Abstract

Limited information regarding the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization resulted in the implementation of this exploratory case study research. The objective of the study was to explore the psychosocial experiences of patients diagnosed with acute leukaemia and factors which impacted on the hospitalization process. The methods of data collection included unstructured interviews, participant observation and documentation. Four participants were interviewed with regard to the objective of the study. The linear-analytical approach was utilized for data presentation of various themes according to biological and environmental, social and psychological components. This study was deemed successful due to the achieved objective, information generated and future research that was indicated. Conclusions were drawn and recommendations were offered.

Key words: Psychosocial, hospitalization, leukaemia, case study research, themes, biological, environmental, social and psychological.

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CHAPTER 1

INTRODUCTION

1.1 Introduction

"... there is very little written about patients with hematologic malignancies, consequently we must extrapolate from what has been written about cancer patients in general." (Henderson and Lister 1990: 783-784).

It is on similar premises, as the above, that this research study is based upon. It will be highlighted that limited information exists regarding the experiences of those individuals diagnosed with acute leukaemia, especially during their hospitalization process. In outlining the above this chapter will focus on providing a general overview regarding the research problem. The background information offered will include discussion of aspects of the treatment and the hospitalization process. This discussion will make special reference to procedures at the Pretoria Academic Hospital. The above will reinforce the rationale for the study. The value philosophy will also be highlighted. In addressing the problem the research title i.e. "*the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization*", will be conceptualized and operationalized. Carl Rogers' Client centered therapy (1987) and Victor Frankl's Logotherapy (1984) are selected for theoretical application with regard to this study. Rogers' therapy is essential in achieving the goals of the research study i.e. the theory is centered on exploring the phenomenological fields (i.e. experiences) of individuals. This is what the study aims to achieve. Frankl's Logotherapy is utilized to reflect on the meaning of the psychosocial experiences of the participants. In attempting to achieve the objectives set out for this study the Case study research design has been selected. This design will be holistic in nature and have a multiple case design. This implies that the study will have one unit of analysis (i.e. the psychosocial experiences of patients) and four cases to be explored. The methods of data collection will essentially be qualitative, as it will utilize unstructured interviews, observations and documentation. The methods of data presentation will be linear

analytical and presented according to themes. The units of analysis will highlight the sampling procedures and dictate that the sample will comprise out of four participants (cases). In conclusion a brief account of the significance and limitations of the study will be provided.

1.2 Overview of the research problem

1.2.1 Background

Various authors such as, Devita, Hellman & Rosenberg (1997); Holland, Bast, Morton, Frei, Kufe and Weichselbaum (1997); Peckham, Pinedo and Veronisi (1995), Henderson and Lister (1990) and Strout and Caliguri (1997) have written about the various treatment options or regimes for treating leukaemia. The treatment method at the Pretoria Academic Hospital is that of cytotoxic chemotherapy. Chemotherapy is essentially drugs, substances or chemical agents that destroy cancerous cells and which can cause severe side effects (Dodd 1987:1; Dorland's illustrated medical dictionary 2000:333). Currently the treatment regimes for treating acute leukaemia at Pretoria Academic Hospital involves a combination of chemotherapeutic drugs that may include Cytarabine (Ara-C), Daunorubicin, Vincristine, Etoposide, Prednisone, L-Asparaginase, Methotrexate, Cyclophosphamide, 6-Mercaptopurine, etc. (Department Medical Oncology 2001). The administration of a combination of cytotoxic substances are dependent on the histology and morphology (i.e. the type of leukaemia e.g. be myeloid or lymphoid) of the disease.

Individuals diagnosed with acute leukaemia are usually in a dire state that demands immediate medical treatment. They are admitted to the Medical Oncology ward where they receive treatment. The duration of hospitalization is in direct correlation with the biological (physical) condition of the individual, the impact and side effects of the

chemotherapy, infections or complications, or the individuals recovery time. The duration of hospitalization can therefore be from any number of days to six weeks or even longer depending on the nature of the treatment, complications, the individual's recovery time, etc.

Death is also a constant reality.

As a result of the toxic side effects of chemotherapy the patient's resistance to other diseases and infections may be compromised. According to the Nursing care plan (2001) the utilization of myelosuppressive chemotherapy induces bone marrow aplasia. This simply means that patients are now prone to infections and other complications as their immune systems are suppressed. In this state where the individual is immune compromised, protective measures are essential and life saving. Individuals are therefore placed in *isolation* (also known as reversed isolation) for the prevention of infections and complications or for the effective management of possible complications (Nursing care plan 2001).

Isolation dictates that the individual is kept, in as far as possible, a sterile environment, has limited visitors (i.e. 2-3 visitors per individual) and that medical staff and visitors (for the protection of the individual) should wear protective clothing. This isolation component of hospitalization may last for a number of days or weeks depending on the patient's biological responses or his or her recovery time.

Previously, some individuals have also been placed on psychotropic drugs (e.g. anti-depressants) to assist them with coping with the isolating traumatic effects of hospitalization. The above hospitalization process may be repeated and therefore causing a disruption from their normal life for more or less six months.

Apart from the manner of treatment being unique within the world context, the patient population and their geographical distances from the Pretoria Academic Hospital are also unique. The Pretoria Academic Hospital offer this specialized services to a diverse population that encompasses not only the Gauteng or Tswane area but also the Northwest, Limpopo and Mpumalanga provinces. As a result regular commuting to the Hospital may be very problematic. This factor of geographical distances therefore also contributes and influences the long-term hospitalization process.

From the above can be deduced that hospitalization can be very traumatic. Although it is considered very traumatic it seldom occurs that individuals diagnosed with acute leukaemia are referred for social work intervention from the start. A number of speculative reasons can be offered to explain this e.g. the perception regarding the role of the social worker, a possible authoritative medical focus, the patient being just too ill to benefit from social work intervention and so forth. Usually individuals are referred later in the treatment process when a crisis arises.

1.2.2 Rationale

From the above it is evident a need exists to understand and explore the experiences of individuals diagnosed with acute leukaemia. Evidently, a scientific approach i.e. research, to gather information regarding the outlined problem is therefore essential.

Further motivations for the proposed study include:

- Hospitalization is a traumatic process especially in the case of acute leukaemia patients that are admitted for prolonged periods of time. Staff has limited understanding of how this affects patients.

- Limited information exists on the experiences of patients diagnosed with acute leukaemia during hospitalization. Due to this lack of knowledge we are therefore not always able to assist them effectively. Acquiring this information will result in effective service delivery to patients.
- To gain information and insight regarding the patients' experiences. This will not only foster an understanding of the patients' experiences but also assist with effective service delivery.
- To equip social workers and others (who deliver a service to these patients) to better understand the patients and to assist them effectively. This will enable the development of a better supportive service.

1.2.3 Value philosophy of research

As a result of the above outlined rationale for the study it is also important to highlight the value philosophy. Due to the lack of information in this specific area of study, the need for research is indicated. The information that will be acquired will enable social change and enable the opportunity for construction of further theories.

The research envisaged can be described as scientific, as it will fulfill the requirements of the theory outlined. The selected theory for this study will guide the researcher in this scientific endeavor and also assist in exploring the possible relationship of the variables identified.

Due to the lack of information that is prevalent in this field the aim is also to generate information to formulate hypotheses in this field of study. This research therefore will be predominantly qualitative in nature and has a phenomenological orientation (i.e. focusing on the subjective experiences of individuals).

The research endeavoured can therefore be considered ground breaking work as it will contribute to the knowledge base, and also measure and explore the phenomenological experiences of the participants.

1.3. Problem statement

1.3.1. Research title

To comprehensively explore the impact of leukaemia and hospitalization the research title is:

The psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization.

1.3.2 Conceptualization and operationalization

Conceptualization and operationalization are viewed as the frame of reference to be utilized as a guide in verifying the meaning of each concept and identifying the relationship among those concepts (Moss in Grinnell 1988: 435-436; Rubin & Babbie 1993: 120).

Concepts conceptualized and operationalized as according to the research topic are:

1.3.2.1 Psychosocial

Dorland's illustrated medical dictionary (1994: 1384) states that psychosocial pertains to both psychic and social aspects. The term psychic is further conceptualized as pertaining to the psyche or mind i.e. the human faculties and capabilities of thought, judgement, emotions, unconscious and conscious processes (Dorland's illustrated medical dictionary 1994:1382,1384). Blakiston's Gould medical dictionary (1979: 1127) and the Oxford concise dictionary (1997:

1106) define psychosocial as all those psychological and social factors as well as all human interactive behaviour.

The parameters of psychosocial for this study are therefore all those psychological, social, emotional, cognitive factors and behaviour of patients with acute leukaemia during the hospitalization process.

1.3.2.2 Experience

This term is self-explanatory. The Oxford concise dictionary (1997: 474) defines experiences as actual observation of practical acquaintance with facts or events. This therefore suggests views and perceptions of patients.

1.3.2.3 Patients

This term refers to those individuals who are ill or receiving medical treatment (Dorland's illustrated medical dictionary 1994: 1245; Blakiston's Gould dictionary 1979: 1008; The Oxford concise dictionary 1997: 1001). In terms of the study patients will refer to those diagnosed with acute leukaemia and hospitalized.

1.3.2.4 Diagnosed

This refers to a diagnosis being placed on the individual. Dorland's illustrated medical dictionary (1994: 458) establishes diagnosis or to be diagnosed as the determination of the nature of the disease or the art of distinguishing between diseases. The Oxford concise dictionary (1997: 372) states it as identifying disease as according to symptoms. The diagnosis or to be diagnosed can

therefore be viewed as nothing more than a classification or a label as a result of symptoms e.g. leukaemia.

1.3.2.5 Acute leukaemia

Leukaemia is generally defined as malignant progressive disease of the blood forming organs which is characterized by distorted proliferation (abnormal cell growth) and the development of leukocytes (white blood cells) (Dorland's illustrated medical dictionary 1994: 918). The Oxford concise dictionary (1997: 782) describes leukaemia as a group of malignant diseases in which the bone marrow and other blood forming organs increase the number of the white blood cells. Leukaemia can be either chronic or acute depending on the morphology. The cell line (that shows blasts) specifically characterises acute leukaemia (Dorland's illustrated medical dictionary 1994: 918; DeVita et al 1997:2295-2296; Holland et al 1997: 2671).

In the light of the study, acute leukaemia will be considered as those malignant (cancerous) diseases that cause an increase in the white blood cells, which necessitate treatment.

1.3.2.6 Hospitalization

Both Dorland's illustrated medical dictionary (1994: 778) and Blakiston's Gould medical dictionary (1997: 627) define hospitalization as the confinement of the patient in a hospital for treatment. The treatment of acute leukaemia may result in the patient being immune-compromised as a result of the severe side effects of the chemotherapy. The patient may therefore be unable to fight infection and precautions against possible infections and complications must be taken. It is

then that the patient will be placed in isolation. Isolation is another facet of hospitalization which refers to separating patients from others and significant others to protect themselves from infection (Dorland's illustrated medical dictionary 1994: 863; Blakiston's Gould medical dictionary 1979: 707).

From this conceptualization it is evident that all those psychological, social, emotional, cognitive factors and behaviour (i.e. the psychosocial experiences) of those individuals diagnosed with acute leukaemia during hospitalization are to be explored, described and understood.

1.4 Theory

Conceptualization fostered clarity regarding the purpose of the research. The Client centred therapy (theory) as according to Carl Rogers (1987) will now be discussed in relation to the purpose of the research.

This theory emphasizes the importance of the client's (individual's) experiences, the description and the understanding of these experiences (Rogers 1987). It is this description of the experiences of the individual i.e. the individual's phenomenal field (Morse & Watson 1977: 168), that needs to be measured, understood and studied. Special emphasis is also on the propositions that Rogers formulated. These propositions will reinforce the study or hold true for it. Essentially all propositions link with the first two propositions as this depicts all facets of human functioning (Unisa 2000:7). These two propositions are:

- The individual experiences a continual changing world of which he is the center of,
- The individual reacts to his phenomenal field as he perceives and experiences it (Rogers 1987: 484-497).

As can be noted, this theory will enable the exploration of the participants' psychosocial experiences.

It is in considering these principles that it will be attempted to ascribe meaning to the four participant's experiences. This discussion will be based on logotherapy as developed by Victor Frankl (1984). Logotherapy refers to assisting man to find meaning in his existence (Frankl 1984: 125). This meaning Frankl (1984) postulates occurs in the prevalence of suffering. This therapy also acknowledges that man may be confronted with an existential vacuum i.e. a meaningless void where despair or the noögenic neurosis (conflict between existential problems) may be prevalent (Frankl 1984: 123-125, 129-130). Existential frustration may therefore be the result (Frankl 1984: 123). This, Frankl (1984: 126) argues, is important to enable meaning of life.

In a very limited scope, some applications regarding this theory will be utilized in facilitating a greater understanding of the participants' experiences. It will be pointed out that all four participants were able to find meaning in their experience however traumatic it may have been. Their existential vacuum and frustrations will also be pointed out. The hospitalization process enforced at the Pretoria Academic Hospital resembles also some sort of captivity even though it is different from the captivity experienced by Frankl (1984: 20-115) in the concentration camps. The difference between hospitalization and the concentration camps is that the concentration camps were instituted to destroy life while hospitals were instituted to save lives.

The foci are solely on the individuals, their experiences and the meaning they attribute to it. This reiterates the purpose of the study in attempting to measure and understand the experiences of patients in a new and changing environment i.e. their phenomenal field. Here can be clearly noticed that Rogers' theory is most suitable in understanding the patients'

experiences as the patient's phenomenal field changes to that of the hospital environment. This environment will therefore give rise to experiences that are foreign to the patient. These experiences in a new and changing phenomenal field are to be explored.

1.5 Research assumptions

Hypothesis refers to a question or a formulation depicting the relationship between the independent and dependent variables (Moss in Grinnell 1988: 436; Collins in McKendrik 1990: 251). Variables for this study are identified even if limited information exists.

The independent variable, as according to Arkava and Lane (1983: 19) may be defined as that which predicts what causes the behaviour and phenomenon under investigation. For this research study the **independent variable** will be the **diagnosis i.e. leukaemia**.

The dependent variable refers to the effect of the phenomenon (Arkava and Lane 1983: 19).

This refers to that which is caused by a diagnosis of leukaemia. Reference is therefore made to all which will be measured, observed, documented, etc. The **dependent variable** for this study is the **psychosocial experiences of patients during hospitalization**.

The assumption of the researcher is that leukaemia impacts on the psychosocial experiences of patients. This impact therefore needs to be considered when dealing with patients that are diagnosed and admitted for the treatment of leukaemia.

1.6 Research objectives

Within the limited scope of the present research, as highlighted above, hypotheses or correlations between the above mentioned variables cannot be made. In a scenario as the above, Moss (in Grinnell 1988: 436) and Grinnell (1988: 225) motivate the formulation of research

questions. The research objective is therefore to explore and answer the following two questions.

1. What are the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization?, and
2. Are there other factors that influence or amplify the extent or the impact of patients' psychosocial experiences during hospitalization?

1.7 Research Design and procedures

1.7.1 Design

As was stated earlier, very limited information exists on the topic to be researched.

Apart from the above, the rationale for the study, conceptualization and the theory discussed, emphasized the need for the research method to be qualitative i.e. to explore, describe, understand and explain the characteristics of the data (to be gathered) and also to generate a wealth of information.

Considering the above, the case study research method is selected as the most suitable research design for this study.

Case study research has been defined by Yin (1993: xi, 4) as a social science inquiry that encompasses research steps that defines topics broadly and covers the contextual conditions. Yin (in Bickman and Rog 1998: 229) furthermore adds that case study research is multifaceted. Arkava and Lane (1983: 187) state that case study research is utilized for in depth investigations of the individual, groups, institutions and communities. Based on the research questions or assumptions it would indicate the case study to be exploratory and descriptive in nature. The case study will also touch on

some explanatory aspects, as it will attempt to explain why certain phenomena occur.

The exploratory case study design has therefore been selected as the design most suitable to achieve the objectives of the study. Reinforcing the above, Grinnell (1988: 225) states that exploratory design should be utilized especially where an area is not well defined. This is specifically true of the intended study. This type of design therefore attempts to build general ideas and tentative theories.

Case studies can also have a single or multiple case design. A single case design is when one case is studied and multiple case design when more than one case is studied (Yin in Bickman and Rog 1998: 238; Yin 1993: 5). Multiple case design also fosters replication and therefore improving the consistency of information (Yin in Bickman and Rog 1998: 239-240). Apart from this, the case study can also be holistic or embedded. Holistic case study refers to when the case study only has one unit of analysis and embedded refers to where the case study has more than one unit of analysis (Yin in Bickman and Rog 1998: 239-241).

For the purposes of this study the case study research will be holistic and have a multiple case design. It is holistic as it has one unit of analysis namely the psychosocial experiences of patients and a multiple case design as it will have more than one case to be researched. Not only will the case study provide a detailed investigation of all psychosocial experiences patients are experiencing during hospitalization but also foster an understanding of these experiences. Apart from this, criterion for construct validity, external validity and reliability will also be satisfied. Construct validity will be satisfied as more than one source of evidence will be utilized (Yin 1989: 42). This will ensure replication. External validity will be satisfied, as the information obtained will only be generalized to participants with acute leukaemia at the Pretoria Academic Hospital.

Reliability will be satisfied, as the same procedures will be used in every case (Yin 1989: 40-41, 43).

1.7.2 Method of data collection

The method of data collection will be essentially qualitative in nature, as it will focus on exploring, describing, analyzing, and explaining data, therefore also fostering an understanding of the phenomena to be explored.

Epstein (in Grinnell 1988: 185-188) states that qualitative methods utilize inductive reasoning (i.e. derive concepts from social entities) and seek the essential character of social and psychological phenomenon. Qualitative methods therefore do not count and correlate social and psychological phenomena. Yin (1993: 57) states that qualitative methods refer to data collected and not converted into numerical variables. Yin (in Bickman and Rog 1998: 246- 248) and Spierer (1980: 21) state that qualitative methods incorporate interviews, observation and documentation (i.e. unobtrusive observation). Yin (1989: 84-94) states sources of evidence in case study research are documentation, archival records, interviews, direct observation, participant observation and physical artifacts. To reinforce the qualitative nature of the intended research the methods to be utilized in this case study are interviews, documentation and observation.

Open or unstructured interviews with patients will be one method of data collection.

Open or unstructured interviews are seen as a purposeful discussion with the individual (Spierer 1980:21). Siedman (1998: 9) views open interviews as in depth and phenomenological. The goal of an open interview is to construct the patients' experiences (Siedman 1998: 9). The advantage of open interviews is therefore that it allows for in depth exploration of all answers. Yin (1989: 89) adds that facts and

opinions can be asked and explored. Via these open interviews, the psychosocial experiences of patients will be explored and described in detail. Note, yet again, the central link to Roger's theory of exploring the individual's phenomenological field. Hence the congruence between research design and theory to be utilized.

Observations from medical (ward) sisters or nurses regarding the patient during hospitalization will also be utilized. The motivation for selecting the sisters and nurses in the ward is that they will provide consistent and corroborative information regarding the patient in the ward as they spend the most time with the patient and are able to directly observe the patients in their phenomenological fields. It must, however be emphasized that a greater value will be placed on the patients' account of their experiences than that of the observation of others.

Documentation or unobtrusive observation i.e. medical records will also be utilized. Both documentation and observation will only be utilized to corroborate and augment evidence and are therefore not the most important source of evidence (Yin 1989: 85-87,91).

From the above methods, construct validity and reliability will also be addressed and reinforced.

1.7.3 Method of data presentation

Spirer (1980: 63) stipulates that data presentation should be both descriptive and analytical. The focus is on evaluating the purpose, methods, time and length of the case study, limitations, relationships of the case study sites, check on data, presentation of findings, conclusion and recommendations. Themes found in the different cases will

also be provided. Yin (in Bickman and Rog 1998: 255) refers to this as the linear - analytical structure of data presentation. Yin (1989: 106) also states the purpose of this general analytic structure is treating the evidence fairly, to produce compelling analytical conclusions and to rule out alternative interpretations. Utilizing the linear-analytical approach to data presentation themes that may emerge will be grouped according to three main categories of the patients' psychosocial experiences during hospitalization namely, biological environmental, social and psychological components. Theme triangulation will also occur.

For the presentation of data, this linear-analytical structure will be utilized to present and reflect on data obtained according to the three broad categories and themes to be explored.

1.7.4 Unit of analysis

The population is the total set of individuals to be studied (Seaberg in Grinnell 1988: 240). The total set of individuals to be studied - according to the proposed research - is the entire adult (i.e. 18 years and older) patients who are diagnosed with leukaemia and who are treated at the Pretoria Academic Hospital. According to statistics provided by the Department of Medical Oncology (2001) the total number of patients diagnosed with leukaemia from 1998 – 1999 have been 113 patients. For the year 2000 there has been 63-ward admittance for acute leukaemia and for 2001, 70-ward admittance. These statistics refer only to those patients aged eighteen years and older, diagnosed with acute leukaemia that were admitted for treatment in the Medical Oncology ward. From the above a sample that is representative of the entire population (Seaberg in Grinnell 1988: 240) must be drawn.

Although Seaberg (in Grinnell 1988: 253- 254) suggests ten percent of a population to be representative of that population, this will however not apply to this case study research. This is largely due to the case study research's extensive, detailed and in depth exploration of one unit of analysis. The sample for the case study will be four patients. Sampling methods in measuring the population will therefore be purposeful as they contain certain characteristics that need to be measured (Spirer 1980: 30). The specific characteristics in the study are all those psychosocial experiences of patients. Spirer (1980: 30) furthermore adds that purposeful sampling is utilized to learn or understand something. According to the aims of the intended research it will attempt to explore, describe, explain, analyze and understand all the psychosocial experiences experienced by patients diagnosed with leukaemia.

The type of purposeful sampling to be utilized is that of *most similar cases* where the selected cases shares commonalties (Henry in Bickman and Rog 1998: 105).

Commonalties of those individuals selected for the sample is:

- all must be diagnosed with acute leukaemia,
- all should have been hospitalized at least once before for treatment of leukaemia,
- they must be aged between eighteen to forty years.

1.8. Significance and limitations of the study

The significance of the study is that qualitative data will be gathered on the patient's experiences. The research findings will also generate knowledge regarding the experiences of patients. As a result of these findings the capacity for future research is also increased. The information obtained will also foster effective supportive service delivery for patients due to

clear conceptions of the needs of the patients. Another aspect, which can be considered as positive, is that focus will solely be on the patient. The understanding of the patients' experiences will therefore not be cluttered with families' or staff's perceptions, thereby ensuring the achievement of the research purpose.

Limitations of the study are that other sources e.g. families or significant others will not be considered.

An understanding of what the family or significant others experience will therefore not be gained. The study's specific area of focus is also during the hospitalization process and not predominantly when patients are in their natural environment. This study is only intended for gathering information and drawing inferences for further research and will not attempt to enforce the findings to be representative of the entire population. Further research, to foster generalization regarding the entire population, is therefore envisaged.

1.9 Summary

This chapter's aim was to provide the reader with a general overview regarding the research to be undertaken. The intended research study i.e. "the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization", was portrayed as being worthwhile as limited information currently exists regarding these patients' experiences. An overview regarding the research problem was provided which also included focusing on aspects of the hospitalization process, specifically at the Pretoria Academic Hospital. In highlighting the rationale for the study the research title was conceptualized and operationalized. The value philosophy also received mention. The client-centered therapy and logotherapy have been selected as the theory which will guide this study. Holistic exploratory case study research

design has been highlighted as the research design to be utilized. The methods of data collection will be qualitative in nature, as it will attempt to gain insight regarding the experiences of patients during hospitalization. This will incorporate unstructured interviews, observation and documentation. The data collected will be presented according to themes via a linear analytic structure. The sample will incorporate four patients, aged between eighteen to forty years who have all experienced one hospitalization period. In conclusion, significance and limitations of this research study were set out. It was noted that the research is of value.

CHAPTER 2

LITERATURE REVIEW 1:

IMPACT OF LEUKAEMIA, TREATMENT AND HOSPITALIZATION

2.1 Introduction

“...Within two hours of finding out my results I was seeing a specialist as I had a very serious case of Leukemia and needed treatment ASAP.

Over these past months I have endured some horrendous procedures, including chemotherapy and of course, the side effects. I can't begin to try and explain

how exactly it feels...”

(Bronwyn Cole 1999).

The aim of this chapter is to foster an understanding regarding acute leukaemia and the hospitalization process. In order to facilitate an intriguing discussion of the psychosocial experiences (to follow in chapter three) some essential discussional points are fundamental. The initial focus of discussion, in this chapter, is to define cancer and leukaemia. Defining these concepts is important, as it will facilitate an extensive understanding of the impact of these diagnoses. Having gained clarity regarding the above, the discussion will center on clarifying the different types of leukaemia – highlighting their symptoms, tests and treatments. In discussing the treatment of leukaemia, clarification of chemotherapy will be provided. The associative side effects of chemotherapy will also be highlighted. The treatment process of leukaemia, the phases involved in the treatment process and especially the procedures followed at Pretoria Academic Hospital will receive considerable mention. This discussion will highlight some aspects of the hospitalization process as well as foster an understanding of it. This will contribute to the quote provided at the start of the chapter. An overview regarding the impact of cancer and the hospitalization process will be provided. It is important to note that a great deal of information will be extrapolated from general and different cancers (as oppose to leukaemia), as a result of the lack of information that exists regarding leukaemia.

2.2 Defining cancer and leukaemia

2.2.1 Defining cancer

Slaby and Glicksman (1985: 14) view a cancer diagnosis as being tantamount to a diagnosis of leprosy. We all are aware of the stigma attached to a cancer diagnosis. But what is this cancer that evokes so much fear in people?

Cancer can be simply defined as malignant growth also known as neoplasm (Cohen in Pervan, Cohen and Jaftha 1995: 18). Barraclough (1999: vii) defines cancer as a malignant disease or tumour growth. It is also said that the term cancer covers more than one hundred different medical conditions which all involve abnormal and excessive division of cells (Barraclough 1999: vii).

Speechley and Rosenfield (1992: 1) aptly define cancer as a disease of cells, whereby the normal functioning of the body cells are disrupted which results in uncontrolled growth (not unlike a swelling). Conti (1989: 23) views cancer as a disease or a group of diseases characterized by abnormal cell growth. The uncontrolled and disordered growth of these cells can spread and ultimately result in death. Cancer may multiply more profusely and quickly than the treatment may kill it (Conti 1989: 23, 26). Rubens and Knight (1980: 3) define cancer as malignant tumours that are the clinical results of disorders in the regulation of cell proliferation (i.e. the accurate cell replication or cell growth).

From the above definitions it is evident that cancer refers to a group of malignant diseases characterized by abnormal cell growth i.e. cell proliferation. Cancer also seems to be viewed as the overall category of a group of malignant growths, which in turn may be sub-divided into different types depending on where the malignancy originated from

e.g. a cancer that originates in the breast tissue may be termed breast cancer or breast carcinoma, etc.

The understanding developed from defining cancer now enables the conceptualization of leukaemia.

2.2.2 Defining leukaemia

Speechley and Rosenfield (1992: 2) state that leukaemia is a form of cancer of the white blood cells, which are formed in the bone marrow. Conti (1989: 49) states that leukaemia is cancer of the blood forming tissues. Thus far we can deduce that leukaemia is a form of cancer (it is therefore a sub category of cancer). The malignancy occurs primarily in the blood system or the blood forming organs (i.e. the bone marrow) but specifically affects the white blood cells.

Linked to the above, Mobarra and Ely (in Pervan et al 1995: 513-514) define leukaemia as a group of disorders characterized by abnormal uncontrolled proliferation of white blood cells and their precursors in the blood forming organs with infiltration into the other body organs e.g. spleen, lymph nodes, liver, meninges, brain, skin, etc. In acute malignant leukaemia the cells are immature and proliferate rapidly (Mobarra and Ely in Pervan et al 1995: 513-514). Once again it can be denoted that leukaemia originates and affects the blood forming organs. Leukaemia cells are immature cells termed blasts and spread rapidly. The following definitions also echo the same perception of leukaemia.

Dorland's illustrated medical dictionary (1994: 918) defines leukaemia as a progressive malignant disease, which is characterized by distorted proliferation (abnormal cell growth) and the development of leukocytes (white blood cells). Accordingly, the Oxford concise dictionary (1997: 782) describes leukaemia as a group of malignant diseases in

which the bone marrow and other blood forming organs increase the number of white blood cells.

The etiology of leukaemia is still very speculative although a number of predisposing factors have been isolated namely genetics, environmental, viral causes, etc. (Mobarra and Ely in Pervan et al 1995: 513-514).

From the above it is deduced that acute leukaemia may be considered as those malignant (cancerous) diseases of the blood forming organs which result in immature cell proliferation with a characteristic increase in the formation of leukocytes (white blood cells). This condition will necessitate treatment.

2.2.3 Formulating leukaemia

For the purposes of this study the different types of leukaemia will not be explored as it will not really be of value in achieving the study's objectives. Treatment of these different types of leukaemia has commonalties resulting and embracing similar test, symptoms, side effects, etc. A general overview or rather a consolidation of symptoms, tests, the treatment and side effects will be provided.

As with most diseases, various types of acute leukaemia have been identified. It is essential to determine the type of leukaemia first, as it will influence the treatment regime to be followed (Nursing care plan 2001). Beck Black (1989: 2) states that early detection influences the morbidity of the disease and resulting quality of life. It therefore seems that early detection does not only involve specific testing but effective chemotherapy. As a result, clarity and assurance regarding the type of acute leukaemia results in the effective management and treatment of the condition.

The process of diagnosing the acute leukaemia inevitably starts with the pre-diagnostic phase. This phase is characterized by the individual experiencing a number of symptoms. These symptoms may include fever, weight loss, fatigue, malaise (bodily discomfort), anaemia, loss of appetite, bone and joint pain, headaches, recurrent infections, bruisability, dyspnea (shortness of breath), signs of abnormal proliferation of white blood cells, petechia or purpura (bleeding under the skin), etc. (Henderson and Lister 1990: 770; Konradi and Stockert 1989: 34; Nursing care plan 2001 and Mobarra and Ely in Pervan et al 1995: 516). If the patient has been experiencing some of these symptoms, tests will be performed in order to identify the condition.

Mobarra and Ely (in Pervan et al 1995: 515), Speechley and Rosenfield (1992: 28, 30) and Conti (1989: 49) all stress various tests employed to identify the type of leukaemia include bone marrow biopsy, blood tests (full blood count), cytogenetics, bone marrow trephine and aspirate, etc. Via these tests the cell type which shows abnormal growth will be identified as the type of leukaemia. The type of blood cell that shows abnormal growth will thus suggest the leukaemia type. The classification of leukaemia is formulated according to the cell type. This distinction or classification is labeled as the morphology of leukaemia. The identification of the morphology is instrumental in administering the most effective treatment regime, to manage inherent problems and to determine the response (Mobarra and Ely in Pervan et al 1995: 514). The above is reiterated by Dorland's illustrated medical dictionary (1994: 918), De Vita, Hellman and Rosenberg (1997: 2295-2296) and Holland, Bast, Morton, Frei, Kufe and Weichselbaum (1997: 2671) who all state that the cell line i.e. the type of cell which shows blasts (immature malignant growth) specifically characterizes the leukemia.

There are two major cell types in which leukaemia may manifest namely the myeloid and lymphoid cells. The two major types of acute leukaemia are therefore acute myelogenous/ myeloid leukaemia (AML) and acute lymphoid/ lymphoblastic leukaemia (ALL) (Konradi and Stockert 1989: 34). Both these two types may be divided into further subgroups. These subgroups will not be discussed further as the emphasis of this study is the general psychosocial experiences of those diagnosed with acute leukaemia and not the effect of the different diagnoses of leukaemia.

Myeloid leukaemia affects the development of myeloid cells. This involves monocytes and granulocytes whose main function is to control infection (Konradi and Stockert 1989: 34). Lymphoblastic leukaemia affects the development lymphoid cells. These cells regulate the immune system (Konradi and Stockert 1989: 34).

The two major types of acute leukaemia are myeloid and lymphoid. Identifying the morphology of leukaemia will determine the treatment regime and the strategy in managing leukaemia. The exploration of the treatment process is therefore now essential.

2.3 Treatment of leukaemia

Once the morphology has been determined the specific treatment may commence. The treatment of acute leukaemia is aimed at long-term remission rather than immediate comfort.

But what type of treatment is given to patients diagnosed with leukaemia?

2.3.1 Chemotherapy

From all the possible treatment available, chemotherapy has been highlighted as the most effective method of treating leukaemia. Leukaemia is a systemic disease and therefore requires a systemic treatment like chemotherapy. Barraclough (1999: 25) and Hughes (1987: 64) both state that chemotherapy is drug treatment. This term chemotherapy can be viewed as short hand for cytotoxic drug treatment. Cytotoxic drugs kill body cells i.e. both normal and cancerous cells (Hughes 1987: 64). Rubens and Knight (1980: 25) state that chemotherapy is the treatment of malignant tumours by which drugs (also known as cytotoxic drugs) inhibit cell proliferation. These agents or drugs are toxic (poisonous) to cells (Rubens and Knight 1980: 25, 28). Conti (1989: 36) reiterates the above by stating that chemotherapy is essentially treatment whereby chemicals are administered. The chemicals used are those that interfere with the reproductive processes of cells, with metabolic processes of cells and with the body's natural resistance to cancer cells (Conti 1989: 36). Freeman (1990: 23) also views chemotherapy as cytotoxic, which is used to treat systemic malignant diseases. Chemotherapy can therefore be considered as cell poisoning whereby the process of cell division is disrupted. Jaftha (in Pervan et al 1995: 678) states that chemotherapy is specific drugs, which can cause side effects. These side effects may be physical (like bone marrow depression) and or psychological implications (which may produce an altered body image). Jaftha is here trying to define chemotherapy as substances which can cause physical and psychological effects i.e. have bio-psychosocial effects. Leon, De Jager and Toop (in Pervan et al 1995: 197) view cancer as the use of chemical agents (drugs) in treating malignant disease. It is also known as anti-neoplastic or cytotoxic which means cell poisoning. Due to the non- selective nature of cytotoxic substances

both normal and malignant cells are affected. This may therefore be referred to as the toxic side effects of treatment (Leon, De Jager and Toop in Pervan et al 1995: 197).

It is therefore evident that chemotherapy is cytotoxic drugs, agents, chemicals or substances that inhibit cell proliferation (cell growth) and attempt to destroy the cancerous cells. The ultimate goal or purpose of the chemotherapy is therefore to eradicate the malignancy by destroying the cancer or leukaemia cells thereby restoring normal hematopoiesis (Nursing care plan 2001; De Vita et al 1997: 2300 and Konradi and Stockert 1989: 39).

Through this discussion it was noted that healthy cells are also affected or destroyed. We are aware that normal hematopoiesis (cell growth) is essential for the effective functioning of the body. Destruction of healthy cells will therefore amount to the toxic side effects of chemotherapy.

2.3.2 Side effects of chemotherapy

Side effects refer to all those undesirable consequences of treatment, in this case chemotherapy.

Mobara and Ely (in Pervan et al 1995: 517) state that the major problem with the side effects of the treatment is the bone marrow failure or toxicities associated with treatment. Chemotherapy is systemic and therefore affects the whole body by affecting or destroying normal cells (Conti 1989: 36; De Vita et al 1997: 2300; Freeman 1990: 23; Leon, De Jager and Toop in Pervan et al 1995: 199 and Konradi and Stockert 1989: 39).

This destruction of cells is due to the treatment's non-selective nature (as was previously stated). This therefore causes unavoidable damage to normal proliferating tissues. In leukaemia, total bone marrow depression or aplasia may occur due to myelosuppressive nature of the chemotherapy (Freeman 1990: 23; Jaftha in Pervan et al 1995: 678 and De Vita et al 1997: 2300).

Simply put, Freeman (1990: 23) states that cells are destroyed and patients have decreased capacity to overcome infection. This is largely due to cell decreases like the white blood cells, red blood cells and platelets. This may result in states of neutropenia, anaemia and thrombocytopenia. Neutropenia is evident, according to Jaftha (in Pervan et al 1995: 675) where there is a greater proneness to infection as a result of the decrease in white blood cells. Anaemia occurs where there is a decrease in the red blood cells and thrombocytopenia as a result of a decrease in platelets, which may lead to uncontrolled bleeding (Jaftha in Pervan et al 1995: 675).

The above occurs on a cellular level which may be overtly manifested by patients experiencing pain, fever, tiredness and fatigue, nausea and vomiting, diarrhoea, stomatitis (mouth sores), alopecia (hair loss), malaise, anorexia, rashes, weakness and an increased proneness to infection, amongst others (Freeman 1990: 23; Jaftha in Pervan et al 1995: 678 and Leon, De Jager and Toop in Pervan et al 1995: 199).

The side effects can be very distressing and uncomfortable. There is therefore a continuous struggle for the patient to remain in control and cope with normal daily tasks which is psychologically very distressing (Jaftha in Pervan et al 1995: 678).

It should be remembered that patients with acute leukaemia are acutely ill when first admitted and then also receive chemotherapy, which cause them to feel worse! As was

stated earlier the focus of the chemotherapy is not on immediate comfort but on long term remission.

2.3.3 Treatment process of leukaemia

The process of treating leukaemia differs from treating other cancers, as the treatment is more aggressive, intensive and demanding.

The drugs utilized in treating the leukemia depends firstly on the morphology (i.e. the cell line) (Mobarra and Ely in Pervan et al 1995: 517). It has been proven that a combination of substances works more effectively in destroying the leukemia.

At the Pretoria Academic Hospital a combination of Cytarabine (Ara-C), Daunorubicin, Cyclophosphamide and Etoposide are administered in cases of acute myeloid leukaemia (AML) and a combination of Vincristine, Prednisone, L-asparaginase, Methotrexate, 6-mercaptopurine and Cytarabine are administered in cases of acute lymphoblastic leukaemia (ALL) (Nursing care plan 2001). In both these cases it must be remembered the patient might get combinations of these substances and not necessarily all the drugs at the same time. A treatment regime is therefore applied and followed. Whichever combination of chemotherapy is offered the process of treatment encompasses three phases namely the induction, the consolidation and the maintenance phase.

2.3.3.1 The induction phase

This is the initial phase of treatment after a diagnosis has been established. The aim of this phase is designed to rapidly eradicate leukaemia cells so as to induce remission of the disease (Holland et al 1997: 26, 29 and Mobarra and Ely in Pervan et al 1995: 517-518). This state of remission refers to when blasts (malignant cells) consist of less than five percent of the bone marrow cells. The

largest number of leukaemia cells should therefore be destroyed in this phase (Konradi and Stockert 1989: 39). If remission was not achieved, this phase may be repeated again.

Severe bone marrow aplasia occurs as a result of the myelosuppressive cytotoxic drugs. The recovery period of the bone marrow is estimated between fourteen to twenty one days or even up to thirty two days (Sister's manual 2001). It is during this time that the patient's resistance is very poor and result in neutropenia (i.e. the decrease of granulocytes or white blood cells) (Portlock and Goffinet 1980: 17; Jaftha in Pervan et al 1995: 678). In dealing with this state of neutropenia, infections or management problems, the Department of Medical Oncology at the Pretoria Academic Hospital adheres to a phase of reversed isolation during the hospitalization process (Nursing care plan 2001).

This isolation refers to a protective environment in which the patient is kept in order to protect them from infection from personnel and significant others (Isolation nursing 2001 and Henderson and Lister 1990: 786). There are many rules and regulations for the process of reversed isolation that have to be adhered to. Some of these include the wearing of protective clothes by personnel and significant others, hygiene, routines, limitations on visitors, nutrition whilst in isolation, etc. (Isolation nursing 2001). Apart from the above a great deal of testing still occurs during this time like interim blood counts and bone marrow biopsies which the patient has to contend with (Nursing care plan 2001).

This period requires a great deal of psychological treatment due to dependency, not being able to leave the room until the bone marrow has recovered (up to twenty one to thirty two days) (Henderson and Lister 1990: 786). Once the

marrow has recovered the patient may be discharged from hospital for a couple of days or weeks depending on the treatment regime. The next phase will commence when the patient is in remission.

Once remission has been established the next phase follows.

2.3.3.2 The consolidation phase

De Vita et al (1997: 2303) and Konradi and Stockert (1989: 39) see this phase as the post remission phase where the aims are to prevent relapses or to eliminate any remaining leukaemia cells (i.e. the appearance of blasts greater than five percent).

This phase involves intermittent cycles of chemotherapy of the same, similar or slightly modified drugs as during the induction phase (Konradi and Stockert 1989: 39). Here these drugs may once again cause bone marrow aplasia, which may result in the isolation procedures to be applied once more. The patient may therefore be hospitalized for more or less a month again. This phase may also be repeated.

When the blast population remains in remission, the third phase follows (Mobarra and Ely in Pervan et al 1995: 518).

2.3.3.3 The maintenance phase

This phase is designed to keep patients in remission by preventing the formation of blasts in the bone marrow (Konradi and Stockert 1989: 39).

Low to moderate (i.e. attenuated) doses of cytotoxic drugs are administered every third or fourth week in order to assist the patient in maintaining a normal

life style (Konradi and Stockert 1989: 39; Mobarra and Ely in Pervan et al 1995: 518 and De Vita et al 1997: 2303).

This phase differs from the first two phases as it attempts to facilitate normalcy and quality of life. Initially the patient was very sick as a result of the side effects of treatment, but during this phase the side effects are less severe and more manageable.

This section focused on providing an overview regarding the treatment, its goal, side effects and the treatment process of acute leukaemia. Aspects discussed touched on the effects or impact of a cancer diagnosis and the hospitalization process. Further consideration regarding the impact of a cancer diagnosis like leukaemia and the hospitalization process will now follow.

2.4 Impact of a cancer diagnosis and hospitalization

2.4.1 Impact of a cancer diagnosis

Cassileth and Lief (in Cassileth 1979: 20-21, 28) view cancer as a bio-psychosocial disease as it not only affects the biological (physical) aspects but also the social and psychological aspects. A cancer diagnosis not only elicits anxiety but also disrupts the lives of patients e.g. routines, tasks, responsibility, etc. This disruption can be closely related to Van Schalkwyk's (in Pervan et al 1995: 647) view that cancer is a crisis situation. Not only is the impact of cancer immediate but the condition also persists over a period of time which categorize itself as a chronic disease (Sidell 1997: 7). Even when treatment has ceased, follow up appointments may extend over months or years. This therefore bears considerable impact on the patient and significant others. As a result it is

therefore only logical to deduce that patients and their significant others may experience loss, coping difficulties and may need counseling.

Apart from this initial crisis situation, a cancer diagnosis may be perceived as punishment, stigmatization and may even threaten the loss of employment (Cassileth and Lief in Cassileth 1979: 24). This links to the earlier statement by Slaby and Glicksman (1985: 14) that a cancer diagnosis is tantamount to a diagnosis of leprosy. Cancer is a disease that is associated with a great deal of stigma and can as a result be very isolating. The patient may therefore even be rejected or experience feelings of rejection.

Beck Black (1989: 1) states that cancer causes a great deal of anxiety as it results in enormous personal and economic hardships. Associated with the above are fears regarding life and death, experiences of vulnerability, hopelessness and stress in coping with the diagnosis and the subsequent treatment (Cohen, Cullen and Martin 1982: 2). Jaftha (in Pervan et al 1995: 675-676) elaborates on the above and explains it as the patient's equilibrium that is disrupted – a crisis occurs and the patient's behaviour becomes unpredictable. This implies that before a cancer diagnosis the patient was coping and therefore in equilibrium (i.e. in balance). The onset of cancer caused a disruption and changed the circumstances. This is an important aspect to be considered as it correlates with the Client-centered therapy developed by Rogers (1987). According to Rogers (1987:1) an individual exists in a continually changing world of which he or she is the center of the experience and consequently reacts according to his or her perceptions. So it is therefore only logical when an individual is exhibiting disorganized behaviour as he or she is removed from his or her familiar surroundings and attempting to make sense thereof. Rogers (1987: 191-195) furthermore states that behaviour is goal

directed. If the individual is exhibiting disorganized behaviour it could be that he/ she may be expressing his or her feelings, perceptions, experiences, etc. The behaviour will therefore have a purpose. It is this goal directed behaviour that this research attempts to explore.

Furthermore, according to Jaftha (in Pervan et al 1995: 675-676) a loss of self occurs as the cancer also affects the patient's perception of body image. This can be due to the cancer itself but also as a result of the visible side effects of the treatment e.g. weight loss, skin reactions, alopecia (hair loss), etc.

Jaftha adds that this change in the body's perception can result from self and the environment. Here we can once again note the impact of the environment on the individual.

Apart from the general impact of a cancer diagnosis, the bone marrow aplasia, which may result from treatment, may cause even greater stress to the patient. This stress may also include the hospitalization process, in itself. There may therefore be numerous psychosocial experiences which the patient may experience. Consideration of the impact of hospitalization is now imperative.

2.4.2 Impact of hospitalization

Hospitalization implies that the individual is suddenly transplanted to a strange environment, which functions according to a different set of rules and regulations (Jaftha in Pervan et al 1995: 675-676). Not only are significant others missed but patients may become confused or uncertain of self, feel inadequate, dependent on others and their total pattern of life changes completely (Jaftha in Pervan et al 1995: 675-676).

It therefore seems that hospitalization, even for a short period of time, may have a massive and disruptive impact on the patient.

Turner and Mapa (1979: 3-4, 39) claim that hospitals are founded on the highest human ideals but result in dehumanizing the patient. The removal of the patient from the familiar environment may cause loss of personal identity, dependency, emotional shock and a lack of peace of mind (Turner and Mapa 1979: 3-4, 39).

Palmer and Bolla (1997: 36-47) reiterate the above by claiming that hospitalization causes dependency, cognitive dysfunctions, mood disorders and malnutrition. It is however important to acknowledge that admittance in hospital is non-negotiable for acute disease like acute leukemia but conversely impairs the quality of life and the independence of the patient (Palmer and Bolla 1997: 36-47). This effect of hospitalization should therefore be kept in mind.

Apart from the above the patient seldom has peace of mind due to a lack of privacy as according to Bäck and Wikblad (1998: 940-945). Privacy is a basic human right and includes solitude and intimacy.

Linked to this peace of mind, Tagliacozza and Mauksch (in Turner and Mapa 1979: 88) mention that patients have fears of being hospitalized. These fears may include safety issues i.e. safety of possessions, safety of treatment, safety of self, etc. The patient may therefore feel unsafe and yet feel like a captive who cannot leave the hospital without serious consequences (Tagliacozza and Mauksch in Turner and Mapa 1979: 88).

All the above may be linked to the aspect of dignity, according to Szasz (in Turner and Mapa 1979: 130-131). There is a fundamental tendency to infantilize the ill person and to parentify the healer. The patient is expected to make all the adjustments and the transformations e.g. patient is expected to trust the physician, the physician may

withhold vital information, patient is expected to impart his intimate bodily and personal experiences, etc. (Szasz in Turner and Mapa 1979: 130-131).

It can be noted from the above that the impact of hospitalization can be devastating. However, the Client-centered approach refers to individuals as dynamic and able to adapt to changes. All that may be needed is perhaps assistance regarding the experiencing of their pain and circumstances and perhaps time for them to deal with their experience holistically. In the process of attempting to cope and experience the phenomenal field holistically, the patient diagnosed with acute leukaemia may be experiencing certain emotions, exhibit certain behaviours and have certain attitudes and beliefs. This may therefore be termed as the psychosocial experiences. It is this psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization that this study is attempting to explore and describe.

2.5 Summary

This chapter provided an overview of cancer and leukaemia and the hospitalization process. In defining cancer and leukaemia the similarities and differences were pointed out. It was mentioned that leukaemia is a malignant disease of the blood forming organs which result in immature cell proliferation and an increase in leukocytes . As a result treatment is required. Before discussing the treatment process of leukaemia- leukaemia was formulated by highlighting the pre-diagnostic phase, which is characterized by symptoms, experienced by patients. A short review was provided about the tests employed in the diagnostic phase. This is where a diagnosis of leukaemia will be made. Furthermore, the morphology of acute leukaemia and their specialization was discussed.

It was only after this clarity was achieved that the treatment of leukaemia could be discussed.

Chemotherapy was highlighted as the treatment of choice in leukaemia. The side effects thereof

also received considerable mention before the consideration of the treatment process. The treatment process was discussed according to three phases namely: the induction, consolidation and maintenance phases. It was during the induction phase that considerable mention was made regarding isolation. The impact of a cancer diagnosis was then explored. This was in turn linked to the theory of choice as highlighted by Rogers (1987). Thereafter a discussion regarding hospitalization followed.

From the discussion it was noted that a leukaemia diagnosis and the hospitalization process have tremendous effects and consequences. It is therefore logical to deduce that the psychosocial impact of a leukaemia diagnosis and hospitalization may be massive.

CHAPTER 3

LITERATURE REVIEW 2:

PSYCHOSOCIAL EXPERIENCES OF A LEUKAEMIA DIAGNOSIS AND HOSPITALIZATION

3.1 Introduction

“Dying is surely the greatest lesson plan we all must confront... I’ve been imagining how it would be if my coming death were caused by a stroke, heart attack or some other abrupt ending. When I do, I thank God I have cancer.”

(David Mumford, 1997: 49).

Very few can view a diagnosis of cancer as Mumford. In contrast to the above, Van Schalkwyk (in Pervan, Cohen and Jaftha 1995: 647) claims cancer to be a crisis situation. It is therefore logical to assume that a spectrum of different views or experiences for everyone diagnosed with cancer may exist.

The previous chapter has centered on defining and formulating leukaemia, describing the treatment process and the subsequent side effects thereof and providing a general overview regarding the impact of cancer and the hospitalization process. It was concluded that the psychosocial experiences are massive. This chapter will explore the psychosocial experiences of patients diagnosed with acute leukaemia. It must however be mentioned that a great deal of information will be extrapolated from literature regarding other cancers. This is as a result of the limited information that is evident regarding experiences of those patients diagnosed with leukaemia. Conceptualizing the term psychosocial experience will receive first focus. It was previously stated that cancer is a bio-psychosocial disease as it affects all spheres of individuals. Their entire phenomenological fields are therefore affected or influenced. It is this that this study attempts to explore. The exploration and presentation of data based on the psychosocial experiences of patients will occur according to three categories i.e. biological and environmental, social and psychological components. Each of these components is sub-divided according to themes of psychosocial experiences. These themes link with the method of data presentation (of the case study research) that will be linear-analytical in nature. The exploration

of the biological and environmental components entails the impact that the physical diagnosis and the hospitalization process have on patients. The social component considers relationships, roles, stigma and support. The psychological component is discussed as according to interpersonal relationships and intra-personal factors. In addressing the interpersonal relationships, themes that emerge are support and losses experienced regarding others. The intra-personal factors are subdivided into eight categories, which encompass those factors that give rise or influence individual responses to a cancer diagnosis. The information presented will be instrumental in the implementation of the research study.

3.2 Conceptualizing psychosocial experiences

Dorland's illustrated medical dictionary (1994: 1384) states that psychosocial pertains to both psychic and social aspects. Psychic furthermore refers to the psyche or mind i.e. the human faculties and capabilities of thought, judgement, emotions, unconscious and conscious processes (Dorland's illustrated medical dictionary 1994:1382,1384). Psychosocial may also be defined as all those psychological and social factors as well as all human interactive behaviour (Blakiston's Gould medical dictionary 1979: 1127; The Oxford concise dictionary 1997: 1106). Hersh (in Ahmed, Coelho and Kolker 1979:175-190) states that psychosocial refers to all aspects that influence the individual. This includes issues like the diagnosis, treatment, hospitalization, relationships, work, social roles, etc. The World Health Organization, as according to Ahmed et al (1979: 87-95) also includes social class, culture, stress, stigma, behaviour, etc. From the above it is evident that psychosocial may refer to all aspects that may have some sort of influence on an individual.

The parameters of psychosocial for this study are therefore all those psychological, social, emotional, cognitive factors and behaviour of patients with acute leukaemia during the hospitalization process.

Exploration of the above factors of psychosocial will occur according to three psychosocial components namely: biological and environmental, social and psychological components.

3.3. Biological and environmental components

In order to understand the psychosocial experiences of patients the biological components need to be understood, as this is where the disease process starts. This affects the general well being of the patient i.e. it impacts on the patient psychologically and socially. By environmental components, as according to this study, reference is made to the hospitalization process.

3.3.1 Biological components

Being diagnosed with leukaemia- that is the actual diagnosis- may bring about certain responses or stress. Slaby and Glicksman (1985: 25) state that with a cancer diagnosis the illusion that one is immortal is forever lost. One is therefore confronted with your fragile and mortal state.

Henderson and Lister (1990: 769) state that a leukaemia diagnosis produces stress as a result of the actual symptoms of the disease (amongst other factors). Cassileth and Lief (in Cassileth 1979:17) view illnesses as discontinuities. This refers to that of life and life tasks. The biological onset of illness although it may be organic in nature not only has a biological effect but a psychological and social influence as well. A cancer diagnosis elicits anxiety, disruption of life and an increase in the uncertainty of survival (Cassileth and Lief in Cassileth 1979: 20;). Cohen, Cullen and Martin (1982: 2) reinforce the above by stating that cancer illicit a fear of life, death, vulnerability and hopelessness.

Due to the prolonged nature of cancer it also influences loss, coping and developmental issues (Sidell 1997: 7). It fosters dependence, as an individual now has to be dependent on the health care system (Slaby and Glicksman 1985: 23-24). Whatever the reaction of the patient to the cancer diagnosis it is as a result of what that diagnosis means to the patient (Barracough 1999: 35-38). This therefore implies differences (or diversity) in experiences. Some may accept and cope with a diagnosis more readily than others. Generally a cancer diagnosis embodies a loss of health. Apart from the above it also represents losses of physical strengths and wellbeing (fatigue and weakness increase), independence, sexual functioning, physical integrity (as a result of changes in body image, appearance and functions, and life expectancy (mortality) (Barracough 1999: 35-38). Regarding losses Sidell (1997: 7) adds that it is significant for adults. The determinants of the profoundness of the loss are age, sex, health and existing social support. Losses can be perceived or real and result in devastating effects.

The individuals that will be interviewed in this study, according to the study's objectives, will be asked regarding their experiences when they first heard of the cancer diagnosis, their feelings, their understanding and the impact of it. Inferences between the four candidates will therefore be made. Rogers (1987: 191-195) states that behaviour is goal directed and therefore has meaning. Their behaviour is therefore exhibited as according to their meaning perceived and perceptions.

Themes to be explored under this component (and as revealed from the above discussion) are:

- losses and discontinuities (experienced as a result of the diagnosis and their experiences associated with it),

- fatigue and weakness,
- independence and dependency (their feelings associated with it),
- issues relating to intimacy (especially difference of perception brought along as a result of the cancer diagnosis.),
- physical integrity (body-image, self-concept, etc.).

3.3.2 Environmental components

For the purposes of this study this component refers to the medical setting i.e. the ward in which the patient will be hospitalized for prolonged periods. Usually the hospital is seen as a sterile environment in which the patient may feel captive. Even though the individual may not actually be imprisoned he/ she will always be dependent on the health care system (Slaby and Glicksman 1985: 23-24). This will therefore reinforce their perceived feelings of captivity. This dichotomy makes the adjustment and the coping exponentially difficult for the patient.

In order to gain an understanding into the hospitalization process and to reinforce the above, the following is a true account of a young patient diagnosed with leukaemia that was transferred into isolation:

“...The nurses cleaned my body as if I were going into a new world of my own...I was really scared and frightened...especially when they began rolling me down the hall in a wheelchair with a sterile sheet over the chair and over me. It was just like being blindfolded and dropped at the end of the world...”

When they stopped pushing, I knew this was it... they pulled the sheet down and asked me to walk across the red line...I felt all alone- no one to even talk to or hold in my arms." *Hersh (in Ahmed et al 1979: 179).*

Hospitals are founded on the highest humanitarian ideals but still contribute to dehumanizing individuals (Turner and Mapa 1979: 3-4, 39). How does this occur? Hospitalization implies that the individual is suddenly transplanted from a familiar (i.e. home) to a strange environment. This environment functions according to a different set of rules and regulations than what the patient is accustomed to (Jaftha in Pervan et al 1995: 675-676). This transplantation into an unfamiliar environment may result in a loss of personal identity, dependency, emotional shock and a general lack of peace of mind. Added to the above, the individual may also miss familiar routines and significant others. Therefore even though the admittance to hospital for acute leukaemia may be non-negotiable it does still impair the quality of life of a patient.

Not only are significant others missed but patients may become confused or uncertain of self, feel inadequate, dependent on others and their total pattern of life changes completely (Jaftha in Pervan et al 1995: 675-676). It therefore seems that hospitalization even for a short period of time may have a massive and disruptive impact on the patient (Palmer and Bolla 1997: 36-47). Cognitive dysfunction and mood disorders may also be evident.

Minor aspects (to medical staff but of major importance to patients) are issues relating to privacy, solitude and intimacy. With hospitalization all this are adversely affected and result in the patient experiencing fear, infantilization, feelings of captivity, etc. (Bäck and Wikblad 1998: 940-945; Tagliacozza and Mauksch in Turner and Mapa 1979: 8; Szasz in Turner and Mapa 1979: 130-131). The above mentioned writers state that the

patients have a lack of peace of mind being hospitalized (as a result of the unfamiliar environment), experience fear due to safety issues (i.e. of self, treatment and possessions) and become infantilized. This may all be linked to issues regarding dignity.

Conti (1989: 54) states that the isolation process allows individuals to withdraw from others. Pollin (in Sidell 1997: 7) adds that hospitalization result in feelings of abandonment, which result in the patient becoming isolated. This seems to be highlighted in the true account provided earlier.

A further question that should be considered is to what extent does hospitalization – especially the isolation process that follows in acute leukaemia- allow for intimacy especially between couples.

Themes that therefore stand out from this discussion are:

- transplantation from a familiar to an unfamiliar environment,
- isolation and feelings of abandonment.
- loss (in particular independence),
- privacy and intimacy,
- quality of life,
- safety (of possessions, treatment and self) and captivity, and
- dignity.

From the above it is noted that the biological, medical or organic diagnosis and the hospitalization process not only results in physical changes but affects the social and psychological spheres of the individual as well.

3.4. Social components

As was stated earlier, cancer is a disease that is associated with a great deal of stigma. In some cases it was reported that the stigma associated with cancer is greater than that of any other disease (Pollin in Sidell 1997: 7; Slaby and Glicksman 1985: 23-24).

Illnesses are discontinuities of states of being and social role performance (Cassileth and Lief in Cassileth 1979:17). Human experiences of illness are diversified according to the cultural background and the individual's personality. The diagnosis of cancer elicits anxiety, disruption of their life routine and uncertainty of survival (Cassileth and Lief in Cassileth 1979: 20).

Henderson and Lister (1990: 773) state that the developmental tasks affected by a leukaemia diagnosis are financial, personal attitude, social and cultural attitudes, social function, etc.

With a cancer diagnosis there is a great deal of losses which symbolizes unwanted role changes. Beck Black (1989: 2) states that a cancer diagnosis disrupts life, future integrity to fulfillment of social roles and activities, to one's general abilities to adjust to new physical a social environment. General losses include loss of independence, role, control (especially regarding the disease process), autonomy, function or limitations thereof (Barraclough 1999: 37-39; Pollin in Sidell 1997: 7; Slaby and Glicksman 1985: 24).

Disruption of roles includes that of school, work and leisure (Henderson and Lister 1990: 769; Cassileth and Lief in Cassileth 1979:24). A cancer diagnosis has therefore a financial implication. This in itself creates tremendous stress and anxiety due to the enormous personal

and economic hardships to the patient and family (Beck Black 1989: 1; Slaby and Glicksman 1985: 10; Henderson and Lister 1990: 773).

In this state one can understand that support is essential. Slaby and Glicksman (1985: 14) state that an individual who has support from family, friends and significant others respond differently to the diagnosis than those who have no support. This links to the existential factors (social) which are all those components like spirituality, religion, family, etc. that assist the individual in coping (Slaby and Glicksman 1985: 17).

As a patient - the individual has to adjust to new roles that may not be necessarily be pleasant e.g. dependency, etc. Szasz (in Turner and Mapa 1979: 130-131) reveals that hospitalization reinforces the fundamental tendency to infantilize the patient and parentify the healer. The patient is expected to make all the adjustments.

Considering the above it will be explored how the cancer diagnosis and hospitalization have impacted on the individual's roles, functioning, coping, activities, etc. Specifically therefore what type of changes occurred socially as a result of a cancer diagnosis. Themes to be explored in this regard will therefore be:

- stigma (experienced or perceived),
- role performances or changes,
- disruptions or discontinuities,
- support and losses (may it include support, control, autonomy and independence).
- cultural or existential factors.

From the above it can be noted that a cancer diagnosis may result in differences regarding relationships and tasks. The study will attempt to explore if a patient diagnosed with leukaemia and hospitalized as a result experience differences as according to the themes highlighted.

3.5 Psychological components

As highlighted in the discussion of the term psychosocial, psychological aspects will refer to all those aspects relating to emotions, thoughts, attitudes, beliefs and behaviour, basically all those factors that influence or determine an individual's personality. In discussing the psychological aspects of patients, reference to two categories will be made, namely interpersonal relationships and intra-personal factors. The interpersonal relationships refer to those factors that influence the relationship between people i.e. between patient and significant others, where as the intra-personal factors refer to those components that predisposes individuals coping, etc.

3.5.1 Interpersonal relationships

A cancer diagnosis creates isolation, even causing the patient to withdraw from others (Pollin in Sidell 1997: 7; Conti 1989: 1989: 54). But hospitalization removes the patient from the accustomed environment and therefore causes the loss of personal identity (Turner and Mapa 1979: 3-4). As we know support is essential to any individual. Those individuals having support such as the presence of family, responds differently to a cancer diagnosis (Slaby and Glicksman 1985: 140).

Hughes (1987: 70) states that those individuals that cope better are those who have stable personalities and relationships. Holland (in Holland and Rowland 1989: 75) states that patients have no choice but to adjust to the diagnosis, prognosis and treatment.

Those that adjust better are those patients with good support and who have minimal

psychological difficulties. It is therefore evident that the psychological wellbeing of a patient is influenced by the support as well. Sidell (1997: 8) states that it is the ultimate goal of the patient to adjust as this will enhance good health. Lack of coping and adjustment can therefore be seen as evidence of poorer health.

Hospitalization and a cancer diagnosis fosters a loss of interpersonal relations, creates communication barriers as well as a loss of sexual functioning (Barraclough 1999: 36-38; Slaby and Glicksman 1985: 10). Henderson and Lister (1990: 772) also stress the effect of a cancer diagnosis causing insecurity in one's sexual role.

It was noted earlier that cancer is a family diagnosis and causes a disruption in the family system (Beck Black 1989: 1, 4; Henderson and Lister 1990: 771). Psychological adjustments therefore have to be made. Where previously the individual had relationships with others, now the patient's primary role and communication is with the health care system on which they dependent (Slaby and Glicksman 1985: 10).

Themes to be highlighted for this component are therefore:

- support,
- loss of interpersonal relationships,
- communication with significant others, and
- intimacy.

Exploration of the patients' lack of support and how it affects them will therefore be explored. This includes their feelings, perceptions and their subsequent behaviour. This refers therefore to phenomenological field.

3.5.2 Intra-personal factors

It has been noted that the manner in which we cope is dependent on predisposing factors. These components will be explored according to the predisposing factors highlighted by Barraclough (1999: 40-44). This will also be highlighted and augmented (where applicable) with other author's views.

3.5.2.1 Age of the individual.

An older person may accept a cancer diagnosis easier. The age of the individual also correlates with the developmental phase the individual is in and the tasks associated with it. Cancer disrupts these life tasks and as a result the individual will respond accordingly. This refers to the selection criterion stipulated earlier that for this study individuals between the age of 18-40 years will be selected. This refers to the young adulthood phase as according to Erikson. Erikson (Dworetzky 1981: 42) postulates that it is in this phase of development that an individual has the most responsibilities and tasks to complete. Disruptions to the roles to be completed will therefore be traumatic for the individual.

3.5.2.2 Gender of the individual.

Studies have shown that females are more prone to depression and anxiety than males (Barraclough 1999: 40-44).

3.5.2.3 Religious beliefs.

Active religious beliefs assist individuals to cope better and with good adaptation (ibid.). This links with the existential factors (social) which are all those components which include spirituality, religion, culture, etc. that assist the individual in coping (Slaby and Glicksman 1985: 17). According to Slaby and Glicksman (1985: 17) this refers to factors which are philosophical, social or religious in nature that assist with the coping of the illness. An integrative

philosophy of life sustains an individual despite overwhelming adversity. It therefore provides a framework for conceptualizing life's despairing moments.

3.5.2.4 Past experiences of cancer.

This may influence the individual to cope better with a diagnosis or the hospitalization process than some one who does not have any experiences in this regard (ibid.). But is this really the situation? This will be explored further in the research study.

3.5.2.5 Past psychiatric history.

This will determine how the individual will react to his/ her diagnosis, treatment and especially the hospitalization process (ibid.).

3.5.2.6 Cultural attitudes and ethnicity.

This also influences the manner in which individuals will cope with their diagnosis (ibid.). This is linked to the existential factors that were discussed earlier.

3.5.2.7 Current life circumstances.

Support is very essential in dealing with cancer (ibid.). Henderson and Lister (1990: 772) state that illness causes more disruption by diminished attachment causing insecurity regarding one's sexual role and issues relating to intimacy. It is therefore a valid consideration especially with regard to the hospitalization process of acute leukemia at the Pretoria Academic Hospital.

3.5.2.8 Personality.

This refers to type of person the individual is (Barraclough 1999: 40-44).

It is postulated that all have characteristics that are unique to us. This therefore results in individualistic responses regarding a diagnosis and hospitalization, which in turn influences individuals to respond a certain way. According to

literature there are a variety of responses that individuals can exhibit. These factors can either be a response or a component to be considered and include: Fear, anxiety and stress. Fears of life and death, hospitalization, safety and security in hospital are pre-eminent for the patient who is diagnosed with cancer and hospitalized (Henderson and Lister 1990: 769; Tagliacozza and Mauksch in Turner and Mapa 1979: 88). Fears arise, as the idea of being immortal is forever lost to the patient. It not only impacts on the individual creating and reinforcing vulnerability, hopelessness, self-pity, feelings of abandonment but it also affect the family, work and leisure (Conti 1989: 54; Pollin in Sidell 1997:1;Cohen, Collen and Martin 1982:2).

Reaction patterns. Hughes (1987:43-44) has highlighted reaction patterns that range from resigned acceptance to mental agony. In this range of emotions there is also denial, depression and anger as a result of the diagnosis. These reaction patterns are also noted by Conti (1989: 54) and Pollin (in Sidell 1997:1). Once again these reaction patterns may also impact on the family.

Apart from the above, Jaftha (in Pervan et al 1995: 675-676) states that the equilibrium i.e. the balance of the patient is so upset by the cancer diagnosis and hospitalization that a crisis may arise and that the patient's behaviour may become unpredictable. Barraclough (1999: 39) refers to the above as a loss of mental integrity. The individual is confronted with unfamiliar emotions, which is out of character. There is therefore not only an emotional impact of the disease and hospitalization but also a behavioural component. These are exactly the experiences that are stipulated by Rogers, which determines behaviour.

Self-concept. It has been reported that cancer impacts on the individual's self-concept. This is largely due to the disfigurement as a result of the cancer and the

treatment according to Henderson and Lister (1990: 769). The above is as a result of the losses and experiences by the patient like losing of hair, body image change, etc. Jafhtha (in Pervan et al 1995: 675-676) reinforces the above statement that the loss of self due the body image and perceptions of self is affected. It is therefore not only the cancer diagnosis that is a challenge for the patient to cope with, but also the side effects of the treatment. These changes, unwillingly experienced by the patient, also cause embarrassment for the patient (Jafhtha in Pervan et al 1995: 675-676).

Losses and threats. Numerous losses are experienced by patients. These in include the loss of privacy, safety, etc. Apart from the above the patient experiences loss of mental integrity (Barraclough 1999: 39). The patient now experiences emotions that are unfamiliar and out of character. Slaby and Glicksman (1985: 11) expand on the above and state that losses include that of autonomy, change in body image, cognitive deterioration, medical complications, failing finances, emotional states, etc.

The patient therefore experiences losses and threats in all spheres of his life. Apart from the above the hospitalization process is also dehumanizing (Turner and Mapa 1979: 3). This is linked to the loss of dignity for the patient as the patient is being infantilized and the healer parentified (Szasz in Turner and Mapa 1979: 130-131).

Needs. Needs arise, as the patient has to deal with emotional disturbances that are reactive to the illness, according to Beck Black (1989: 3). The study will therefore explore needs which may have developed or changed as a result of a leukaemia diagnosis or the hospitalization process.

From the above discussion it is evident that certain themes may be highlighted:

- feelings of helplessness and hopelessness,
- influence of existential components,
- emotional reactions and responses,
- issues relating to self-concept and a lack of self worth,
- loss of autonomy, body-image, cognitive integrity,
- coping, and
- needs.

3.6 Summary

This chapter explored the psychosocial experiences of patients diagnosed with acute leukaemia. It was noted that a leukaemia diagnosis and hospitalization impacts on an individual bio-psychosocially. As a result this was explored according to three components namely biological and environmental, social and psychological components. It was stipulated that the biological component referred to the actual diagnosis. It was shown that this diagnosis alone affects patients psychosocially. Environmental components referred to hospitalization. The social components discussed incorporated themes of stigma, support, roles and changes. The psychological components considered all the emotional, cognitive and behavioural responses of patients. This component was divided into interpersonal relationships and intra-personal factors. Interpersonal relationships explored the nature and effects of relationships on patients. It was deduced that patients with good support do better than those patients without support. Intra-personal factors considered eight categories of factors that predispose humans in coping with a cancer diagnosis. From this discussion a number of themes were highlighted regarding

the psychosocial experiences of patients. Apart from the above, patients' responses are individual and unique.

CHAPTER 4

METHODOLOGY

4.1 Introduction

The aim of this chapter is to acquaint the reader with the methodology applicable and selected for this study. By way of introduction and motivation for the selected methodology i.e. the case study research design, focus will first be to highlight the rationale and value philosophy for this case study research. A brief explanation of the case study research will be provided. It will be identified that the exploratory case study research will be applicable to establishing and investigating the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization. Variables will also be identified as this will be an important consideration for the pattern matching mode of analysis in presenting data. The discussion regarding units of analysis will identify the study to have a holistic and multiple case design. Purposeful sampling, in specific - most similar cases, will be utilized in selecting the respondents. To ensure the efficacy of the study, criteria for quality will also receive considerable mention. Focus will be on construct, external validity, reliability and replication. Acknowledging the skills of the investigator will be the first point of discussion in considering methods of data collection. It will be proven that the investigator is indeed skillful, capable and qualified to perform the study. The sources of evidence will acknowledge the applicability of the unstructured interview, documentation and participant observation in achieving the objective of answering the specific research questions. The linear- analytical structure of data presentation will be identified as the method of presenting data as according to the themes highlighted. Added to the above, precision pattern matching will be identified as the mode of analysis as there will not be a precise way of comparing the effect of the independent on the dependent variable due to the lack of information that exists. Concluding this chapter will be the consideration of the significance and limitations of the study.

4.2 Rationale and value philosophy for the study

Chapter one encompassed a background regarding patients diagnosed with leukaemia, their treatment and hospitalization process. It was concluded then that little information is currently known regarding these patients' experiences. The necessity of this study in exploring their psychosocial experiences during hospitalization was concluded. As was outlined a number of motivations for this study were formulated, namely:

- Hospitalization is a traumatic process especially in the case of acute leukaemia patients who are admitted for prolonged periods of time. Staff has limited understanding of how this affects patients.
- Limited information exists on the experiences of patients diagnosed with acute leukaemia during hospitalization. Due to this lack of knowledge we are therefore not always able to assist them effectively. Acquiring this information would result in effective service delivery to patients.
- To gain information and insight regarding the patients' experiences. This will not only foster an understanding of the patients' experiences but also assist with effective service delivery.
- To equip social workers and others (who deliver a service to these patients) to better understand the patients and to assist them effectively. This will enable the development of a better supportive service.

Linked to the above outlined rationale is the value philosophy for the study.

As was stated earlier a lack of information in the field to be explored was evident. As a result the need for research was indicated. This information acquired will enable both social change

and the opportunity for construction of further theories. The research envisaged can be described as scientific, as it will fulfill the requirements of the theory outlined. The selected theory for this study will not only guide the researcher in this scientific endeavour, but also assisted in the exploration of the possible relationships of the variables and themes identified. Foci are therefore to explore the psychosocial experiences and to generate information to formulate hypothesis in this field of study. This research is predominantly qualitative in nature and has a phenomenological orientation (i.e. focusing on the subjective experiences of individuals).

The research endeavoured may therefore be considered as valuable as it will contribute to the knowledge base but also measure the phenomenological experiences of the respondents.

In the light of the above it was decided that it was essential to explore the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization via exploratory case study research design. This is considered essential as it will direct or enable better client centered service delivery. Consideration of the research design is necessitated in motivating the selected study.

4.3 Case study research

Case study research according to Yin (1989: 14) contributes to acquiring knowledge of the individual, organization, social and political phenomena. Spierer (1980: 15) echoes this sentiment by stating that it provides richness of information and allows for evaluations to avoid meaningless or misleading questions. It is therefore an empirical social science inquiry that encompasses research steps not only to define topics but also more importantly to investigate contemporary phenomena within its real life context where boundaries between phenomena and context are not clearly defined (Yin 1989: 23; Yin 1993: xi, 4). It is therefore instrumental in generating information regarding the phenomena. All social and personal complexities are

portrayed via describing, analyzing and organizing phenomena (Spierer 1980: 13-14). Here one can denote the extensive application of case study research.

Apart from being multifaceted, the case study research centers on utilizing in-depth investigations i.e. qualitative means- in investigating phenomena that is applicable to individuals, groups, institutions and communities (Yin in Bickman and Rog 1998: 229; Arkava and Lane 1983: 187). It is therefore applicable in various scenarios.

It is because of this in depth investigation dictated by the case study research as well as the emphasis on empirical inquiry into social phenomena that it has been selected as the research method of choice. In acknowledging the motivations highlighted, the case study research will also contribute in acquiring the information, as outlined in the rationale and the research study. Case study research embraces qualitative research and this is exactly what this study wants to achieve i.e. to find, correlate and present qualitative data or inferences than quantitative.

4.3.1 The research design

Research design refers to a plan, which includes every aspect of the proposed research study (Grinnell 1988: 219). Reid and Smith (1984: 64 in Collins 1990: 256) reiterates the above and state that it is a plan or strategy whereby research questions and hypothesis are answered. Research design is therefore an action plan that guides the process of data collection and presentation (Yin 1989: 28). Apart from being logical it also attempts to establish causal relationships amongst variables under investigation. In other words it is the logic that links the data to be collected to the initial question of the study (Yin 1989: 27-29). It can therefore be denoted that this design is rational and specific.

It was already motivated that the emphasis of this study as encompassed by the research title “i.e. the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization” is necessitated due to the lack of information regarding this phenomena specified. As a result hypothesis could not be formulated as the lack of information hampers the feasibility of any inferences to be drawn. It was however still deemed important to pose two research questions. It is this study’ objective to answer these following questions:

1. What are the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization?, and
2. Are there other factors that influence or amplify the extent or the impact of patients’ psychosocial experiences during hospitalization?

The lack of information also contributes to difficulty in formulating any sort of relationship between variables. However necessity demands the formulation of variables for qualitative exploration as according to the pattern matching mode of analysis i.e. the data presentation strategy.

As known, the independent variable predicts what causes the behaviour or the phenomena under investigation (Arkava and Lane 1983: 19). Howell (1989: 12) states that the experimenter usually controls this variable. It therefore represents that which influences the phenomena to be investigated. For this research study the **independent variable** will be the **diagnosis i.e. acute leukaemia**.

The dependent variable refers to the effect of the phenomenon (Arkava and Lane 1983: 19). Howell (1989: 12) states that the dependent variable is that which is being measured, in other words the data. According to the study, what does a diagnosis of

acute leukemia cause or result in i.e. the psychosocial experiences. Reference is made to all that will be measured, observed and documented. The **dependent variable** for this study is therefore the **psychosocial experiences of patients during hospitalization**.

For the purposes of this study the dependent variable was divided into three components namely the biological and environmental, social and psychological components. These components were explored in detail via various themes.

4.3.2 Exploratory case study research design

The exploratory case study research design has been selected as the strategy to acquire information regarding the phenomena highlighted in this study.

Exploratory design attempts to acquaint the characteristics of the research target (Collins 1990: 257). The principle is to refine concepts, develop questions and hypotheses for further research. Grinnell (1988: 225) echoes the above by stating exploratory design is selected if any area is not well defined, developed and where no sound theories exist. The aim is therefore to build general ideas and tentative theories. Based on the research questions it would indicate this case study to be predominantly exploratory in nature. The case study will also touch on some descriptive and explanatory aspects, as it will attempt to describe and explain certain phenomena. The exploratory case study design has been selected as the design most suitable to achieve the objectives of the study i.e. to answer the research questions posed.

The above echoes the rationale for the design selected. As was stated initially, limited information exists regarding the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization and as a result, hypothesis and inferences between variables cannot be drawn. Apart from just generating information regarding a

limited research area the research will also attempt to understand the experiences of the patients in order to offer a better client target driven service delivery. Of importance now is to explore the unit of analysis and sampling procedures for this exploratory case study research design.

4.3.3 Units of analysis

Case studies can also have a single or multiple case design. A single case design is when one case is studied and multiple case design when more than one case are studied (Yin in Bickman and Rog 1998: 238; Yin 1993: 5). Multiple case design also fosters replication therefore the consistency of information (Yin in Bickman and Rog 1998: 239-240). Apart from this the case study can also be holistic or embedded. Holistic case study refers to when the case study only has one unit of analysis and embedded to where the case study has more than one unit of analysis (Yin in Bickman and Rog 1998: 239-241).

For the purposes of this study the case study research will be holistic and have a multiple case design. It is holistic as it has one unit of analysis, namely the psychosocial experiences of patients and a multiple case design as it will have more than one case to be researched. Not only will the case study provide a detailed investigation of all psychosocial experiences patients are experiencing during hospitalization but also foster an understanding of these experiences. This refers to the 2x2-matrix design as highlighted by Yin (1989: 46).

4.3.4 Sampling

This study has a multiple case design and therefore more than one unit of analysis. Seaberg (in Grinnell 1988: 253- 254) suggests ten percent of a population to be

representative of that population. This will, however, not apply to this case study research due to the case study research's extensive, detailed and in-depth exploration of one unit of analysis. The sample for the case study will be four patients.

Sampling methods selected for this study will be purposeful, as certain characteristics will be measured. Spierer (1980: 30) states that purposeful sampling is geared at measuring certain characteristics but also utilized to learn or understand something.

According to the aims of the intended research it will attempt to explore, describe, explain, analyze and understand all the psychosocial experiences that patients diagnosed with leukaemia experience.

The type of purposeful sampling to be utilized is that of *most similar cases* where the selected cases share commonalties (Henry in Bickman and Rog 1998: 105).

Commonalties of those individuals selected for the sample is:

- all were diagnosed with acute leukaemia,
- all were hospitalized at least once before for treatment of leukaemia,
- they were all aged between eighteen to forty years.

4.3.5 Criteria ensuring quality

To ensure the efficacy of the study quality assurance is of the utmost importance. These criteria include construct validity, external validity and reliability. Construct validity refers to the establishing of the correct operational measures for the concepts or the phenomena being studied (Kidder in Yin 1989: 40-41). This will be satisfied by utilizing more than one source of evidence (Yin 1989: 42). Construct validity in this study will be satisfied as more than one source of evidence will be utilized namely interviews, participant observation and documentation. This will ensure and reinforce

replication as well. In case study research, replication does not refer to sampling logic but to the use of multiple cases (Yin 1989: 53-54).

External validity refers to extent to which the study's findings can be generalized (Kidder in Yin 1989: 40-41). The information obtained in this study will only be generalized to those patients with acute leukaemia that participated in the study at the Pretoria Academic Hospital. Inappropriate and unfounded conclusions will not be drawn and generalization to the entire population will not be made.

Reliability refers to what extent data collection procedures i.e. the sources of evidence, can be repeated (Kidder in Yin 1989: 40-41; Yin 1989: 42-43, 45). Yin (1989: 45) furthermore states that steps need to be as operational as possible. Reliability will be satisfied, as the same procedures will be used in every case. The procedures ensuring reliability that will be utilized in this case study research are:

- consideration of the documentation for every case (this is to ensure the diagnosis, treatment, hospitalization and verifying identifying details),
- informed consent offered to all participants,
- signing of the informed consent,
- unstructured interview facilitated with all participants respectively and
- consideration of participant observation.

4.4 Methods of data collection

4.4.1 Skills of the investigator

Before considering methods of data collection for this study an important consideration namely the skills of the investigator is essential. It is Yin (1989: 62) that specifies that the investigator should be well trained. The investigator should be able to ask questions and interpret answers. Here can be noted that communication skills are paramount. Yin (1989: 62) furthermore expands that good listening skills, flexibility, adaptability, unbiasedness and a firm grasp of issues are instrumental for a skilled investigator. The investigator of the intended study complies with these requirements. The investigator has been trained as a social worker and therefore has excellent communication skills. These skills are instrumental in exploring the phenomena. The investigator is also skilled in utilizing the client centered approach i.e. the approach of choice in dealing with the participants. The client centered therapy dictates that the counsellor should be unbiased, open, warm and should show unconditional acceptance (Rogers 1987: 19-36) This will satisfy the criteria for a skilled investigator. The researcher has also been employed in the Department Medical Oncology for the last seven years. The researcher is therefore familiar with issues regarding patients. The above assures the trustworthiness of the researcher.

4.4.2 Sources of evidence

The methods of data collection will essentially be qualitative in nature, as it will focus on exploring, describing, analyzing, and explaining data. An understanding of the phenomena to be explored is also fostered.

Epstein (in Grinnell 1988: 185- 188) states that qualitative methods utilize inductive reasoning (i.e. derive concepts from social entities) and seek the essential character of

social and psychological phenomenon. It does not count and correlate social and psychological phenomena. Yin (1993: 57) states qualitative methods refer to data collected and not converted into numerical variables. Yin (in Bickman and Rog 1998: 246- 248) and Spierer (1980: 21) state that qualitative methods incorporate interviews, observation and documentation (i.e. unobtrusive observation).

Multiple sources of evidence i.e. interviews, documentation and observation will be utilized for this case study. The rationale for this is that it will strengthen the validity of the information collected, as was also suggested by Yin (1989: 96). Furthermore it also allows for the investigator to address a broader range of issues. Apart from this it also allows for converging lines of inquiry i.e. triangulation (Yin 1989: 96-97).

4.4.2.1 Unstructured interviews

Yin (1989: 88-89) states that interviews are essentially a source of case study information. Spierer (1980: 21) identifies interviews as qualitative methods of data collection Grinnell (1988: 185-187) states that qualitative methods seek the essential character of the psychological and social phenomena. The emphasis is to comprehensively describe the meaning of events of individuals. The purpose of interviews is to assemble detailed descriptions of social reality (Grinnell 1988: 185-187).

Open or unstructured interviews with patients will be one method of data collection. Open or unstructured interviews are seen as purposeful discussions with the individual (Spierer 1980:21). Siedman (1998: 9) views open interviews as in depth and phenomenological. The goal of an open interview is to construct the patients' experiences (Siedman 1998: 9). The advantage of open interviews

is therefore that it facilitates in depth exploration. Yin (1989: 89) adds that facts and opinions can be asked and explored. Via these open interviews the psychosocial experiences of patients will be explored and described in detail. Note, yet again, the central link to Roger's theory of exploring the individual's phenomenological field. Hence the congruence between research design and theory to be utilized.

The client centered approach allows for purposeful discussion that will be comprehensively attempting to explore and describe the phenomena i.e. psychosocial experiences. Details of the purposeful discussion will essentially incorporate the main themes outlined in chapter three under the following components namely biological and environmental, social and psychological. For detailed descriptions of themes to be explored consider chapter three and the data presentation.

Similar procedures will be applied during every interview. These steps are to inquire patients' willingness to participate, explain procedures via the informed consent (see the annexes), initiate and maintain the interview as according to the principles of the client centered therapy and lastly to conclude and contract in cases where further counselling will be required.

The aim therefore of using the unstructured interview is to generate a wealth of information.

4.4.2.2 Documentation

Documentation or unobtrusive observation i.e. medical records will also be utilized. Both documentation and observation will only be utilized to corroborate and augment evidence and is therefore not the most important source of

evidence (Yin 1989: 85-87,91). Spierer (1980: 21) refers to this as unobtrusive data collection.

This is solely important for verifying identifying details like name, age, diagnoses, etc. of the patient for the intended study.

From the above methods construct validity and reliability will be addressed and reinforced.

4.4.2.3 Participant observation

Observations from medical (ward) sisters or nurses regarding the patient during hospitalization will also be utilized. The motivation for selecting the sisters and nurses in the ward is that they will provide consistent and corroborative information regarding the patient in the ward as they spend the most time with the patient and are able to directly observe the patients in their phenomenological fields. It must, however be emphasized that a greater value will be placed on the patients' account of their experiences than that of the observation of others.

4.5 Method of data presentation

Spierer (1980: 63) stipulates that data presentation should be both descriptive and analytical. The focus is on evaluating the purpose, methods, time and length of the case study, limitations, relationships of the case study sites, check on data, presentation of findings, conclusion and recommendations. Yin (in Bickman and Rog 1998: 255) refers to this as the linear - analytical structure of data presentation. Yin (1989: 106) also states the purpose of this general analytic structure is treating the evidence fairly, to produce compelling analytical conclusions and to rule out alternative interpretations. Mules and Huberman (in Yin 1989: 106) state that this

strategy is about placing information into different arrays, a matrix of categories, displays, tabulation or placing data into a chronological order using a temporal scheme.

Utilizing the linear-analytical approach to data presentation, themes that may emerge will be grouped according to three main categories of the patients' psychosocial experiences during hospitalization namely, biological and environmental, psychological and social components.

This refers to the exploration of the dependent variable as outlined.

4.5.1 Themes

Each of the above mentioned components encompasses various themes. These are:

4.5.1.1 Biological and environmental components

4.5.1.1.1 Biological components

- losses and discontinuities (experienced as a result of the diagnosis and their experiences associated with it),
- fatigue and weakness,
- independence and dependency (their feelings associated with it),
- issues relating to intimacy (especially difference of perception brought along as a result of the cancer diagnosis.),
- physical integrity (body-image, self-concept, etc.).

4.5.1.1.2 Environmental components

- transplantation from a familiar to an unfamiliar environment,
- isolation and feelings of abandonment.
- loss (in particular independence),
- privacy and intimacy,

- quality of life,
- safety (of possessions, treatment and self) and captivity, and
- dignity.

4.5.1.2 Social components

- stigma (experienced or perceived),
- role performances or changes,
- disruptions or discontinuities,
- support and losses (may it include support, control, autonomy and independence).
- cultural or existential factors

4.5.1.3 Psychological components

4.5.1.3.1 Interpersonal components

- support,
- loss of interpersonal relationships,
- communication with significant others, and
- intimacy.

4.5.1.3.2 Intra-personal components

- feelings of helplessness and hopelessness,
- influence of existential components,
- emotional reactions and responses,
- issues relating to self-concept and a lack of self worth,

Another criticism is that case study research takes long and is not simple (Yin 1989: 21; Spierer 1980: 16). In response to the criticism of the lack of accountability, this study has criteria in place for ensuring quality and accountability. Even though it is envisaged that the study may be detailed, the result of this exploration will be qualitative which equals value with regard to assisting individuals.

Limitations of the study are that other sources e.g. families or significant others will not be considered.

An understanding of what the family or significant others experience will therefore not be gained. The study's specific area of focus is also during the hospitalization process and not predominantly when the patient is in their natural environment. This study is only intended for gathering information and drawing inferences for further future research and will not attempt to enforce the findings to be representative of the entire population. Further research, to foster generalization regarding the entire population, is therefore envisaged.

The significance of the study is that qualitative data will be gathered on the patient's experiences. The research findings will also generate knowledge regarding the experiences of patients. As a result of these findings the capacity for future research is increased. The information obtained will also foster effective supportive service delivery for patients due to clear conceptions of the needs of the patients. Another aspect, which can be considered as positive, is that focus will be solely on the patient. The understanding of the patients' experiences will not be cluttered with the family's or staff's perceptions, therefore ensuring the achievement of the research purpose.

4.7 Summary

This chapter identified and discussed the methodology utilized for this study. The rationale for the study identified the lack of information that exists regarding the phenomena and as a result the need for the exploration in this area. The exploratory case study research design was identified as the methodology of choice to achieve the objective of answering the research questions posed. In the process criteria for ensuring quality i.e. the construct -, external validity, reliability and replication were addressed. Units of analysis and sampling were also discussed. It was concluded that the 2x2 matrix design for this study is holistic and multiple case design. Purposeful sampling in specific that of most similar cases was opted for, as the sampling for respondents. Four cases were selected as the sample. The skills of the investigator initiated the discussion regarding methods of data collection. It was pointed out that the investigator is skillful and capable. The sources of evidence for this study are interviews, documentation and participant observation. The above were identified to be effective and instrumental in achieving the objective of the study which is to answer the research questions. Methods of data presentation highlighted the linear- analytical structure for presenting the themes highlighted according to the biological and environmental, social and psychological components. The precision pattern matching was identified as the mode of analysis in comparing variables as limited information exists. In conclusion the significance and limitations of the study were discussed.

CHAPTER 5

FINDINGS

5.1 Introduction

This chapter's main focus is to present the data collected via unstructured interviews, documentation and participant observation. A brief background sketch of the four participants, who volunteered to share their experiences, will initiate the data presentation. Pseudonyms were either selected by or given to the participants to ensure confidentiality. The structural linear analytical approach to analyzing data will be utilized in presenting data according to the themes identified for the various components of the dependent variable i.e. the psychosocial experiences of patients during hospitalization. This will be followed by the interpretation of data according to the precision pattern matching of variables according to case study research methodology. This discussion will confirm that the study's objective was achieved. It will outline the effects of the independent variable i.e. a diagnosis of acute leukaemia on the themes of the dependent variable. The format of the discussion will be firstly, according to the three broad components of the dependent variable identified namely biological and environmental, social and psychological components. Secondly, the discussion will be according to theme triangulation. Where, indicated diagrammatical representations in graph format will be utilized to suggest the possible relationship that exists between themes. A table identifying losses and gains will also be offered. The table and graphs may be consulted in the annexes section. Thereafter a reflection of theory will occur. The validity, applicability and value of the study will be pointed out. Here both questions that were posed as the objective of the study will be answered. This will be followed by a discussion regarding the various impressions that the study fostered. It will be concluded that the study was of great value.

5.2 Individual case presentation

This section will be characterized by an introduction to all four participants. A brief background will be provided on each. Pseudonyms were selected for or by the participants, in order to ensure confidentiality.

5.2.1 Davey

“You comply because you want to get better.” Davey (2002)

Davey is a soft spoken withdrawn twenty year old individual. She was able to express her feelings honestly especially if she was able to trust.

Davey seemed to have known a life of hardships, rejection, turmoil and suffering. These very situations made her stronger and empowered her to cope with the extremes that life brought her - like her diagnosis.

She became very ill in the middle of 2001. A low red blood count, dizziness, pains and weakness characterized the onset of her condition. She was referred from her local hospital in the northwest of the Limpopo Province to her nearest secondary hospital for further medical attention. Three hospitals later, she was introduced to the medical oncology team at the Pretoria Academic Hospital in September 2001. Every transfer from hospital to hospital took her further away from her home and those she loved and cared for i.e. her family, her one year old son and specific friends.

She was not prepared for the immediate treatment, the impact thereof and the long hospitalization that was necessitated. She was diagnosed with acute lymphoblastic leukaemia (ALL). Her entire hospitalization and treatment included a range of chemotherapeutic substances such as Daunorubicin, Vincristine, L-Asparaginase, Methotrexate, Cytarabine, Cyclophosphamide, 6-Thioguanine, 6-Mercaptopurine and

Prednisone. This was administered at the appropriate treatment phases respectively or in combination.

Since September 2001, Davey had been admitted to hospital six times. The first two hospitalizations she was admitted for 60 and 40 days respectively. The treatment process was tremendously difficult for her as she was uprooted and far from every one. Regardless of the sudden disruption of her life she was very co-operative with staff right through her entire treatment process. During her first month at the Pretoria Academic Hospital signs of her longing for her family and her withdrawal were interpreted, by her medical doctor, as depression and she was started on anti- depressants.

Davey exhibited a strong drive to cope with her condition. It is with immense sadness that it is mentioned that Davey had been diagnosed with central nervous system acute leukaemia relapse after the interview. She is now considered terminal.

5.2.2 Aryal

“You have no choice. You must just go through it.” Aryal (2002)

Aryal a thirty-year-old male, married to a foreigner is the most traveled and cosmopolitan of all the participants. He was born in South Africa. He grew up under very difficult circumstances characterized by delinquency (from school at an early age), family stresses, substance abuse (all legal and non- legal drugs) and then finally about three years ago he settled down in a Middle Eastern country. Despite this, he grew up as a very privileged individual with regard to financial security and material possessions. He always had the resourcefulness to maintain a good standard of living through family support and “connections”.

In 2000 he suddenly became ill and was diagnosed in the country where he was residing in. He was then married for three months. As a result of his South African citizenship he had to return for treatment. His family acquired accommodation for his wife and himself whilst residing in South Africa. They also fulfilled his material needs like providing him with a microwave, videos, games, food, etc., whilst hospitalized. This all assisted in making his hospitalization processes more bearable.

Aryal relayed that when he was diagnosed with acute myeloid leukaemia (AML) and came to the Pretoria Academic Hospital for treatment, he did not know what to expect. He knew only that he had leukaemia and had to be helped. He had no impression regarding leukaemia, that it was cancer and also no information regarding the treatment he was to receive. With admittance he continually informed all staff that he previously abused drugs. He thought that his drug abuse was the cause of his condition.

Information regarding leukaemia was provided to him. He was, however still in denial that it was cancer. At this time he was placed on anti-depressants due to his emotional state.

Being diagnosed with AML he received Daunorubicin, Ara-C and a stem cell transplant. As a patient of Pretoria Academic Hospital he had been admitted six times, all of which had been long term hospitalizations.

He first understood the implications of his diagnosis when he was confronted with the side effects of his treatment. He then only realized the severity of his condition. This contributed to his difficulty in coping with his condition during hospitalization.

From participant observation and documentation evidence it was noted that Aryal had great difficulty in coping at certain times during hospitalization. Due to his resourceful nature, he made several attempts to make this hospitalization process easier to deal with.

He was also well liked by staff and could benefit from privileges that other patients could not benefit from.

Aryal is currently in remission and travels on a regular basis to South Africa for his appointments. He is doing well.

5.2.3 Jewel

“Isolation: you get (sic) a lot of private time...Isolation and hospitalization felt like the end of the road.” Jewel (2002)

Jewel is a thirty four year old male. With admittance to hospital he was married for only two months. He had two children that were born out of wedlock. In his lifetime as provider of his family he had been unemployed and was struggling with finding work. As a result of these conditions he was residing with his parents who assisted in maintaining himself and his family.

Jewel resided in the Limpopo province. He also had a long tiresome journey via transfers between four hospitals. He mentioned that this journey was painfully difficult for him as he had to leave his family behind.

His initial suspicion regarding his condition, characterized initially by breathing problems, was that his smoking caused it. He realized the seriousness of his condition when he was transferred to other hospitals. His immediate suspicion was that he was HIV positive. He thought he had Aids as a result of the life-style he lived at that time.

At the time of the diagnosis of leukaemia and his referral to Pretoria Academic Hospital he was not prepared for the long hospitalization, the separation from his family and the tremendous impact of the treatment. He felt that information prior to his hospitalization would have helped in dealing with his situation. He was diagnosed with acute

lymphoblastic leukaemia (ALL) and received similar treatment as outlined for Davey. His initial admittance was in August 2001. Since then he has been admitted eight times. The first two hospitalizations exceeded a month. Jewel is currently in the maintenance phase of treatment and follows up at in a regular basis at the Pretoria Academic Hospital.

5.2.4 General

“...my stuff works with God...I respect and accept rules and regulations. I don't have any problem being in hospital and following the rules.”

General (2002)

With a keen sense of military precision and discipline General orders his life. General is thirty-three years old, married and has two children. His subordinates regard him as a good leader.

General explained that prior to the onset of his diagnosis he developed swollen glands. He felt powerless. This was transcribed into feelings of weakness, dizziness and an inability to fulfill functions. As a result of this he thought that he was HIV positive. His friend died of Aids previously with similar swollen glands. His friends also thought that he was HIV positive. He requested several HIV tests to be performed, as he did not believe the results when it proved negative. He was also transferred via several hospitals, from the Limpopo province to receiving treatment at Pretoria Academic Hospital.

He was diagnosed with acute lymphoblastic leukaemia (ALL) and therefore received similar treatment as Davey and Jewel. At the time of the interview, it was only his second long-term hospitalization. His first admission was from June to August 2002.

General claimed that he felt much better after treatment than before his treatment. He did not experience any difficulty adapting to the hospital setting. He only missed his family as he did not see them often.

General is currently still undergoing intensive treatment for his condition.

5.3 Data presentation

As it was explored in the preceding chapters, components were identified to represent the findings according to the structural linear analytical approach. It was highlighted that the dependent variable was divided into three components, the biological and environmental, social and psychological. Each of these components was explored via numerous themes. Data received from the unstructured interviews with all participants were presented as according to these components and their respective themes.

5.3.1 Biological and environmental components

The themes listed for these components referred to the impact of the diagnosis, treatment and the medical setting on the participants.

5.3.1.1 Biological components

This component encompassed five themes identified from the literature review. Themes that were represented were losses and discontinuities, fatigue and weakness, independence and dependence, issues relating to intimacy and physical integrity. The effects of the biological impact of the disease on the four participants were measured.

5.3.1.1.1

Losses and discontinuities

All of the candidates experienced a diversity of losses and discontinuities as a result of the onset of the disease i.e. not just being labeled with a diagnosis but also the impact thereof.

Davey's onset seemed to have had a dramatic impact on her life. The sudden onset was characterized by dizziness at school, back pains and nervousness. Apart from this she acquired a yellow skin colour, which was an immense shock for her. Her physical bodily changes resulted in her being rejected, treated differently and treated like an outcast. She experienced this rejection from family, peers and others within her community. This resulted in the loss of peers and support based purely on her overt physical changes. She also defined that she experienced a loss of being of value, as she was ill. This was even more reinforced due to her family treating her like an invalid. Accordingly, they took over the care of her child. Her family and peers' reactions towards her caused her to feel devalued and of no or limited importance. It resulted in her questioning her body image, self-concept and self worth. This physical impact of the onset of her illness co-operatively led to a loss of self-concept, body image and bodily integrity, wellness, health, loss of education, roles, responsibilities and functions (particularly pertaining to motherhood).

The biological impact of the onset of an acute leukaemia diagnosis rendered Aryal unemployed and ill. Furthermore, he could not receive medical treatment in the country where he was employed and had to return to South Africa. He therefore had to be uprooted. Aryal admitted

that his perception of his diagnosis was not that he had cancer. As a result, he had limited concern regarding his real condition. He knew he was ill and needed help. His greatest concerns were safety and security as he lived previously in a country with where there was no crime. Apart from the above his disease also rendered him helpless and dependent on others.

Jewel felt the impact of an acute leukaemia diagnosis and hospitalization was massive. He experienced losses regarding autonomy and independence due the onset of the illness. Loss of opportunities, functions and roles were also major losses for Jewel as a result of the diagnosis.

The biological onset and impact of the diagnosis made General feel powerless. This powerlessness, according to General, referred to the fatigue and weakness experienced prior to his diagnosis. He experienced periods where he was unable to fulfill certain tasks. The major loss caused by this diagnosis was the inability to fulfill the tasks and requirements of his occupation. It must be pointed out that General had a survival mentality that enabled him to cope with adverse difficulties. A minor loss that he noted was the lack of contact with family, as he had to come for treatment far from home. His physical integrity was also challenged from the onset of the diagnosis as a result of swollen glands. This changed body image resulted in him being labeled as having Aids. Apart from the above Jewel and General were able to identify positives as a result of the diagnosis, treatment and hospitalization.

To Jewel positives were that he stopped smoking and drinking. In fact as a result of hospitalization, consistent behavioural changes occurred. He became more spiritual and prayed more. Conversely he affected and maintained major life-style and behavioural changes. General considered it positive that his health and condition improved as a result of the efficacy of treatment.

5.3.1.1.2

Fatigue and weakness

Fatigue and weakness seemed to have emerged in three of the candidates as routine side effects of the medical treatment. It was only General who denied any fatigue as a side effect of treatment. He however experienced this fatigue and weakness prior to being formally diagnosed with acute leukaemia. The fatigue therefore experienced by General was as a result of the onset of his disease and not the side effects of treatment.

All three the other candidates described their fatigue and weakness experienced as a result of the side effects of treatment as extreme. The prevalence of it rendered them helpless and dependent on others for assistance even in fulfilling basic tasks.

Aryal experienced a great deal of frustration as a result of the dependence it fostered.

It not only fostered dependency for Jewel, but also a change in sleeping patterns. An increase in sleeping time occurred, necessitating him to sleep during the daytime as well. He had difficulty in accepting this pattern change, as it was foreign to him. He however had no control over these physical and biological demands. The greatest frustration

associated with this, was the long recuperation necessary to recover from this fatigue and weakness.

From the above it would seem that as the participants experienced an increase in fatigue and weakness with an increase associated with losses, dependency and feelings of hopelessness and helplessness. This resulted in a decrease regarding feelings of autonomy.

5.3.1.1.3

Independence and dependence

As could be noted from the first two themes discussed, it became evident that dependency automatically emerged as a result of the impact of a leukaemia diagnosis, the treatment and the hospitalization. The difference and diversity were with the perception of the participants regarding dependence.

Davey and General both indicated that their dependency on staff during hospitalization was not a problem for them. Davey saw this dependence as good as the staff's intentions were to help to make patients feel better. General stated that he had no problems with dependency. His motivation was that he accepted and respected rules and regulations.

Aryal stated that it was as a result of his weakness that he was forced to become dependent on staff. This was especially frustrating and difficult to accept, as he felt helpless. He indicated his loss of autonomy and control as a direct implication of his dependency.

Jewel stated that as a result of the impact of treatment and his weak general condition he became dependent. Dependence felt bad to him as he thought that he was dying. He also felt that the staff's intentions were

not honourable. He felt that staff harboured feelings of pity hence their willingness to help him. He however had no choice but to accept it.

It would seem that dependency, which emerged, might be associated with fatigue and weakness or even just the impact or the result of treatment. Helplessness and a decrease in feelings of control and autonomy in this regard were also noticed.

5.3.1.1.4

Issues relating to intimacy

It must be stated that all humans have diverse conceptualizations of intimacy. Intimacy may therefore refer to sexual and non-sexual contact or relationships, as were interpreted by the participants.

Davey indicated that she had no interest regarding intimacy as a result of the termination of her relationship with the father of her child prior to her diagnosis and as a result of the impact of the treatment. She also felt intimacy to be impossible due the biological and physical changes she experienced. This referred to the changes influenced by the diagnosis and side effects of treatment. She was also adamant that the hospital setting did not provide the right scenario or atmosphere for intimacy to occur between couples.

The diagnosis and treatment affected Aryal totally. Before his diagnosis Aryal and his wife had an extremely physical relationship. His diagnosis and treatment did not allow for any intimacy especially within the first two months of treatment. Biologically it was also more difficult to attempt to establish sexual intimacy. As a result he felt inadequate and a failure for not maintaining his standard of sexual functioning. This led

him to question his functioning and value. He also referred that the rooms were not very private which also did not allow for or fostered intimacy. He admitted to having sexual intercourse with his wife whilst he was hospitalized. The love making process was rushed due to the fear of being caught. What he appreciated the most was that special arrangements were made for his wife to stay over. This as well as his wife being with him, the hugging, kissing, caressing and other forms of affection added to their relationship. He suggested that the hospital or ward staff should encourage this with all patients.

Jewel never had his own family visiting him from the Limpopo province and as a result he could not comment on the privacy and intimacy in the hospital. He however admitted that he missed his wife intimately whilst hospitalized. He was however able to be intimate with his wife after being discharged, once he recovered from his fatigue and weakness.

General stated that he appreciated to just be with his wife and child when he was in isolation. This was all the intimacy he required.

It therefore seemed that family contact experienced whilst and during hospitalization were not only beneficial for patients, but also added or maintained relationships with significant others.

From this evidence it can be concluded that the impact of intimacy on the participants were massive as it either contributed or minimized their relationships.

5.3.1.1.5**Physical integrity**

All four candidates experienced some sort of physical impact as a result of the diagnosis and treatment.

Davey expressed that she was very angry regarding the overt physical changes before and after treatment. This resulted in her being rejected.

As a result of the treatment she experienced hair loss and weight loss.

Significant others assumed that she was diagnosed with Aids. Due to the pain of being rejected and her attempts to contend with a changed unacceptable body image, she not only withdrew from others but also questioned her self-concept and self-worth. Later she also expressed anger as a result of the added diagnosis of epilepsy, which was difficult to control at first.

General' s swollen glands, his weakness and his feelings of powerlessness reinforced others to believe that he had Aids. The treatment only caused minimal weight loss and a loss of appetite. He felt more positive of his treatment as it made him look and feel better. His physical integrity was restored as a result of the treatment. The glands disappeared and did not experience any hair loss. The biggest challenge for General occurred before treatment and not after. As a result of the good physical response that the treatment caused, his significant others were shocked, as they did not expect him to be alive, but readily accepted him back.

Aryal' s weight and hair loss was a shock to him as it contributed to him having a poor self-concept. These losses also reinforced the severity of

his condition. He also felt less attractive. This with his diminished sexual drive and functioning were major obstacles to overcome for him.

Jewel's accepting nature assisted in accepting his physical changes of hair and weight loss. The effect of the above could particularly be seen in the reactions of his peers. They felt sorry for him. They were also shocked and thought that he was dying of Aids.

In all four cases it would seem that an internalization of the physical changes also occurred. This internalization and the unfavourable reactions of others regarding their physical appearances affected them tremendously. Apart from this the inability to resume normal functioning due to the biological impact of the treatment and hospitalization also compounded the negative aspects which they internalized. In other words they felt and looked different. As a result they now had to change their self-concept, against their will.

5.3.1.2 Environmental components

These themes highlighted the impact of the hospitalization process on the four participants. This therefore referred to the effect the independent variable i.e. a diagnosis of leukaemia had on patients whilst hospitalized. All the possible influences of the above were explored. Themes that were explored via unstructured interviews, documentation and participant observation were transplantation from familiar to unfamiliar, isolation and feelings of abandonment, loss, privacy and intimacy, quality of life, safety and dignity.

5.3.1.2.1**Transplantation from familiar to unfamiliar**

All four candidates were forced from familiar circumstances to an unfamiliar environment. They were all from places not readily accessible to Pretoria. Two of the participants (General and Aryal) had relatives in the surrounding areas that could provide some sort of assistance during hospitalization. Each experienced this differently.

Davey expressed anger and helplessness as a result of being transplanted.

She was also sad, not only as a result of the compelling separation from loved ones, but also the distance that she was transplanted from them.

They were therefore unable to visit her during hospitalization. The routines and life style were also different from what she was accustomed to. She received little preparation regarding what to expect and was forced to adapt to a strange environment, routines, food, cultures, etc.

This new environment which she was confronted with caused her to think a great deal of death and the dying process. She thought she was removed from her family because she was dying. The environment was a constant reminder of death but also contributed to the experience of continual fear. This fear related to her dying alone and separated from family. The food served in hospital were the biggest point of frustration for her as it not only encompassed the painful separation from loved ones, but also represented the loss of her culture. The food she considered to be unfamiliar and inedible.

Aryal stated that during the first months of treatment he did not mind the transplantation as he knew he needed help and had to be hospitalized. He claimed that it became very difficult later. Aryal and his family were

financially secure. As a result, his support system could ensure that he was comfortable in the ward. This they did in fulfilling all his basic and higher order needs that also involved providing him with luxury items like having his own microwave in his room, etc. All this cushioned his transplantation into the hospital environment and facilitated the adaptation. To him his adaptation was without event or obstacle. From participant observation and documentation it would seem that he encountered some difficulty whilst hospitalized. At these times he utilized his resourcefulness in establishing his autonomy again. He was also emotional when he was admitted, initially and received anti-depressants.

Jewel also stated that he had to adapt to his unfamiliar environment as he had no choice. A big struggle for him was the food that was served. The meals impressed him to be in favour of patients who had a westernized culture and not geared at the needs of the majority. He also stated that his transplantation was via four hospitals. During this time almost two months elapsed and no one informed him about what to expect until his admittance at the Pretoria Academic Hospital. He felt lost and alone due to the limited contact with family. Due to the lack of preparation for this new environment in which he had to spent a great deal of time, he had difficulty adapting to the new routines that he was confronted with.

General also verbalized his disappointment regarding the quality and quantity of the food served. He however expressed no concerns regarding the unfamiliar environment. He claimed that he was able to adapt, adjust, that he respected and accepted the rules. It would seem that his military

background contributed to his coping in strange and diverse environments. To solve his food problems his brother supplied him with accustomed food, on a regular basis.

The transplantation could therefore be seen as extremely difficult and stressful. This transplantation also gave rise to a great deal of fear, concerns and self-doubt. Two candidates indicated that their adjustment process had not been so difficult. This could be seen as a result of family support, resources or personality strengths. All four candidates expressed their displeasure regarding long-term hospitalization and the food that was served.

5.3.1.2.2

Isolation and feelings of abandonment

The geographical distance from home, loss of family contact and unsatisfactory food influenced and reinforced Davey's withdrawal and feelings of rejection. This made her to feel alone, unhappy and sad. The sudden onset of her condition resulted in an immediate disruption from her life. As a result she was not prepared. It also fostered feelings of isolation and abandonment. The actual isolation process i.e.

hospitalization reinforced the seriousness of her condition and as a result the belief (which significant others had prior to her hospitalization) that there must be something seriously wrong with her. Hence the rejection from others made sense and received real influential and traumatic dimensions.

Jewel and General admitted that they had experienced feelings of abandonment whilst hospitalized. For Jewel this was particularly

evidenced when family that resided near Pretoria refused to visit him.

Even though he understood that his own family could not visit him due to the geographical distance, he still felt alone. When General experienced these feelings he read the Bible and prayed. He also suggested that talking to others about these feelings helped.

Aryal admitted that isolation was difficult but denied that he experienced feelings of abandonment. He had a number of visitors during hospitalization. When his wife would return to her country of origin he felt very alone. It was at these times that he would attempt to re-establish his autonomy.

The above indicated that feelings of abandonment increased as there was a lack of family contact. This seemed to be a definite aggravating factor in contributing to the experiences of the hospitalization process.

5.3.1.2.3

Loss

As was stated earlier losses occurred as a result of an acute leukaemia diagnosis and the hospitalization process.

Environmental losses that were experienced by all candidates were as a result of the transplantation from familiar to unfamiliar environment.

This transplantation not only demanded their adaptation but also the loss of an accustomed environment, life style, familiarity and the freedom to do as desired. This new environment demanded compliance to a new set of rules and routines to which they had limited or no control.

Davey stated that it was particularly difficult to accept the distance that she was separated from family and friends. This new environment caused

her the loss of mothering her child. It also caused her to feel alone as she lost her cultural identity and therefore her support base. Whilst hospitalized her cultural identity seemed to be of no importance or value. She also found herself devoid of any constructive activity in this new environment. Most of her social roles of functioning determined by her familiar environment were lost or temporarily discontinued whilst in the hospital environment. Her vocational desires could also not be fulfilled as a result of hospitalization. This new environment also deprived her of support, which she so much needed. This deprivation of the support was as a result of the distance from home.

Aryal maintained that he did not experience a great deal of losses generally. However the disruption the onset of the diagnosis caused, received mention. There was a definite loss regarding his accustomed and carefree lifestyle. He lived in the lap of luxury and in a world that was not marred by crime. It was therefore not just an occupational loss that he experienced which resulted in his loss or discontinuation of roles regarding responsibility. It was during this time that his wife had to carry the entire financial burden. The loss of life style resounded in the loss of social functioning, the loss of security and safety. Receiving treatment in South Africa increased his level of fears. Aryal had more contact with his family whilst hospitalized than before his diagnosis, hence the view that support and communication improved after the diagnosis of leukaemia.

As with Davey, Jewel's physical and geographical separation from family, friends and the familiar seemed to be the most affected as a result of being transplanted into a hospital setting. His diagnosis and treatment

forced him to adapt to a new and strange way of relating to his significant others. This new environment also caused dependency and for him to miss occupational opportunities that could reaffirm independence and self-worth. The environment caused and reinforced feelings of helplessness and that there was something seriously wrong with him.

This environment therefore bestowed, reinforced and reaffirmed his sick role. This hospital setting also facilitated the loss of privacy and dignity.

This he motivated by the disrespect he received as a patient. He likened this to being treated like a child. But for Jewel the hospital setting also brought positive changes into his life. He stopped smoking and drinking, stopped his flirtations with women and started to worship God.

General claimed to have experienced little difficulty in adapting to the hospital environment. He equivocally informed the interviewee that he appreciated and respected rules and regulations. Regardless of this compliance with the treatment process, certain losses were also facilitated. This could be described as the losses of fulfilling and maintaining occupational requirements, his roles and responsibilities regarding his family life. Separation from his family for a long period of time was however not out of the ordinary for him and his significant others.

Numerous losses therefore seemed to have been experienced due to long and frequent hospitalizations. Apart from the above Jewel and General were able to identify positives as a result of the diagnosis, treatment and hospitalization. Aryal received more contact from family and communicated more with them than before.

5.3.1.2.4

Privacy and intimacy

Aryal expressed that privacy was really not evident in hospital and resulted in decreased intimacy with his wife. They were however able to have some intimate contact whilst he was hospitalized. The quality of the intimacy also became affected due to the fear of being caught.

Davey, Jewel and General all felt that privacy were not violated and that it was not a major issue for them. All three in fact appreciated the disturbances. Without these disturbances they felt alone.

At this point we need to consider why some patients wanted the disturbances. Could it be as a result of a lack of visitors, personality or culture? Does this also imply that if they had significant others with them more frequently that they would actually then want more private quality intimate time?

For General separation from his wife did not affect any quality regarding intimacy, as part of his job often was far from home for long periods of time. Separations from his wife as a result of hospitalization was therefore not out of the ordinary.

All participants had however indicated that some bodily functions and activities which they thought to be private previously was treated as public knowledge whilst hospitalized. These aspects referred to fluid in- and output, passing of stool, the nature of the stool, bathing demands, etc. This caused some sort of embarrassment for the participants. Jewel seemed to have been the most affected by this. It should be noted, as indicated by Jewel, whom the individuals were that asked this considered private information i.e. males or females, the manner in which the

information was requested, the reasons given for the necessity of this information, where and when this information was requested i.e. in private or in the presence of others.

Privacy and intimacy seemed to have been affected as a result of the impact of the diagnosis, treatment and the hospitalization process. It should be questioned whether the participants were informed and prepared regarding the nature of private issues to be asked, with admittance.

5.3.1.2.5

Quality of life

All four participants agreed that during hospitalization their quality of life was very poor. This was largely as a result of being fatigued, weak, helpless and dependent on others for basic needs. All the participants except General indicated that they experienced frustration as a result of this decrease in quality of life. After the alleviation of the impact of treatment and its side effects, their quality of life also improved, as they were able to resume some activities which they had discontinued when diagnosed, as a result of the side effects of the treatment or a result of hospitalization. They also indicated that as a result of hospitalization their lives were put on hold. Jewel stated that his diagnosis and hospitalization meant lost opportunities. The three participants, Davey, Jewel and Aryal, indicated that it was the lack of activity and the general lack of energy to do things for themselves that depleted the quality of life. General experienced minor effects regarding his quality of life. His motivation was that he understood the reason for his hospitalization and

the reasons for his weakness. He accepted it and as a result could cope with the demands.

Davey specifically indicated that even after discharge her quality of life did not improve, as others would treat her differently because they believed her to be bewitched and HIV positive. This resulted in her withdrawing and living a less purposeful life.

All candidates stated that the first cycle of treatment and hospitalization were the most difficult. Quicker adaptation after this was easier. This did not mean that the quality of existence within the hospital improved.

Improvement could be noticed at home when they were able to resume some part of their normal activity. Jewel however expressed that the resumption of normal activity was frustrating, as the adjustment process was long. As a result the quality of life did not restore to normal after immediate discharge.

It was evident that the quality of life seemed to be totally affected by not only the impact of the diagnosis and treatment but also as a result of hospitalization. It was evident that hospitalization reinforced and compounded the effects of treatment.

5.3.1.2.6

Safety

Davey acknowledged that she felt imprisoned, as she could not leave the room once in isolation. She was concerned regarding the safety of treatment as it could result in death. Isolation compounded her fears regarding death and fostered even more questions regarding her safety as a result of her diagnosis and treatment.

Aryal also acknowledged that he felt captive during isolation as a result of all the restrictions. Safety issues that he experienced were regarding treatment, the side effects and personality clashes with despondent staff. He stated that as a result of this personality clashes he questioned the staff's reliability in offering him the best possible service. As a result he did not feel safe if certain particular staff members were on duty. He would oversee their tasks and responsibilities. Regarding the treatment, he expressed his confidence. He was however fully aware that the side effects of treatment may also be lethal. Apart from this safety aspect he was also concerned regarding the safety and security of being in the context of South Africa.

Jewel also felt as if he was imprisoned. He had numerous fears whilst in hospital as staff were too busy. He felt compelled to oversee their duties and tasks as he feared that they could do something wrong and endanger him. Apart from this he also feared that the staff's busyness and the treatment could result in his death. He claimed to never have felt totally at peace or safe during hospitalization.

General was in opposition to the above. He did not feel captive during isolation or hospitalization. He claimed he understood the necessity of hospitalization. He in fact stated that he felt very safe in the ward. Once again acknowledgement of differences has to occur. In specific, consider the existential factors, which affected General.

It would seem that safety issues could be affected by a number of factors like the fear of death, attitude and busyness of staff, the side effects of

the treatment and the fear of treatment and hospitalization and the safety within a crime society.

5.3.1.2.7

Dignity

Three out of the four participants felt that their dignity was affected. This they claimed was especially noted in the manner the staff communicated or performed certain tasks.

Aryal claimed that he was stripped of his dignity by staff he had personality clashes with. They apparently disrespected him and treated him like a child. He felt that his dignity was particularly affected when he had to be dependent on staff as a result of fatigue or weakness.

Jewel also indicated that the manner in which staff asked questions that he considered private or when they bellowed orders to him was dehumanizing. It made him feel like a child. It was extremely difficult and painful. It took a great deal of restraint and acceptance to allow this not to affect him too much.

General stated that he did not experience any violation of his dignity. It must however be stated that General's attending doctor infantilized him by apparently shouting at him. He however could deal with this very effectively. It posed no further problems for him.

Davey did not feel that her dignity was affected during hospitalization even though she experienced losses regarding self-worth, fulfillment and culture.

It can be concluded that dignity during hospitalization was affected. The difference was with regard to how the individual participants dealt or handled the violations of their dignity.

5.3.2 Social components

These components referred to all the themes that encompassed a social impact or influence. This referred to the wider repercussions associated with an acute leukaemia diagnosis. Themes explored included stigma, role performance, disruptions and discontinuities, support and losses and cultural or existential factors.

5.3.2.1 Stigma

Aryal and General claimed not to have experienced any stigma from friends and family as a result of their diagnosis. In fact General experienced stigma prior to his diagnosis as it was thought that he had Aids. After his first treatment his physical appearance improved and his friends accepted him back without hesitation. General also mentioned that the onset of his diagnosis was as a result of being bewitched. This and the fact that they thought he had Aids were apparently the only stigma he had experienced.

Davey's stigmatization as a result of her disease had been very painful. She withdrew as a result of rejection by others. People generally thought that she was bewitched and had Aids. This stigma made her to feel unloved and unwanted. Her quality of her life was also severely affected as she now withdrew from others regularly as opposed to her behaviour before the onset of the diagnosis.

This also fostered her to have a less qualitative life, as she did not want to venture out of the safety and the reinforcement of difference that home provided. Jewel painfully conveyed that his diagnosis stripped him of his dignity. People (including friends) thought that he had Aids. They felt sorry for him and gossiped about his appearance and condition. This stigma resulted in him being treated differently. He felt that he lost his privacy, dignity and control of his life as a result of the stigma. Changes in life style like becoming more religious and cessation of previous unhealthy behaviour promoted his exclusion from friends as he was no longer like before.

Stigma therefore seemed to be an inherent result of the onset of a leukaemia diagnosis, as were proven by three of the participants.

5.3.2.2 Role performance

All participants experienced some sort of changes regarding role performances. As a result of the treatment requirements all of the candidates had to discontinue or disrupt previous roles as they occupied a new role of patient whilst hospitalized.

Davey experienced numerous role changes of which her biggest challenge was not fulfilling the role of being the primary care giver of her son. Her family took this role from her. She also lost or discontinued roles relating to her as a daughter, a valued member of her family, vocational and occupational roles.

Aryal felt his biggest loss regarding roles was the loss of occupation. As a result of diminished sexual functioning he also experienced a change or loss in the roles pertaining to sexual functioning.

Jewel identified that he lost and discontinued his roles of husband, father, son and breadwinner as a result of the diagnosis, treatment and hospitalization.

General identified his occupational loss but also the loss of his role of father and husband.

As a result of their diagnoses and hospitalization these participants acquired the role of patients if they liked it or not. Aryal stated that “if you liked it or not that you had to accept it.”

It was therefore noted that the acquisition of unwanted roles like patient and the loss of valued roles were the result of a diagnosis but compounded by the hospitalization process.

5.3.2.3 Disruptions or discontinuities

From the findings it seems that there is a close relationship between losses, discontinuities and disruptions.

Davey identified her disruption of her roles as mother, sister, daughter, and pupil the most traumatic for her. Her entire life changed as a result of her diagnosis but the disruption amplified and continued with long term hospitalization and the commitment to the treatment process. This disruption of her previously ordered life was unwanted. She had hopes and aspirations that were now unrealized and unfulfilled. The separation from her child caused by hospitalization resulted in her absence during his key developments. Their relationship was disrupted. Uncomfortability was experienced when she was reunited with her child. Long-term hospitalization also compounded the inability for her in relating with her family normally i.e. before the onset of the diagnosis.

Aryal and General experienced disruptions specifically regarding their occupations. Their diagnosis also impacted on their accustomed life style. Disruption in the consistency and familiarity of marriage and family life also occurred. The impact of this on both seemed temporary and they claimed that they could adapt to this disruption by resuming normal functioning after discharge.

Jewel stated that he experienced a great deal of disruption as a result of hospitalization. Disruptions were experienced in his roles like father, son, husband and breadwinner. This disruption also filtered down to his lifestyle, routines and friendships. On a positive note, according to Jewel, previous behaviour like smoking, drinking and chasing women were disrupted and discontinued by both the impact of the treatment and hospitalization. These were roles or behaviour that he was glad to discontinue.

Apart from the above all the participants indicated that a disruption in their quality of life, functioning and accustomed self concept were disrupted by firstly the diagnosis, secondly the need for treatment and thirdly amplified by hospitalization. The extremes of these disruptions were experienced during isolation when even more restrictions were placed on them.

It was evident that it was not just the biological onset of a leukaemia diagnosis that disrupted but also the long and intensive hospitalization process.

Hospitalization seemed to amplify the disruption and losses.

5.3.2.4 Support and losses

Davey's overt physical changes as a result of the impact of the diagnosis and the side effects of the treatment caused her to develop feelings of inferiority and

insecurity. As a result she questioned her self-concept and identity. This was influenced even more so by her loss of her social functioning within her family and community. She lost her social roles of being a viable member of her family, as she was unable to perform certain tasks like domestic chores, etc. She was labeled as an invalid. Her social roles of motherhood and the responsibilities associated with it were totally taken away from her. She even had limited input in the upbringing of her child. Apart from the above social losses she also had to give up on any occupational or vocational dreams she may have had, as she had to discontinue her schooling as a result of long term hospitalization. All her peers and the community also rejected her due to their assumptions, prejudices and beliefs. Due to the above losses she found it immensely difficult to establish relationships with others. She also became very distrustful of others. She had however made friends with some patients. Her new found friends at the hospital i.e. other patients became her support. She admitted that she still struggled coming to terms with the losses experienced.

Aryal indicated that he did not experience a great deal of losses. A disruption and some losses did however occur. Apart from discontinuing his accustomed life style and the privileges associated with it, he lost his occupation, as a result of hospitalization. He also lost his sense of safety and security as he had to function in a crime riddled South Africa. This social threat of crime affected him psychologically. His significant others also offered and provided the necessary support he required. This enabled feelings of acceptance, which was a valuable factor for his self-preservation. Support for him therefore fulfilled an important role.

Jewel experienced a range of social losses that affected him tremendously. Because friends and those in the community thought that he was HIV positive he was treated differently. He stated that this difference in their treatment emulated in him losing his right to privacy. He felt as though his dignity was stripped from him. He was also confronted with a change in his peer support. Their sympathy caused him to withdraw from them. He became isolated from them and with support limited to his significant others. Apart from this the effects of the treatment regarding a change in his behaviour also caused more boundaries and differences between him and his social groups. He stopped smoking and drinking, stopped his flirtations with women and resorted to worshipping God. In essence his friends wanted to associate less with him as he had now changed and was considered 'less fun'. His church also thought he had Aids and separated from him. His diagnosis, the regular and intense treatment compliance also caused him to lose opportunities of employment, vocational accomplishment and fulfillment of his role as provider and breadwinner. Apart from this he also lost or discontinued his role fulfillment of son, husband and father during his hospitalization process. In all Jewel defined his social losses to be encompassed by the loss of his autonomy. He felt that he was stripped from everything. Jewel therefore definitely experienced a reduction regarding support. General's powerlessness, fatigue and weakness pre-diagnosis caused him to be unable to perform his occupational and family roles and responsibilities, which he was accustomed to perform without difficulty. Due to his disease presentation significant others thought that he had HIV and as a result treated him as if he was dying. But compliance with the treatment process also facilitated certain losses. This could be described as the losses of fulfilling and maintaining

occupational requirements, his roles and responsibilities regarding his family life. Due to the restoration of physical integrity and appearance i.e. back to normal as a result of treatment, his social group and family accepted him back without delay. He also experienced limited difficulty in adapting back to his pre-morbid life style. It should also be emphasized that General operated in social strata that embraced distances apart from family and friends due to the nature of his occupation. Being hospitalized in Pretoria was therefore not strange to his family and friends. He was fortunate in not experiencing any losses with regard to support.

Support, as can be noted was an important factor during the hospitalization process. As a result of the impact of the diagnosis, treatment and hospitalization two participants experienced extensive losses in this regard.

5.3.2.5 Cultural or existential factors

Davey claimed that she found her strength in God. She felt God gave the doctors the ability to cure her. This belief made it easier for her to accept her reality and to trust the doctors with her life. Believing in God also provided comfort for her when she was in dire need of support.

Aryal believed his family and wife contributed to his recovery. He drew a great deal of strength from them. He also felt supported by them and could therefore continue with the treatment and hospitalization processes. He adhered to Islamic doctrines and found this to assist him in coping through especially difficult times.

Jewel believed that it was his new found spirituality and those individuals who all prayed for him that helped him through the difficult times. His cultural

beliefs did not have any great value for him except when it came to food. He claimed that he did not draw any strength from his cultural beliefs or sought answers from it. Comfort was experienced from those who came to pray for and with him. From his newfound spirituality he found a great deal of strength, which extended to enforce major life changes.

General also believed that his faith in God, prayer and reading the Bible helped him to cope through difficult times especially when he experienced feelings of helplessness and hopelessness. He also received a great deal of support from his church. General claimed that even before a formal diagnosis was made his prophet at church told him that he had cancer. What was even more comforting to him was that the prophet informed him that he would be cured. He also believed in the power of visions. He saw a vision, which symbolized his recovery, hence his ability to be content with hospitalization and his diagnosis. For General it would seem that his visions and the prophet's message were of great comfort to him and assisted him to deal with his situation. He was therefore able to make sense of why he was diagnosed with cancer. He ascribed it to him being cursed. In combating the curse he was required to wear white garments. The above all sustained General with the hope and beliefs that he would be cured.

It therefore seemed that beliefs or hopes in culture, God, prayer, reading spiritual literature and support from others all contributed in sustaining the participants through their difficult time.

5.3.3 Psychological components

These components referred to all those themes that encompassed feelings, thoughts, beliefs and behaviours of the participants regarding the impact of their diagnoses, treatment and the hospitalization. Themes were divided according to interpersonal and intra-personal factors.

5.3.3.1 Interpersonal factors

Themes under this factor referred to those factors that influenced relationships between people. It was explored what influences an acute leukaemia diagnosis had on relationships. Themes explored were support, intimacy, loss of interpersonal relationships and communication with others.

5.3.3.1.1 Support

The support from others was an important component in coping whilst hospitalized.

This was particularly evidenced for Aryal where his family contacts and support from significant others eased his burden regarding adaptation to the hospital environment. His significant others made the process especially easier during difficult times. It assisted in alleviating his emotional state. Here it can be noted that the social support had a psychological impact.

Davey, Jewel and General all had limited or no contact with significant others during hospitalization. This particularly influenced their feelings of aloneness, abandonment and helplessness. Due to this lack of support it was difficult for them to cope with the hospitalization process.

Jewel's and Davey's diagnoses were also a problem, as they could not really communicate this with their families.

General, Jewel and Davey indicated that more frequent and qualitative family contact would have made the hospitalization more bearable. All three indicated that there were times when they needed this input and contact more often.

The psychological dimensions of support can here be noted. With support the participants were able to cope better or handled the hospitalization more appropriately. It also fostered and enabled acceptance.

5.3.3.1.2

Loss of interpersonal relationships

As was stated earlier Davey and Jewel lost a great deal of support and interpersonal relationships with others as a result of the physical changes experienced during the onset of the disease and as a result of the side effects of treatment. Long periods of hospitalization also disrupted relationships.

Friends and family rejected Davey, which resulted in a few individuals who supported her. The most important relationship that was disrupted was with regard to her child. She was unable to fulfill the tasks and responsibilities of her role as mother.

Jewel was faced with a similar scenario. His relationships with his wife, children and family were all affected by hospitalization. Definite relationship losses were experienced with regard to friends and his church. His friends felt pity for him and as a result he had limited contact

with them. His church members all thought that he had Aids and not only gossiped about him but withdrew from him.

General and Aryal admitted that they did not experience any loss of interpersonal relationships. Aryal in fact gained more contact with his family as a result of his return to South Africa, his diagnosis and hospitalization. He also stated that communication improved between himself and significant others.

General missed his family whilst hospitalized. The separation from loved ones was however common to him due to his occupational requirements. After treatment his overt glands disappeared which resulted in his acceptance back by his colleagues, friends and family.

Two participants experienced loss of interpersonal relationships as a result of the onset of the diagnosis. These losses affected them severely during the hospitalization process.

5.3.3.1.3

Communication with significant others

Davey indicated that her communication with significant others was worse after diagnosis than before the onset of leukaemia. This was due to their lack of understanding regarding her condition. She particularly observed this in their manner of treating her or avoiding pertinent subjects like her diagnosis. This was even more evident when her family took over the care of her child as they felt that she was unable to care for him. She felt helpless and as a result allowed them to do what they thought was right. Her long hospitalization also reinforced her limited input on how her child should be raised.

Aryal actually believed that his communication with others improved as a result of this diagnosis. His family and friends drew closer. He was able to express his thoughts and feelings how he pleased.

Jewel admitted that communication changes occurred. He would not see his family for weeks or months. The communication would then generally be telephonically. His parents were able to understand the diagnosis due to their lack of medical training. Difficulty however arose with the disclosure of feelings. Returning home also resulted in his experience of some uncomfortability.

General experienced no changes regarding communication with any significant others. He had been displaced from his family on several occasions and was therefore able to adjust back into the old routines without any difficulty.

From the above it can therefore be noted that two of the respondents experienced severe communication changes which affected their relationships with significant others. Where good support was evident, the participants exhibited minimal difficulty in communicating with others.

5.3.3.1.4

Intimacy

As was stated earlier it seemed that intimacy was affected during periods of separations or hospitalizations.

Davey expressed that intimacy was not considered a viable option during hospitalization. The hospital was not considered to be a place of intimacy.

General felt the contact with his wife and daughter whilst in hospital provided him a great deal of intimacy regarding their bond and relationship. This contact assisted in coping better and reaffirming their affection.

Jewel identified that the absence from his wife was difficult. He missed her in particular.

Aryal was the only candidate that received regular visitation from his wife. This regular contact also fostered sexual intimacy, which he indicated he needed for feeling loved but also to re-established his self-concept of a virile man. He was also privileged as his wife was allowed to stay over in his room. Her closeness and caressing were what made their relationship stronger during that time. He in fact suggested that the ward should explore this in allowing a partner to stay over at least once. This fostered feelings of safety, security and containment regarding their relationship.

The effect and impact of intimacy during hospitalization therefore had bearing regarding maintaining relationships, enabling the coping process, reinforcing support and self-worth.

5.3.3.2 Intra-personal factors

These factors included the themes that predisposed the individual to cope with the impact of their diagnosis, treatment and hospitalization. Themes explored were feelings of hopelessness and helplessness, influence of existential factors, emotional reactions and responses, issues relating to self concept and self worth, loss of autonomy, coping and needs.

5.3.3.2.1**Feelings of helplessness and hopelessness**

All candidates claimed to have experienced the above. Davey experienced this after treatment. The side effects of the treatment like weakness and dizziness forced her to accept help from others. She also had nothing to occupy herself in the ward, which compounded these feelings. In order to assist in the management of these feelings she was placed on anti-depressants.

Aryal was placed on anti-depressants with admittance, as he was considered prone to feelings of helplessness and hopelessness. He was found to be very emotional. He expressed these feelings as a result of the dependency that was fostered due to the side effects of the treatment.

This frustrated him immensely. He claimed that he had no choice but to accept it. This however affected his self-concept negatively. He admitted that he then tried to do whatever he could to regain his autonomy.

Jewel especially experienced these feelings prior to his diagnosis until after his diagnosis. He ascribed this to the fact that he was unsure about what was happening. He felt helpless, as staff at previous hospitals could not inform him of the expected process. These feelings dissipated as he received information and support from staff. Feelings of helplessness prevailed due to the long recuperation time he had to endure.

General also admitted to experiencing these feelings. When he experienced these feelings he prayed and read the Bible. He also claimed, like Jewel, that once he understood the process of treatment it was not difficult to adjust.

All candidates experienced feelings of helplessness and hopelessness due to dependency, separation, lack of information and the lack of self-worth. These were all direct results of diagnosis, treatment and hospitalization.

5.3.3.2.2

Influence of existential factors

Davey asked God what she had done to deserve her condition i.e. leukaemia. Jewel echoed the same sentiment. He also asked God why he had to experience suffering. This referred not only to his diagnosis and the implications thereof but also to his unemployed status, his previous car accident, and his separation from his wife and family. Jewel felt that he did not deserve this diagnosis. He therefore questioned why God was punishing him so severely. He did not consider himself worse than others. To him it seemed as if God was punishing him more severely than He did others. These questions and concerns caused a great deal of panic and fear, and he became scared. He looked for answers, which were left unanswered.

Apart from the above, Davey also expressed her belief in God in guiding doctors to cure her. Jewel, despite his questions, also developed spiritually and drew a great deal of strength from God in coping with his diagnosis and hospitalization. This belief in God sustained him.

General admitted that his existential beliefs in culture, magic, God, prophets, visions and the Bible sustained him through the disease process, the treatment and hospitalization. During times of helplessness and hopelessness, whilst hospitalized, General prayed and read the Bible. He believed it sustained and helped him in coping through these difficult

times. These feelings of sustainment were of God, but were also augmented by prophecies regarding his healing. This with his symbolic visions regarding his cure facilitated and reinforced his hope in being cured and surviving his condition. The support from his church was therefore extremely beneficial. As with Davey and Jewel questioning God regarding their illness, General made sense of why he developed leukaemia. His prophet informed him that he had been cursed. As part of combating the curse and to indicate that he had been cured from cancer, he was required to wear white outer garments. This requirement and answers received, contributed to him being confident regarding being totally cured.

Aryal felt that his Islamic beliefs and the support from his wife and family sustained him through dealing with his diagnosis and hospitalization.

It is therefore evident that beliefs or hope in culture, God, prayer, reading spiritual literature and support from others all contributed to the psychological wellbeing of the participants through their difficult times. Existential factors had a major impact in coping with the acute leukaemia diagnosis and hospitalization.

5.3.3.2.3

Emotional reactions and responses

Davey experienced predominantly anger, helplessness, hopelessness, abandonment and aloneness. These feelings particularly emerged when she was questioning her suffering, when she had to be dependent on the staff, missing her family and when she developed epilepsy. It was

interesting to note that Davey previously stated that dependency was good. However it can now be noted, that dependency had a purpose but caused emotional reactions or repercussions for her. She also expressed a great deal of anger as a result of her physical changes, which were unwanted. Due to her helplessness in this regard, as she could not control it, she felt it best to internalize her feelings and to withdraw from others. She experienced extreme anger when she developed epilepsy during hospitalization.

Aryal admitted that he experienced a range of emotions that at times seemed uncontrollable. He was unable to deal with his internal reality and needed external assistance in coping. It was only through support, the physical presence of significant others, the administration of anti depressants and counselling that he seemed to cope with his diagnosis. General felt that he experienced normal emotions. He experienced anger when he was moved out of isolation. His wife was unable to contact him telephonically. The family thought that he had died. He felt that this stress he could have done without. He also became hopeless and helpless at times. He coped with this by reading the Bible and praying.

Jewel admitted to experiencing feelings of hopelessness and helplessness, anger and fear regarding his safety and that of treatment. He also experienced frustration due to his long recuperation and as a result of his dependency on others.

Various emotional reactions were evident. The extent of the emotional reactions could be seen as influenced by the pre-morbid personality and coping.

5.3.3.2.4**Issues relating to self concept and lack of self worth**

As a result of Davey's physical changes before and after diagnosis and treatment, people rejected her. These unwanted physical changes caused her to be angry and she found it difficult to accept herself. With the change in the body image she had to deal with the change in her self-concept. She no longer felt confident and also started to question her capabilities as her family assumed her responsibilities. This contributed to her withdrawal. She admitted that it was better for her to become friends with patients, as they understood what she was experiencing.

Aryal stipulated that his weight loss and hair loss affected his self-image and concept. He no longer found himself to be attractive. Due to his impaired sexual function he also started to question his self worth.

Although the other losses also impacted on him, a decreasing sex drive and sexual functioning seemed to have had the most impact on his self-concept.

Jewel stated that the change in body image caused him to have feelings of dying. His family and friends were especially shocked at his changed physical appearance. Most pitied him. He felt inadequate, like an outcast and withdrew. His self worth also decreased as result of the lack of functionality, role performance and responsibilities.

General indicated no change in his self-concept. He had been so far the most fortunate of the participants as he experienced minimal side effects from the treatment. He experienced minimal weight loss, which he ascribed to poor eating rather than the effect of the treatment in hospital and no hair loss.

It would seem that every aspect of the diagnosis, side effects and the hospitalization affected their self-concept and self-worth.

5.3.3.2.5

Loss of autonomy

Aryal attempted to deal with his reality i.e. hospitalization by seeking to re-establish his autonomy. He would perform tasks to establish autonomy. These tasks would however not be specific to his role as patient and would at times create conflict between him and the staff.

Jewel experienced a loss of autonomy and as a result complied totally with orders from staff. This he did without question. He saw himself as having no choice with regard to their requests or demands. He considered this a violation of his human rights. This lack of self worth was particularly reinforced in the manner the staff would request things from him and made demands on and from him. His lack or discontinuation of role fulfillment and missing out on employment opportunities also reinforced his lack of autonomy. He felt less valued.

General did not experience any loss of autonomy as he was conditioned to comply with rules and regulations without question. He felt his adaptation had been quick and effective. He readily complied with requirements.

Davey identified that dependency was good as it contributed to the recovery process. With hospitalization dependency was fostered. Her self worth and the ability to perform tasks were therefore affected. She became less autonomous.

Autonomy reinforced self-worth, value and was greatly affected during hospitalization. When a lack of autonomy was prevalent the participants either complied totally (even when their rights and dignity were totally violated) or became self reliant (which staff termed difficult patients) as they attempted to re-establish their autonomy.

5.3.3.2.6

Coping

All four participants felt that they coped with the impact of their diagnosis, treatment and hospitalization. The efficacy and the extent thereof was however a different matter.

Davey felt she would have coped better if she could have been kept busy whilst hospitalized. She felt her belief in God sustained her during hospitalization and to deal with trauma that arose as result of the diagnosis.

Aryal perceived his coping in terms of that he survived the process. Little coping were identified. He expressed that his acceptance of his diagnosis, the necessary treatment and hospitalization assisted him in coping with his situation. He also ascribed a great deal of credit to his wife and family who supported him through his experience.

Jewel felt that he could cope with his diagnosis. He could cope because of his spirituality and his beliefs. Others, like those who visited him whilst hospitalized, also contributed to him coping. He was also able to accept his diagnosis and adapt to the process. He therefore considered himself as a survivor. He summed up his philosophy as that of “...*don't*

complain and don't believe in immediate relief." Patience, strength and endurance were therefore required.

General felt that his coping utilized was to tell God about his experience. This made him to feel better. He inherently also believed that his military training contributed a great deal to his survival in the ward. He also suggested that talking and sharing ideas with others were important as this will assist in feeling better. He also felt that he had the ability to feel at home in the ward.

The manner of coping with the diagnosis and especially during hospitalization seemed to be an individual construct. This was however influenced by pre-morbid personality, beliefs, influence of cultural, existential factors and support.

5.3.3.2.7

Needs

Davey, Jewel and General could identify needs. Aryal said that his family fulfilled his needs.

All three participants indicated a need for better or more culturally specific foods. General pointed out that to buy his own food whilst hospitalized was very expensive. Davey and Jewel also expressed the need for family contact or visitation as often as possible. Added to this, Davey suggested that money should be made available for patients to comply with treatment and also to ensure that family will visit. Jewel also highlighted that if the family was unable to visit that more visitors should be organized by staff to visit patients.

Davey felt that all patients diagnosed with acute leukaemia should receive immediate disability grants as this will assist with the transportation costs and care of their family. Jewel also felt that patients should be informed at their local hospitals as to what to expect as this will help in the preparation of the patient and family.

General suggested that sharing ideas with others could be of benefit. This will assist in the coping.

Some of their needs seemed to be very idealistic as it involves the radical rectification of integral bureaucracies that govern disability grants and policies regarding the process of applications. It will also be difficult to filter the necessary information to peripheral hospitals in order to ensure effective preparation of patients. The food issue will be difficult to resolve as the meals are prescribed by dieticians and have to fulfill in the hospital budgetary constraints.

5.4 Data interpretation

As was indicated in the earlier chapter for this research study variables were identified.

Limited information was prevalent regarding the experiences of patients diagnosed with acute leukaemia during hospitalization hence it was very difficult to predict any correlation between the variables. Hypotheses could not be drawn.

The objective of the study was highlighted as to answer two questions:

- What are the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization?

- Are there any other factors that influence or amplify the extent or impact of patient's psychosocial experiences during hospitalization?

The dependent variable i.e. that which the case study research set out to measure, was the psychosocial experiences of patients during hospitalization. Acute leukaemia was identified as the independent variable. It was hypothesized that the independent variable had an effect on the dependent variable. The nature of this effect had to be explored, described and analyzed, due to limited information that existed prior to the resumption of this exploratory case study research. In the attempt to explore the impact of the independent variable on the dependent variable it was necessary to construct, explain and explore the dependent variable i.e. the psychosocial experiences according to three components, which in turn comprised out of several themes. The general impression acquired from the data measured and presented was that the independent variable had an extensive effect and impact on the dependent variable. This effect measured, pertaining to the four participants, whether positive or negative correlation, was considered enough proof to satisfy the objective of the study as outlined. The second question was also answered and will be outlined later in this chapter.

Consideration of these findings, in utilizing precision pattern matching of the variables as determined by case study research methodology, will occur by firstly providing an overall impression of the information acquired via the three broad components outlined for the dependent variable. Secondly the triangulation of themes as explored under the components will be presented. Themes will therefore be grouped together. Not only will this data interpretation reinforce the research study's objective outlined but also confirm the theoretical applications and value.

5.4.1 Overview of the broad components

5.4.1.1 Biological and environmental components

With a biological diagnosis implications were evident as pointed out by the four participants. The diagnosis of leukaemia resulted in the prevalence, absence or amplification of various themes. It was not possible to stipulate if the impact of the independent variable on the dependent variable resulted in a positive or negative correlation. The specific themes under this component should be considered in exploring the relationship amongst themes. It was however noted that the biological diagnosis amplified or decreased the extent and intensity of the various themes of the dependent variable. Here it can be noticed that the independent variable influence on the other components i.e. the independent variables gave rise to the measured and accounted effects of the dependent variable i.e. the themes listed according to the three components. It is without doubt that it can be assumed that a diagnosis of acute leukaemia had major implications on the participants.

5.4.1.2 Social components

The themes discussed under the social component explored the effects the independent variable exerted on the social aspects of the dependent variable. The effects were massive and impacted on all other facets. These effects also had a great influence on the participants, whilst hospitalized. The results of these findings proved that there was a relationship, positive or negative, between independent and dependent variable. The effects of the independent variable not only impacted the participants biologically but also influenced or affected them with regard to all the themes outlined for the social themes.

5.4.1.3 Psychological components

The independent variable and other components that related to the dependent variable affected the psychological components, be on a inter- or intra-personal level. These psychological themes also in turn influenced the other components related to the dependent variable. These components either aided the coping and adjustment process during hospitalization or complicated it. The independent variable had an effect on the psychological components of the dependent variable.

From the above it can be concluded that the effects of the independent variable i.e. a diagnosis of leukaemia had profound repercussions. This can particularly be noted in information generated via unstructured interviews with the focus on theme exploration.

5.4.2 Triangulation of themes

From the findings presented, correlation between themes existed. Consideration of the relationships, triangulation and the correlation between certain themes occurred. In discussing the above the triangulation between themes will be diagrammatically represented, where applicable. Consult the annexure section for all figures and the table. The diagrammatic representation will be hypothetical, without any statistical value and based on the applicable information provided by the participants regarding the particular themes. This theme triangulation will occur across the various components i.e. the biological and environmental, social and psychological, and therefore not necessarily limited to themes of a particular component of the dependent variable.

5.4.2.1 **Losses, discontinuities and disruptions, role performance and support**

In considering the information it seemed a strong connection or relationship was evident between losses, discontinuities and disruptions, self-concept and support. Losses, discontinuities and disruptions resembled one another. A prevalence of losses, discontinuities and disruptions occurred as a result of limited support. This support was from family, peers and other significant others. A negative correlation therefore seemed to be evident. With the decrease in support participants experienced more losses.

Two of the participants, Davey and Jewel, had limited support during hospitalization. This impacted on the experience and intensity regarding losses, discontinuities and disruptions. With regard to Jewel, Davey and General it was evident that the geographical distance from home and loved ones impacted on the quality of support and influenced the losses. It was based on these three participants that the relationship between themes was represented as a negative correlation as in figure 1. In considering these themes triangulated it was noted that these themes also cut across all components. As was stated earlier the information is tentative and further empirical evidence via scientific inquiry is necessary.

Table 1 depicts the losses experienced with a diagnosis of leukaemia and hospitalization and the various changes experienced by patients once diagnosed with acute leukaemia. This table was formulated by considering all the losses all the participants indicated. It is a generalized overall view of the information provided by the participants.

From all the information received it confirmed that participants had a great deal of losses, discontinuities and disruptions which resulted changes. These changes

were mostly unwanted and encompassed both negative and positive effects of a diagnosis of acute leukaemia, treatment and hospitalization. As Rogers (1987: 481-3) highlighted, individuals are able to cope with their changing circumstances and realities. These participants proved this to be true. Role performances also changed, as losses were experienced. Their old roles had to be discontinued as a result of the impact of the diagnosis, treatment and hospitalization. They had to fulfill and perform the tasks related to a new role namely that of patient.

5.4.2.2 Stigma, physical integrity, losses, discontinuities and disruptions, dignity, quality of life, privacy and communication with others.

Losses, discontinuities and disruptions also had a relationship with stigma. Stigma in turn affected support and the participants' communication with others. As stigma increased or was experienced by the participants so their losses, discontinuities and disruptions increased. As can be noted this indicated a positive correlation as depicted in figure 2. This was based on findings from Jewel, Davey and General.

With the experience or presence of stigma the participants felt less supported. They also had difficulty in communicating with others. The separation from family and long-term hospitalization amplified these experiences for Davey and Jewel, specifically. The triangulation of these three themes may be represented as a negative correlation as depicted in figure 3. With the prevalence of stigma, support decreased. Adequate or effective support seemed evident in the absence of stigma.

Three participants experienced stigma. Aryal was the only respondent who indicated not to have experienced stigma. General experienced this before hospitalization due to the compromise of his physical integrity. Davey and Jewel experienced stigma after their diagnosis, during hospitalization and after discharge. All three these participants indicated that others thought they had Aids. It would seem that as the respondents' physical integrity (i.e. change in appearance either because of the onset of the leukaemia or the side effects of treatment) were compromised, the more readily and overtly they experienced stigma. The change in physical integrity led to an increase in stigma experienced. As soon as the physical integrity normalized (according to standards established by the respondents' significant others and societies) a decrease in stigma was experienced. This was particularly evident with General. From Davey and Jewel it were evident that the prevalence of stigma resulted in a decrease in their quality of life, dignity, privacy and support. Stigma therefore impacted these themes negatively. It can therefore be assumed that a negative correlation seemed to exist between these themes. Stigma was a social theme that seemed to have impacted on the individual not only with regard to social aspects but also regarding all other aspects. This experience was more evident during hospitalization where there was a specific decrease in the quantity and quality of support. This was based on the information provided by Davey and Jewel.

Self-concept and self-worth correlated with physical changes or physical integrity, support, autonomy, stigma and coping.

5.4.2.3 Fatigue and weakness, losses, dependency, autonomy, feelings of hopelessness and helplessness.

Fatigue and weakness correlated with loss, dependency and autonomy. From the findings it was evident that fatigue and weakness experienced resulted in losses, dependency, lack of autonomy and feelings of hopelessness and helplessness.

The participants self worth, self-concept and dignity were also affected. As fatigue and weakness increased so the dependency and feelings of hopelessness and helplessness increased. This in turn resulted in a decrease in autonomy and independence. Figure 4 represents the assumed positive correlation that existed between fatigue and weakness, dependence and feelings of hopelessness and helplessness. Figure 5 represents an assumed negative relationship between fatigue weakness, autonomy and independence.

5.4.2.4 Autonomy, dependence, feelings of helplessness and hopelessness, self worth and role performance

As the dependency increased so the autonomy decreased. Autonomy during hospitalization seemed to have been affected especially when dependency increased. It can therefore be assumed that a negative correlation existed between dependency and autonomy. This is depicted in figure 6.

An increase in dependency resulted in an increase in feelings of helplessness and hopelessness. A positive correlation existed between dependence, hopelessness and helplessness as presented in figure 7. These conclusions were drawn from the information provided by Aryal, Davey and Jewel.

Autonomy could be further linked with the themes of physical integrity, self-concept, self worth and role performance. The lack of autonomy suggested a decrease in the role performance.

5.4.2.5 Abandonment, feelings of hopelessness and helplessness, dependency, losses, quality of life and autonomy

Feelings of abandonment, helplessness and hopelessness were particularly amplified or prevalent with limited support, where disruptions occurred, limited autonomy and increased dependence were evident. All four the participants contributed to this conclusion respectively.

As a result of the above the quality of life during hospitalization was severely affected.

The quality of life of all candidates was affected. This theme had a rippling effect through all the various components of the dependent variable.

Hopelessness and helplessness triangulates with dependency, support, abandonment, fatigue and weakness. All these themes were linked. With the prevalence of hopelessness and helplessness were affected by the lack of support, the increase of dependency, increase in feelings of abandonment, fatigue and weakness. A positive correlation therefore existed between helplessness and hopelessness, dependence, abandonment, fatigue and weakness. A negative correlation was prevalent between support and feelings of hopelessness and helplessness. It was noted that with limited support an increase of feelings of hopelessness and helplessness were evident.

5.4.2.6 Physical integrity, losses, discontinuities and disruptions, autonomy, dignity and self-concept

All participants indicated that their physical integrity was affected. This theme of physical integrity was triangulated with the themes of support under both the social and psychological components of the dependent variable. Losses regarding physical integrity occurred in all categories but specifically under the biological components and with regard to the self-concept, self-worth and autonomy as specified under psychological components of the dependent variable. With the indication of a lack of physical integrity affected the self-concept, self worth and autonomy experienced a negative impact. This specifically related to Davey and Jewel.

5.4.2.7 Interpersonal relationships, disruptions and discontinuities, losses, stigma and communication with others.

Interpersonal relationships triangulated with disruption and discontinuities, losses, stigma and communication with others. It seemed that as a result of hospitalization interpersonal relationships were disrupted or lost. This was definitely applicable to two of the participants. Their communication patterns also changed. Stigma also amplified the losses or disruptions stated previously.

Aryal was the only candidate who could state that as a result of his diagnosis and the hospitalization in South Africa, his support and communication with others improved. He did not experience a loss in this regard. The reason could be that he had now more interpersonal contact with his family than before.

5.4.2.8 Existential factors, support, coping, hopelessness and helplessness

It seemed that existential factors influenced the individual to cope. From the respondents perceptions it was evident that the existential factors had a major impact on coping, especially whilst hospitalized.

Support was the one theme that was prevalent in all the components, which comprised the dependent variable. Support during hospitalization proved important to deal with the transplantation process but also with the impact of the diagnosis. With the decrease in support two candidates became withdrawn. It was also noted here that with limited support during hospitalization, an increase in feelings of hopelessness and helplessness were evident. Social support during hospitalization will also increase the quality of communication between the participants and family.

5.4.2.9 Transplantation, support, coping and existential factors

Transplantation from the familiar to the unfamiliar affected all four participants. This can be triangulated with the themes of support, coping and existential factors. Themes that were not listed but surfaced under this component were issues relating to death and dying, fear, material possessions, comfortability in the ward and food.

It would seem that with the presence of support, the respondents either felt supported or coped better. Pre-morbid personality functioning, the individual's coping ability and the prevalence of existential factors assisted in the participants adaptation and coping with the environmental demands. This was a prevalent theme with all candidates even if it was only the hope of support or family contact at times.

5.4.2.10 Intimacy, privacy and support

Intimacy and privacy seemed to have a correlation. Due to the lack of privacy, intimacy decreased as indicated by Aryal. Intimacy however was also absent with limited visits during hospitalization. The possibility of intimacy was also dependent on the biological functioning of the respondent as a result of leukaemia diagnosis, the impact of treatment and hospitalization

5.4.2.11 Safety and intimacy

Safety themes affected all the other components. Triangulation was therefore possible with most themes. This was possible because safety can be considered as such an integral requirement for all.

There was also a correlation between feelings of safety for intimacy to occur. Imprisonment, staff, treatment, death and dying all affected this safety theme. Fears, death and questions regarding the dying process furthermore influenced feelings of safety and security.

5.4.2.12 Dignity, privacy, self worth and autonomy

Dignity seemed to be triangulated with privacy, autonomy, self-worth and issues that staff could influence. The participants felt that their dignity was compromised when there were no privacy and when staff treated them poorly. Once the dignity was affected it seemed that the self-worth was also negatively affected. This influenced the participants to feel less autonomous.

5.4.2.13 Emotional reactions, dependency, coping, support, existential factors, hopelessness and helplessness

The candidates expressed a variety of emotions that they experienced during hospitalization of which anger, feelings of hopelessness and helplessness were the most common. It could also be noted that hospitalization resulted in a variety of emotions experienced. The pre-morbid personality functioning, their coping strategy and support contributed a great deal to the quality of coping.

The manner in which participants were able to cope with the diagnosis i.e. independent variable and the impact of hospitalization was definitely influenced by personality, existential factors and support.

From the above discussion it could be evident that the independent variable had various effects on all the themes relating to the different components of the dependent variable. Numerous theme triangulations therefore existed. This theme triangulation formed the basis for future research to be explored.

5.5 Theoretical considerations and value of the research study

As can be remembered the objective of the study was to answer the two questions posed, namely:

- What are the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization?
- Are there any other factors that influence or amplify the extent or impact of patient's psychosocial experiences during hospitalization?

The research definitely seemed to have answered the questions highlighted.

From the information acquired by the participants it was evident that a wealth of information was acquired in exploring the psychosocial experiences of patients diagnosed with acute leukemia during their hospitalization process. All possible impacts that could be explored were mentioned. Where possible in this exploration, triangulation, the impact of various themes and possible hypothetical relationships were pointed out. This therefore refers to the first question of the objective that was posed namely: *what are the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization?*

During this discussion it was noted that other factors which influenced or amplified the hospitalization process were prevalent. This referred to answering the second question of the objective namely: *are there any other factors that influence or amplify the extent or impact of patient's psychosocial experiences during hospitalization?* These factors included:

- pre-morbid personality of each individual participant,
- personal coping,
- geographical distances from home and family,
- limited support and family contact during hospitalization,
- stigma experienced as a result of a physical bodily changes,
- loss of identity (personal, physical and cultural),
- losses experienced (referring to the type, quantity, quality and impact thereof),
- inedible food,
- financial constraints,
- lack of activity during hospitalization,

- fatigue and weakness,
- dependency and
- long and recurrent hospitalizations.

As can be noted, the above reaffirms the value of the research as valuable information was acquired from participants. Addition to the knowledge base therefore occurred. The research will therefore be of more value as this knowledge will be utilized for further scientific inquiry to confirm the experiences of patients diagnosed with acute leukaemia and to assist these patients better during their hospitalization process.

Apart from the value of the research and the satisfaction of the objective, reconsideration of the criteria for ensuring quality has to occur.

As was noted, purposeful sampling i.e. of most similar cases, was utilized in selecting the four participants. All the participants were aged between 18 to 40 years, diagnosed with acute leukaemia and had experienced hospitalization. One common factor was that all participants for this study were transplanted far from their homes.

For this study construct validity was ensured as three sources of evidence were utilized namely participant observation, documentation and unstructured interviews. As was pointed out the most value was ascribed to the unstructured interviews with participants, as their psychosocial experiences needed to be explored.

External validity was also satisfied as the information was generalized to the four participants and not to the entire population. Only further scientific inquiry will allow generalization to be

made to the entire population. Replication was also ensured due to the use of multiple cases i.e. four participants.

Reliability could also be ensured as the same procedures were followed with every respondent.

This implies documentation was considered with all participants, informed consent was provided to participants, informed consent was signed, unstructured interviews occurred and participant observation was considered.

It is noted that this research endeavour was of value and successful. It achieved the objective it set out to measure and fulfilled criteria of quality i.e. construct, external validity and reliability. Apart from the above this research study provided a great deal of important information, insight and understanding regarding the tremendous effect and impact of an acute leukaemia diagnosis, treatment and hospitalization.

5.6 Impressions drawn from empirical evidence

The initial impression was that this study was of great value. This was not only as a result of the wealth of information received but also the insight and understanding gained.

From findings it was evident that the diagnosis and hospitalization were very difficult experiences for the participants. From the theme representation it seemed evident that an acute leukaemia diagnosis and the necessitated hospitalization, affected all aspects of the participants.

This research also proved to be valuable as insight and understanding regarding the participants' experiences was acquired. Knowledge for future research and intervention was therefore acquired. Apart from this certain impressions were also acquired.

A diagnosis of acute leukaemia had massive implications on all the participants. The hospitalization process amplified and influenced these implications.

For the participants it was a painful reality that they were judged according to their physical appearances. This refers to the physical changes (i.e. compromised physical integrity) that occurred as a result of the onset of the disease and the side effects of the treatment. Three of the participants experienced this as a devastating reality. It was sad to think that society (which compromised out of significant others) perpetrated this stigma. This was depicted from the findings acquired from Jewel and Davey.

Personality, especially pre-morbid personality functioning affected, influenced or was of benefit in coping or dealing with a leukaemia diagnosis and the demanding invasive life changing hospitalization process. Each respondent utilized their own coping abilities, strengths and routines in dealing with the diagnosis and the hospitalization process. The above contributed to effective or poor coping. What should be noted is that more emphasis should be placed on individual strengths which can be utilized to assist patients with coping during the hospitalization process. It is therefore suggested that the propositions one and two as formulated by Rogers (1987:481-3) receive more consideration in allowing the individual patients to define their own experience and develop their own strategy, with experienced staff's assistance, in dealing with their diagnosis and hospitalization. The individual patient should therefore be acknowledged and considered as an expert in their own coping and psychosocial wellbeing. The participants who partook in this study proved that they were able to cope with their circumstances if allowed to. As supporting staff we should be aware of their inability to cope at certain times, show them unconditional warmth and acceptance through out the process. This as can be noted is in line with the formulations of Rogers (1987).

The dynamic nature of individuals was also noted. This dynamic nature enables the continual adaptation of individuals in adverse settings or conditions.

Apart from the above it was also noted that existential factors like beliefs, culture, religion or spirituality played an important role in assisting in the coping with the diagnosis and the hospitalization process. Existential factors in fact were considered to have a greater impact than the medical information. Traditional treatments, religious beliefs and rituals were perceived to be more potent and of value. This also provided comfort to the participants. The value of these factors in individuals' lives should therefore never be underestimated.

A challenging question would obviously be how to minimize the physical side effects that the participants experienced e.g. the hair loss. Is there any way that we as a medical oncology team can get external stakeholders involved to reinforce a positive body image, provide beauty tips and to reinforce a positive self-image? This will have to be explored.

Regular contact with the family seemed of the utmost in helping with the coping process. Three of the participants suggested that more contact and support from family would have been more beneficial. One participant had a great deal of support, which he indicated assisted him in dealing with his diagnosis and hospitalization. As a result of this he also did not experience any stigma.

Stigma was particularly evident in the absence of support. Based on this information it would seem only prudent of the Department Medical Oncology to explore means of either ensuring the individual patient's own family to visit regularly or to acquire volunteers for visitations. This should however be executed on an individual basis, as not every individual may want these contacts. Further research will affirm the value and necessity of the above for the entire population.

What needs to be considered with the above is obviously the economic, political and geographical factors. This in itself can be indicated as an aggravating factor, which could amplify the hospitalization experiences. As was noted three of the participants' families were unable to visit or even visit on a regular basis due to the geographical distance between home and hospital and economical constraints. The limited contact as a result created major repercussions.

As was also mentioned keeping occupied or busy whilst hospitalized seemed to be of benefit. Added to this was also talking about the experiences. Even though further research is necessitated, the applicability of exploring which activities will be conducive to the hospitalization process and also not place patients at risk should be explored. For this however, the biological limitations that will occur as result of the impact of treatment and individual preferences must be considered. Here once again the application of Rogers' theory regarding the individuals' decision-making and influences were noted.

As one participant indicated, the ability to have had his own possessions whilst hospitalized, assisted in coping and dealing with the entire hospitalization process. It would therefore seem that the consideration of resources and economical circumstances of individuals should be acknowledged before one would encourage this. Not all participants were able to comply with this.

All the respondents pointed out that meals that were served were not always edible. It was very difficult to attempt to solve this as it involves structures of the entire health care sector. Meals were prescribed and cooked according to strict dietary regulations. To accommodate patients will be very difficult. Options in solving this issue need to be considered and explored. It would be good to motivate family's to provide meals to individual patients. The problem existed

where there was a massive geographical distance from hospital. This will therefore not always be feasible. Once again it can be noted that whichever future strategy to be considered it should be individualized. The assistance of private stakeholders in this regard need to be considered.

The respondents expressed a great deal of fear and emotions that they seldom or rarely shared or verbalized with staff during their hospitalization process. It should therefore be considered that fears occupied individuals and as far as possible it should be appropriately attended to.

It is a staggering realization to note that the diagnosis of cancer does not evoke fear as before. This is particularly evident when considering the social impact of the disease. As was indicated by three participants, it was considered that they had Aids. As a result of this stigma that they experienced they were also treated differently. HIV or Aids are definitely more feared. This allows for consideration in how to de-stigmatize cancer and differentiate it from Aids.

Community empowerment is therefore of the utmost. This in itself has financial implications to consider. Consideration should also be given to the filtering of information to primary health care facilities. Here bureaucracy may be a stumbling block.

Intimacy was an important factor for couples. The challenge lies in not only planning for or allowing intimacy, but to cultivate environment for intimacy in the ward and to secure the privacy for couples to explore this. This should not contribute to a sense of perversion.

Confidentiality in this regard is of the utmost. Consideration of risks regarding infection, possible tearing, etc. should occur. Sterility and hygiene needs to be ensured. Undoubtedly it can be concluded that intimacy was difficult to maintain within a hospital setting that violated privacy.

To a very limited extent some positives could be highlighted. In the greater scheme of the diagnosis, treatment and hospitalization, these positives had minimal impact as with regard to all the negatives experienced by these participants.

5.7 Summary

This chapter focused on presenting the data that was acquired from the four participants via unstructured interview, documentation and participant observation. This data was presented via the themes outlined under the three components namely biological and environmental, social and psychological components of the dependent variable. The aim of this discussion was to present the impact the four participants experienced as a result of being diagnosed with acute leukaemia.

Thereafter the data was interpreted according to precision pattern matching as outlined by case study research methodology. It was concluded that the independent variable had an extensive impact on the dependent variable. This effect was furthermore confirmed via theme triangulation. The nature of these themes was also represented diagrammatically at applicable discussions. Consideration of the theoretical implication for the study and the value of the study followed this discussion. It was pointed out that the study was of great value and that both questions of the study's objective were answered successfully. In conclusion several impressions that the study made were offered.

CHAPTER 6

OVERVIEW, CONCLUSIONS AND RECOMMENDATIONS

6.1 Introduction

The aim of this final chapter is to provide an overview of the research study. The various facets that pertained to this study will therefore receive mention. Impressions regarding this exploratory case study research design will also be provided. Here the value philosophy will also receive mention.

After this extensive overview, various conclusions that were drawn for this study will be considered. This discussion will also encompass Victor Frankl's logotherapy (1984) and Rogers' Client centered therapy (1987) in relation to the experiences of the four participants. The final point of discussion will be to offer recommendations in addressing certain issues that stem from the findings for further service delivery. Numerous hypotheses for further research endeavours will be suggested

6.2 Overview of the outlined case study research

This exploratory case study research explored the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization.

Chapter one introduced the reader to the rationale and value of the outlined research study. It was pointed out that due to the uniqueness of the long hospitalization (as a result of treatment purposes) of acute leukaemia patients at the Pretoria Academic Hospital, limited information existed regarding the topic to be researched.

The problem statement involved the identification of the research title, the conceptualization and operationalization of the variables. The **independent** variable was identified as acute leukaemia. The **dependent variable** was identified as the psychosocial experiences of patients during hospitalization. The study set out to measure and explore the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization. The theory that was selected to guide the research was that of Rogers' client centered approach. This was particularly

instrumental with regard to the unstructured interviews conducted with participants.

Logotherapy was also selected specifically for the purpose of contributing meaning to the psychosocial experiences of patients. This will receive further mention in discussing the conclusion of this chapter.

As was highlighted, due to the limited information that was available, it was difficult to draw any hypotheses regarding the relationship that existed between the dependent and independent variable. It was therefore the study's objective to answer two questions. These questions were:

- What are the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization? and
- Are there other factors that influence or amplify the extent or the impact of patients' psychosocial experiences during hospitalization?

The significance and the limitations of the study were also highlighted. The significance of this study was that qualitative data were gathered regarding the psychosocial experiences of the four participants, that insight and understanding regarding their psychosocial experiences were gained, and that this information will be used for further research as well as to foster qualitative intervention with regard to patients diagnosed with acute leukaemia.

The limitations of this study were obviously that only the participants' experiences were considered and not that of their significant others, that the study was representative of the four participants only and not the entire population. Generalizations to the entire population were therefore not made.

The literature review presented information that was largely extrapolated from other cancers and not necessarily that of leukaemia. Both cancer and leukaemia were defined. Information

regarding the treatment process, treatment offered and treatment phases were highlighted. From this discussion it was concluded that a diagnosis of acute leukaemia necessitated immediate treatment that had massive implications on the patients. It was noted that a diagnosis of acute leukaemia involved major life changes and demanded long term hospitalizations.

This discussion facilitated the consideration of the impact of a cancer diagnosis and hospitalization. It was argued that acute leukaemia was a bio-psychosocial disease and as a result affected the entire individual. Hospitalization also had massive effects.

The literature review furthermore conceptualized and operationalized the psychosocial experiences i.e. dependent variable. This variable measured was constructed into three broad components namely biological and environmental, social and psychological components. Each of these components was in turn divided into several themes.

The biological and environmental components referred to the impact of the diagnosis and hospitalization had on the participants. The biological components highlighted five themes that were explored in this study's implementation phase namely losses and discontinuities, fatigue and weakness, independence and dependence, issues relating to intimacy and physical integrity.

The social components of the dependent variable referred to all those themes that influence the participants on a social level. Themes that were explored were stigma, role performance, disruptions and discontinuities, support and losses, and cultural or existential factors.

The psychological components referred to all those themes that encompassed feelings, thoughts, beliefs and behaviour. These themes were presented as either interpersonal or intrapersonal factors.

Themes discussed as interpersonal factors (i.e. the factors that influenced relationships between people) were support, intimacy, loss of interpersonal relationships and communication with others.

Themes discussed under the intra- personal factors (i.e. the factors that predisposed participants to cope) were feelings of helplessness and hopelessness, influence of existential factors, emotional reactions and responses, issues relating to self-concept and lack of self worth, loss of autonomy, coping and needs.

All these themes were explored in terms of the methodology outlined by the case study research. This exploratory case study research considered evidence from four units of analysis i.e. four participants whom were presented via pseudonyms to ensure confidentiality. The delineation of the case study was that it was holistic, embedded and exploratory. It also satisfied construct, external validity and reliability. Construct validity was ensured as the study encompassed three sources of evidence which included documentation, participant observation and unstructured interviews.

External validity was ensured as the findings are only generalized to the four participants and not the entire population. Replication was also ensured as four units of analysis i.e. participants were utilized for this study.

Reliability was ensured as the same procedures were followed with every participant i.e. consideration of documentation, the informed consent was provided to participants, the informed consent was signed by all participants, the unstructured interview was facilitated with all participants and comments from participant observation were sought. The study therefore fulfilled the methodological criteria.

The data acquired was presented via the structural linear analytical modes of analysis. This occurred via themes. After this data presentation the findings were interpreted and further analyzed according to precision pattern matching as outlined by the case study research methodology. It was at this point of discussion that the extensive effects of the independent variable on the dependent variable were highlighted once again. Theme triangulation occurred and where applicable relationships between these specified themes were diagrammatically represented (see annexes). This occurred as general overall predictions between the dependent and independent variables were not possible.

Answering of the questions outlined under the objectives also occurred at this point. The applicability of methodology and findings were highlighted.

6.3 Impressions and value of the exploratory case study research

It is noted via the data presentation that a diagnosis of acute leukaemia i.e. the independent variable had massive effects on the participants. These effects i.e. the psychosocial experiences or the dependent variable were extensive. It was realized that the participants experienced great difficulty in not only coming to terms with a diagnosis of acute leukaemia, but also with the impact of the treatment and hospitalization. From the participants it was drawn that hospitalization had far reaching effects, which in turn, compounded their experiences.

Another aspect that was noted was that support from significant others was of the utmost importance, as it not only assisted the participants but also facilitated feelings of acceptance, coping and self worth. All participants deemed this to be important.

Aids were indicated as the most feared disease. Participants experienced stigma as a result of this.

This research also provided for extensive understanding and insight regarding the impact of a leukaemia diagnosis and their experiences associated with it. The researcher in fact felt privileged and valued that the participants could share their inner most experiences as honestly as they did.

The objective was not only achieved but also the value of the research performed was reinforced. It is with confidence that it can be mentioned that this research study will be utilized as a building block for future, dynamic, valuable and scientific inquiry.

Even more so than what was highlighted, was the individual participant's capacity to cope, handle, interpret and deal with their experiences. There should therefore be more emphasis regarding the individual taking control of their emotional recovery. This should be encouraged as these four participants pointed out they had the capacity to cope with difficult and traumatic situations.

6.4 Conclusions

Considering the information explored, several conclusions can be drawn. These conclusions were with regard to the entire study.

This research was successful in that it answered the two questions outlined under the objective i.e.

- What are the psychosocial experiences of patients diagnosed with acute leukaemia during hospitalization? and
- Are there other factors that influence or amplify the extent or the impact of patients' psychosocial experiences during hospitalization?

Apart from the above, further conclusion can also be drawn with regard to the efficacy of the study.

This research study has proven to be invaluable as a wealth of information was acquired regarding the psychosocial experiences of patients diagnosed with acute leukaemia, during hospitalization. Understanding and insight were therefore gained. This study allows for future research to occur. There was a major and extensive contribution to the knowledge and value base of not only the social work profession, but also all related professions that provide a service to these patients. All that is hoped now is that this knowledge be utilized effectively.

All participants received and acquired the label of a cancer diagnosis that resulted in significant implications. The psychosocial experiences of participants were massive and numerous. A leukaemia diagnosis impacted greatly on all the participants. This impact needs further exploration and consideration.

The participants experienced a great deal of losses, discontinuities and disruptions as a result of their diagnosis, the impact of treatment and the hospitalization process. Most of the changes they experienced were unwanted. Changes referred to that which the participants experienced or acquired as a result of their diagnosis, treatment and hospitalization. These changes were either positive or negative. Table 1 of the annexes section highlights some changes and losses experienced by the participants. Some of these changes included new roles that were acquired for example sick role, patient, helplessness and hopelessness, imprisonment, dependency, etc. The participants felt that they were helpless with regard to these changes.

It must however also be pointed out that positives were also highlighted. These positives emerged as a result of a leukaemia diagnosis and hospitalizations. These positives refer to those factors, which had a positive effect on the participants. Some positives that were highlighted

were the cessation of certain behaviours such as smoking, drinking, womanizing and the development of spirituality i.e. a closer relationship with God. This effect i.e. positives identified, was however minimal in contrast to the extent of the negatives that the diagnosis and hospitalization fostered.

From the evidence it was also noted and realized that HIV or Aids are the most dreaded diseases in our society. Society does not allow for the differentiation between these diseases. As a result participants diagnosed with acute leukaemia were treated as if they had Aids. They also experienced a great deal of stigma and rejection as a result. The participants identified that perpetrators of this rejection and stigma were usually their family members, peers and members of their communities. The filtering of information to our societies is therefore of the utmost importance.

All of the participants were transplanted from their familiar environment. The geographical distances from home were immense. This impacted on the quantity and the quality of support. As was also concluded, support from significant others were what the participants needed most during hospitalization. It therefore had an important role to fulfill. This not only assisted with the coping process but also in enabling feelings of self worth and acceptance.

All the participants' physical and body images changed. This affected them profoundly as they either experienced stigma, rejection, losses, loss of their self-concept, self worth and autonomy. This also affected their right to privacy. Due to the overt changes, people were prone to talk about this, hence the violation of privacy. As could be noted significant others were the biggest perpetrators and reinforces of stigma.

It can be overwhelmingly concluded, based upon the perceptions of the participants, that the food served during hospitalization was inedible. Several reasons may be provided for the above. Participants stated that the taste of the food served in the hospital did not suit their taste preferences. Food was also prepared differently to what they were normally accustomed to. The food served in the hospital and particular in isolation was steam prepared. It therefore lacked salt and other preservatives that enhance flavour. The participants stated that food served in hospital was also less filling. This may be due to the limited starches consumed whilst hospitalized than when at home. It must be remembered that food served in the hospital is strictly according to dietary requirements. Further consideration of this therefore needs to occur. Suitable feasible options in this regard like liaising with dieticians and acquiring assistance from private stakeholders should be considered.

A diagnosis of acute leukaemia and hospitalization also stripped the participants' from their identity i.e. cultural, personal and physical. Changes in physical appearances are the result of the sudden onset of the disease and the side effects of treatment. The participants were therefore challenged with changes in their personal and physical identity. Due to this new setting i.e. the hospital a new set of routines and roles were provided to them. All the participants had no choice but to conform to this new patterns, requirements and environment. Some of the participants experienced this as a new culture they had to operate in. Their own cultural values and familiarity were not important in the hospital setting. They therefore experienced this as a loss of cultural identity.

Fears were always prevalent during the entire hospitalization. This incorporated fears of safety, security, death and dying. The possibility of death and the actual dying process were a constant

reminder for them, especially once they experienced the tremendous side effects of treatment. The participants did not however communicate this regularly to staff, family, peers, etc.

The impact of treatment not only resulted in fear but also in fatigue and weakness. This led to the fostering of dependency. Fatigue and weakness, once they occurred, undoubtedly resulted in heightened dependency. This in turn led to feelings of helplessness and frustrations, as they could not control their dependency.

All participants were not ready for immediate long-term hospitalization. This would therefore suggest that further consideration be explored regarding the phenomenon of transfer of patients from different hospitals and filtering of information to those hospitals.

Hospitalization definitely violated intimacy and privacy in a variety of spectra. All staff need to be aware of this in order not to perpetrate these violations.

Intimacy definitely decreased during hospitalization due to the lack of privacy, limited visitations, the impact of the treatment, fatigue and weakness, amongst other factors.

Quality of life decreased during hospitalization as a result of the impact of the treatment, lack of role fulfillment, life style changes and the lack of activity. A decrease in the quality of life was however expected considering the impact of the diagnosis, treatment and hospitalization.

Feelings of captivity and imprisonment were definitely evident during hospitalization but particularly during the isolation phase of treatment.

The dignity of all the participants was affected. At various points of the hospitalization the participants were all treated like children i.e. they were infantilized by staff.

Coping with a diagnosis of acute leukaemia, the impact of treatment and hospitalization was still individual based and influenced. Each participant's coping abilities were diverse and varied from each other.

Existential factors exerted greater influence than medical facts or assurances. These factors provided meaning and sustainment to all participants. Considering the effects of existential factors one wonders how patients would have coped or reacted without it.

Numerous factors were prevalent that influenced and amplified the hospitalization experience. These were the pre-morbid personality of each individual participant, personal coping, geographical distances from home and family, limited support and family contact during hospitalization, stigma experienced as a result of physical bodily changes, loss of identity (personal, physical and cultural), losses experienced, inedible food, financial constraints, lack of activity during hospitalization, fatigue, weakness, dependency and long hospitalization.

Apart from the above conclusions drawn several important connections and conclusions may be drawn with regard to the theories postulated namely client centered therapy and logotherapy.

As was pointed out, the client centered therapy proposed by Rogers (1987) assisted with regard to the interviewing process. This theory also highlighted the exploration of the individuals' phenomenal field (Morse & Watson 1977: 168). This was achieved in this study.

It can be acknowledged that the participants presented diversity with regard to their psychosocial experiences. Hence the reinforcement of Rogers's (1987: 484-497) two major principles:

- that the individual experiences a continual changing world of which he is the centre of,
- the individual reacts to his phenomenal field as he perceives and experiences it

The experiences of these four participants will now be considered in terms of Frankl's logotherapy (1984).

The four participants were from diverse backgrounds, different ages and had different lifestyles. Their common factors were their diagnosis, the treatment process, and the hospital where the treatment was administered.

All four participants attempted to make sense of their diagnosis and hospitalization process i.e. their suffering. They attempted to find meaning in their experiences. According to Frankl (1984: 121) this referred to the search for meaning as the primary motivation of life. Frankl (1984: 120, 126) believed that even in the most difficult sufferings individuals are able to find meaning.

Considering Davey's account, one received a sense of her immense turmoil and suffering she experienced with regard to her rejection encountered from family, friends and the community, the loss of her vocational aspirations and the lack of fulfillment of her roles. Even though her prognosis is considered poor she finds meaning in being able to mother her child. This refers to her ability to give love and to receive love. Love according to Frankl (1984: 133-134) is one of the means to experience one's purpose in life and to assist with the self-actualization process.

Above all Frankl (ibid.) mentioned that this love also encompasses the essence of the individual to love himself. This can be particularly of value to Davey if we consider the rejection she has

experienced by others due to her physical changes. She herself also disliked her new body image. Accepting the above seemed to have given her a new meaning. For Davey certainly, meaning was not about what life and others can do for her but her worth in contributing to life, her child, etc. This correlates with Frankl's (1984: 20-115) experience where even meaning and the contribution to be made to others and life were encouraged even in the concentration camps. Davey also experienced a great deal of distress and despair, i.e. the experience of the existential frustration (Frankl 1984: 123), when she experienced the inability to fulfill her previous established roles, tasks and functions.

Aryal's searches for meaning were different from all the others. The applicability of Rogers' (1987: 484-487) first two principles should therefore be noted, which stresses that the individual experiences his world and reacts or responds accordingly.

Like with Davey and Jewel, Aryal also experienced the extent of the impact of the treatment on his body image. His changed physical appearance was difficult for him to accept. This caused him to have existential distress (Frankl 1984: 125). Aryal's extensive familial support during this time gave him courage and comfort to endure his sufferings and hospitalizations.

He found his meaning of life and suffering from the love he experienced from others. This therefore was the essence of his existence (Frankl 1984: 133). Aryal had sexual intimacy with his wife whilst hospitalized. Frankl (1984: 134) states that sex is an expression of love. Where love prevails sex is therefore justified. Even though others like Davey may think that sexual intimacy is not appropriate whilst hospitalized, sexual intimacy is a valid expression of love.

Also highlighted from Frankl's (1984: 20-115) concentration camp experience, he continuously thought of his wife. The same seems to be with Aryal. One can therefore assume that Aryal's need for sexual intimacy was the expression of his love towards his wife. His need was also to feel like a virile sexually skilled man as before his onset of his disease and the side effects of

treatment. He wanted to resume and assume his physical role again. By loving his wife and receiving her love via sexual intimacy his needs were fulfilled, his existential vacuum satisfied and meaning restored. This existential vacuum refers to the meaningless void according to Frankl (1984: 129-130). This sexual intimacy during hospitalization enabled his self-actualization process. This self-actualization or self-transcendence encompasses the discovery of meaning in his psyche (Frankl 1984: 133-134). This also enabled hope to prevail with regard to his future meaning.

Jewel, like Davey, also experienced a great deal of losses like continual rejection, employment difficulties, etc. He, as all the other participants, numerously questioned why he had to suffer in the manner that he did. He continuously searched for meaning regarding his circumstances. He also thought that the extent of his suffering were worse than that which others experienced. This could be seen as the existential vacuum and frustration that emerged (Frankl 1984: 123, 128-129). He found meaning in the positives the hospitalization process enabled. Apart from that he also continually thought of his wife and the love they shared. This and his hope of recovery and the contribution he would be able to make to his family, with regard to being the breadwinner and fathering of his children, gave him meaning.

General's strong will to meaning enabled him to accept his suffering and to find meaning regarding it. He is the only one of the four participants that remained fairly positive throughout his hospitalization. When existential problems or frustrations like feelings of hopelessness and helplessness emerged he would utilize his beliefs and hopes to contend with this. These feelings of hopeless and helplessness were his existential vacuum. Frankl (1984: 128-129) stated that this existential vacuum might arise out of boredom. Remembering that the General was fairly

active in his life style but only had limited activity during hospitalization, it would therefore only be logical that this existential frustration and vacuum would arise.

The participants all experienced feelings of hopelessness and helplessness as a result of the dependency they experienced due to the side effects of treatment and hospitalization. It is during this time that it can be said that they have experienced an existential vacuum, as according to Frankl (1984: 128-129). Their essence of existence can therefore be said to be minimal i.e. the quality of meaning (Frankl 1984: 131). The participants all emerged from their despair due to the love experienced or given, the realization of the meaning of their suffering or due to the assistance from existential factors to cope.

Davey and Aryal both received anti-depressants. According to Frankl (1984: 125) it would have been better to assist them to deal with their existential distress than to aid it with substances.

Even though it seemed that the anti-depressants assisted them in dealing with the hospitalization process, the question should be asked if their coping improved due to the anti-depressants or the expectations that it would assist them. Apart from Frankl's postulations it can also be noted that the first two propositions of Rogers' theory (1987: 484-497) also has some valid application as it acknowledge the individual's capacity in dealing with their experiences.

It is therefore obvious that more credit should be given to individuals to define their own meaning to the hospitalization, disease and sufferings. Where an individual may experience an impasse in dealing with their suffering logotherapy's noö dynamics may then be utilized.

Frankl's (1984: 126-127) noö dynamics refer to existential dynamics in polar fields of tension with regard to meaning and the person to fulfill it. This dynamic is a technique in fostering the individual to gain meaning

Apart from the above it also seems evident that Frankl's (1984) theory as well as his imprisonment could be paralleled with the hospitalizations experienced by the patients. In both instances they were 'captive' against their will, had to comply with rules enforced on them, eat horrible food, be tortured in some sense and hope for freedom. The difference was the purpose of the so-called captivity. Frankl's (1984: 20-115) experience was as a result of hate and the destruction of human life based on the notion of pure race. The four participants' hospitalization was as a result of their diagnosis, the intensive treatment process and its implications. Hospitalization's purpose was therefore to save and extend the life of the participants and to provide effective treatment for their disease. Hospitalization and the treatment process, how unwanted and displeasing it may have been, have their purpose grounded in the facilitating and encouraging the will to meaning. Further research with the focus on paralleling logotherapy in specific Frankl's captivity in the concentration camp with hospitalization will not only make for interesting research but also valuable research with regard to the contribution and extension of the knowledge base of social work or counselling.

6.5 Recommendations

Various recommendations can be made due to the valuable information received from the four participants.

Due to the nature and value of the research, future scientific inquiry will be facilitated. Not only were variables highlighted but effective hypothesis will also be formulated. The formulation of these hypotheses for further research study is therefore recommended. Hypotheses suggested are:

- A decrease in support for acute leukaemia patients during hospitalization results in an increase of losses, discontinuities and disruptions to be experienced

- Extensive role performance changes are evident with a diagnosis of acute leukaemia and hospitalization.
- Stigma is experienced due to the onset of a diagnosis of acute leukaemia as a result of the changed physical integrity
- Stigma is experienced due to a diagnosis of acute leukaemia and the overt physical changes experienced due to the side effects of the treatment.
- Stigma experienced result in a loss of support, dignity and quality of life.
- Acute leukaemia and its treatment result in a decrease or change in physical integrity.
- Fatigue and weakness are experienced as a result of treatment.
- Fatigue and weakness cause an increase in dependency.
- Dependency caused by fatigue and weakness results in frustration and a lack of autonomy.
- The increase in feelings of dependency leads to patients with acute leukaemia to feel more hopeless and helpless.
- Fatigue and weakness as a result of the treatment leads to a loss of autonomy.
- Privacy is affected during hospitalization.
- The need for privacy for acute leukaemia patients during hospitalization is individually and culturally specific.
- Patients diagnosed with acute leukaemia seldom feels safe during the hospitalization process.
- Fears for those diagnosed with acute leukaemia and the hospitalization process is paramount.

- Death and dying is a constant reality for patients diagnosed with acute leukaemia during hospitalization.
- Transplantation from familiar to unfamiliar environment result in numerous losses and disruptions.
- Positives are evident even when individuals are diagnosed with acute leukaemia diagnosis and hospitalized.
- Patients diagnosed with acute leukaemia cope better with their diagnosis and hospitalization as a result of the continual influence of existential factors
- Existential influences assist in the coping process of those diagnosed with acute leukaemia.
- Sexual intimacy is required and needed during hospitalization.
- Sexual intimacy during hospitalization has a positive effect on self worth.

Further research is strongly recommended in the same or related focus area. This will enable definite generalizations to be drawn to the entire population of patients diagnosed with acute leukaemia. The challenge will be to confirm this qualitative data acquired via this study, with quantitative research methodology that will count and correlate the psychosocial data. This therefore implies the verification of results and the generalization to the entire population.

The information acquired can also be utilized in drafting a better program of intervention with patients diagnosed with acute leukaemia during hospitalization. It is recommended that this be individualized to the entire population with further research.

From the diverse information acquired, from the four participants, it will only be prudent that the staff who provide services to this population group take cognizance regarding treating and handling these individuals with respect. All participants stated that the manner in which staff treated them could be improved. This is only the perception of participants. Further research regarding the quality of service delivery of staff will therefore be necessitated. If the quality of service delivery is lacking then training should be offered with special emphasis on professional conduct.

It is also suggested that attempts be made to de-stigmatize leukaemia but also to differentiate it from HIV or Aids. As were noted three participants were thought to have had Aids instead of leukaemia and family, friends and the community treated them as such. The differences between these two diseases need to be stressed. Added to the above it is also recommended that attempts should be made and explored regarding the filtering of information to primary health care institutions. This will be particularly helpful especially where an individual will be referred from such a setting. Empowerment of communities with prevalent knowledge is therefore of the utmost.

In filtering information to communities Government's health promotion task force may be contacted. It is with regard to their policy that suggestions may be made in addressing pertinent health care issues. Stakeholders may also be contacted to sponsor health awareness projects or even outreaches in different areas. The students who are placed in various departments at various hospitals may also be utilized in empowering different communities with health information.

With regard to the above acknowledgement of the existential beliefs should occur. It will be very difficult to dispel cultural perceptions or myths pertaining to diseases. The difficulty regarding this is due to the collectivity, the identity and the acceptance of common held beliefs.

Consideration of the food served should also occur. Attempts should be made to make recommendations regarding this. Added to this is to explore the input or assistance from private stakeholders in this regard. An example of this would be to prepare traditionally cooked food under hygienic conditions that can be served to patients in hospital.

Added to the above the possibility of private stakeholders' involvement in offering assistance or support with regard to transportation of significant others of patients needs to be explored. This particularly refers to enabling families to visit patients more regularly especially if they reside far from the Pretoria Academic Hospital. Transportation companies may be approached in achieving the goal of family visitation. Assistance can also be sought with regard to the implementation of activities during hospitalization. The need for this should however first be ascertained for the entire population via further research.

It is also suggested that exploration of the feasibility of volunteers to visit patients during hospitalization should occur. Good sources to assist in this regard are obviously social work students who have client centered skills and whom are cable to follow a program or departmental requirements. Volunteers that will be properly trained via specific training program may also be considered.

A further recommendation would be to have further research to point out the similarity and differences between Frankl's (1984: 20-115) captivity with that of hospitalization of the acute

leukaemia patients. Incorporating other theorists that have developed theories based on captivity could augment the above-suggested exploration.

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ANNEXURES

ANNEXURE

A

Table 1 Losses and Changes

Losses	Changes
<ul style="list-style-type: none"> -Environment, culture -The familiar -Identity (personal, physical and cultural) -Life-style, freedom, care freeness, luxuries -Roles -Relationships -Tasks, functions, responsibilities -Vocational and occupational roles and abilities -Accessibility -Routines, old accustomed ways and behaviours -Security and safety -Privacy and intimacy -Fearlessness regarding death and dying -Body-image/ physical integrity -Personality/ self-concept -Independence, autonomy, dignity, self-worth -Adult status -Quality of life -Communication with others -Support 	<ul style="list-style-type: none"> -Helped/ cured -Improvement of physical appearance -Behavioural and life-style changes -New routines or life style (changes) -New culture: hospital routines -Faith and relationship with God -Support -Dependence -New roles : patient, sick and child role -Helplessness and hopelessness -Fatigue and weaknesses -Imprisonment/ captivity -Insecurity -Distrust -New support systems -Label (diagnosis)

Figure 1: Losses and Support

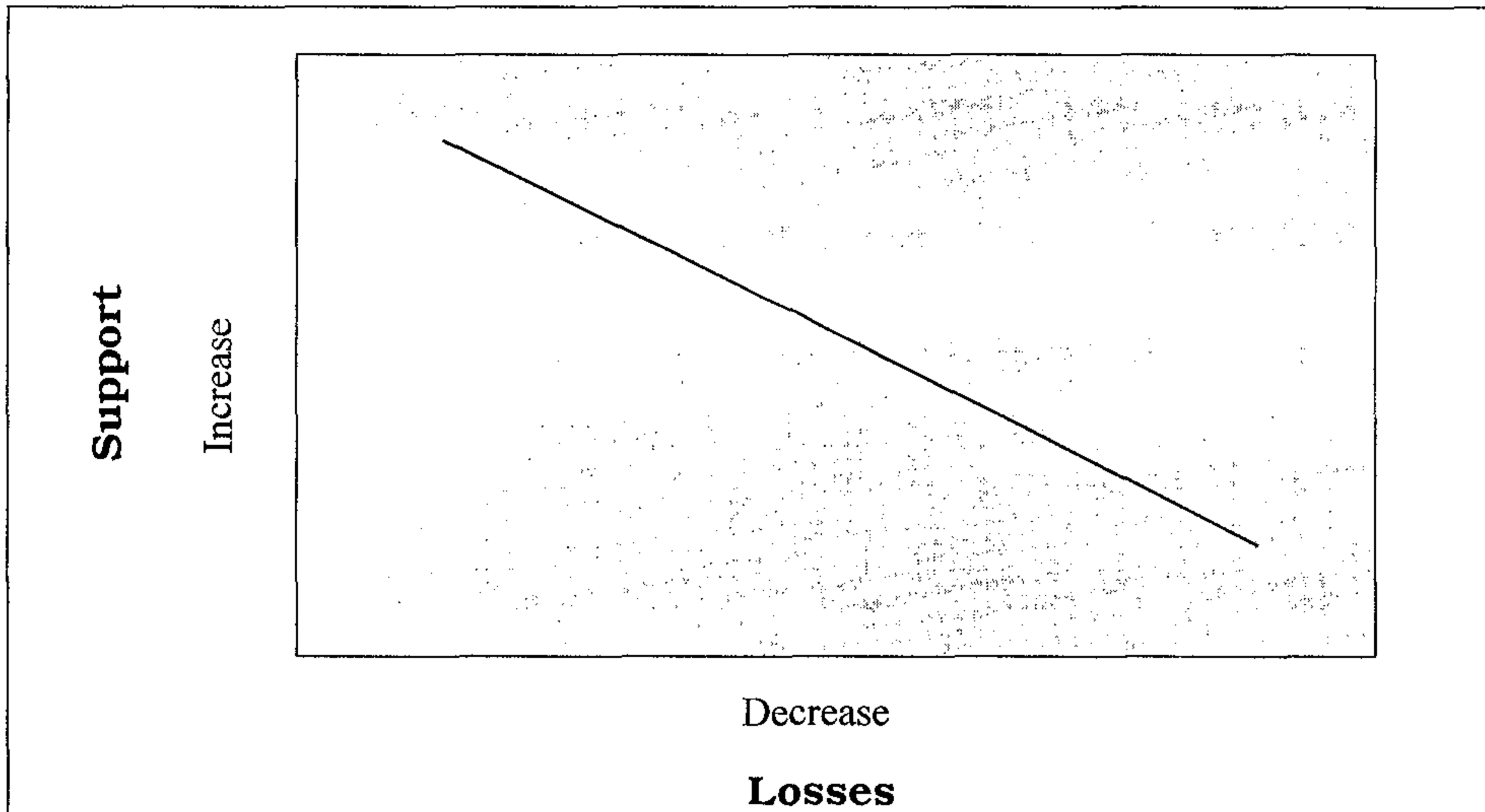


Figure 1 represents a negative correlation between support and losses. An increase or prevalence of support results in a decrease in the losses to be experienced

**Figure 2: Stigma and Losses
(Discontinuities and Disruptions)**

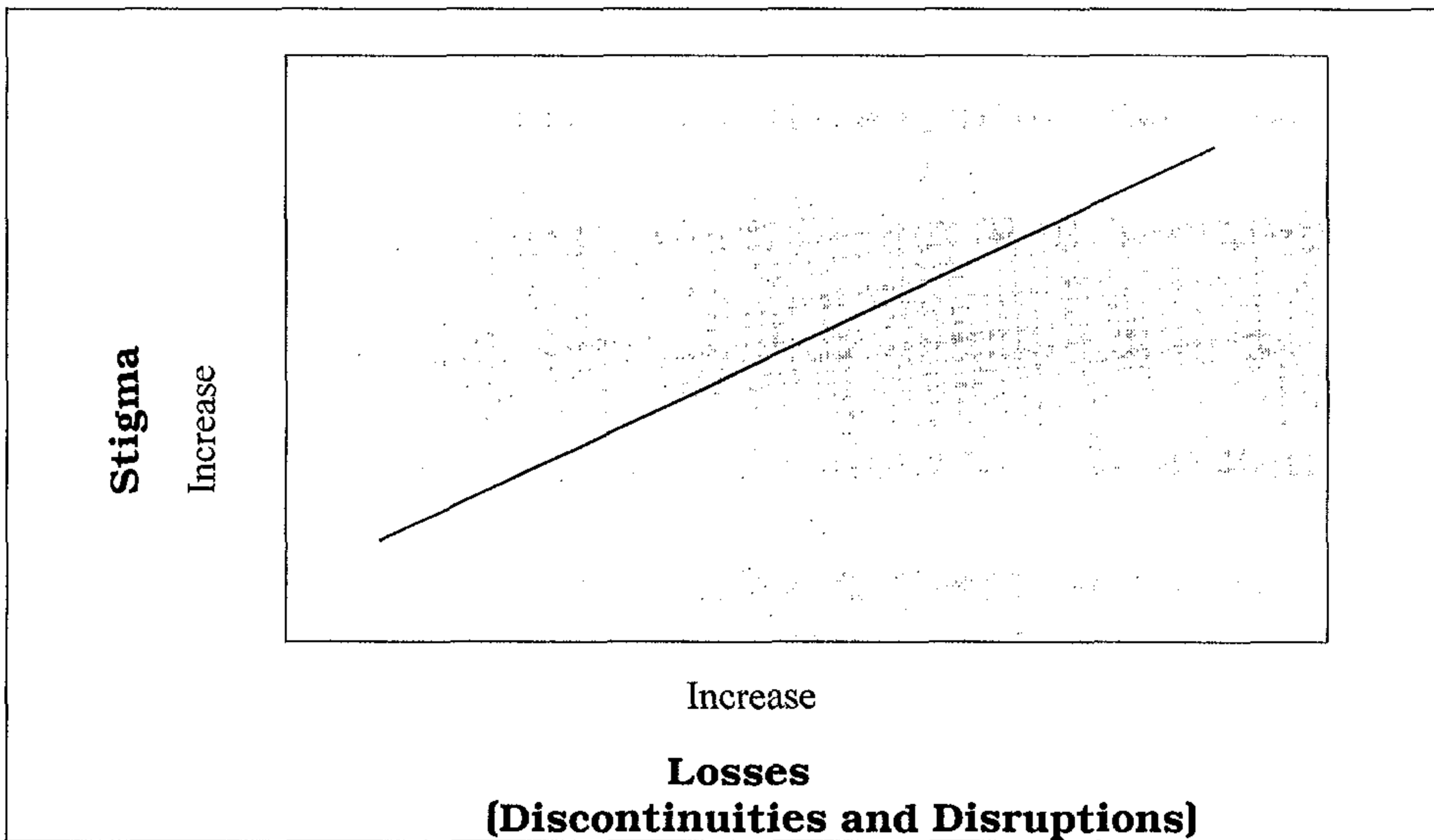


Figure 2 represents a positive correlation between stigma and losses. An increase in the experience of stigma results in an increase of losses

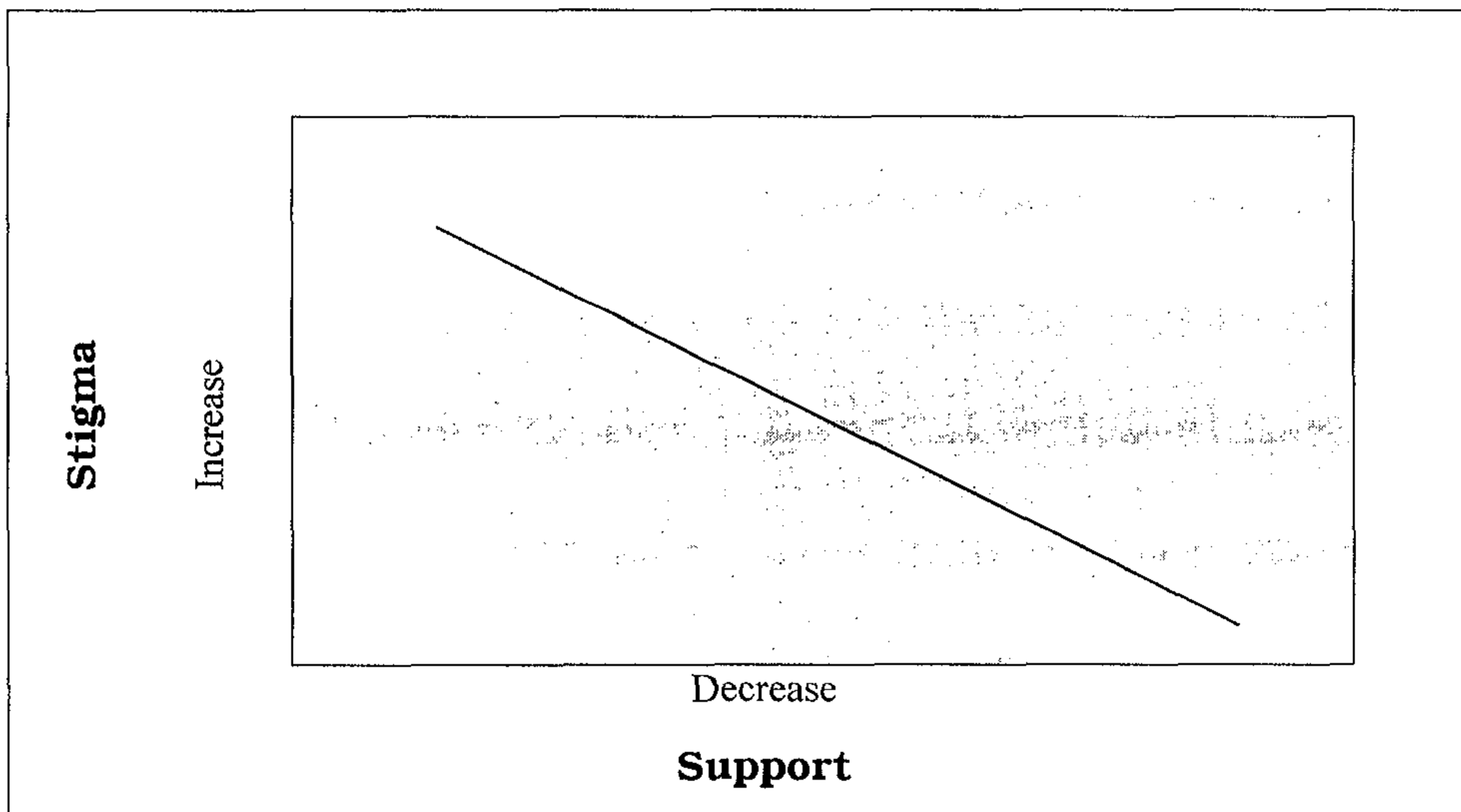
Figure 3: Stigma and Support

Figure 3 represents a negative correlation between stigma and support. The prevalence or increase in stigma experienced results in a decrease in support.

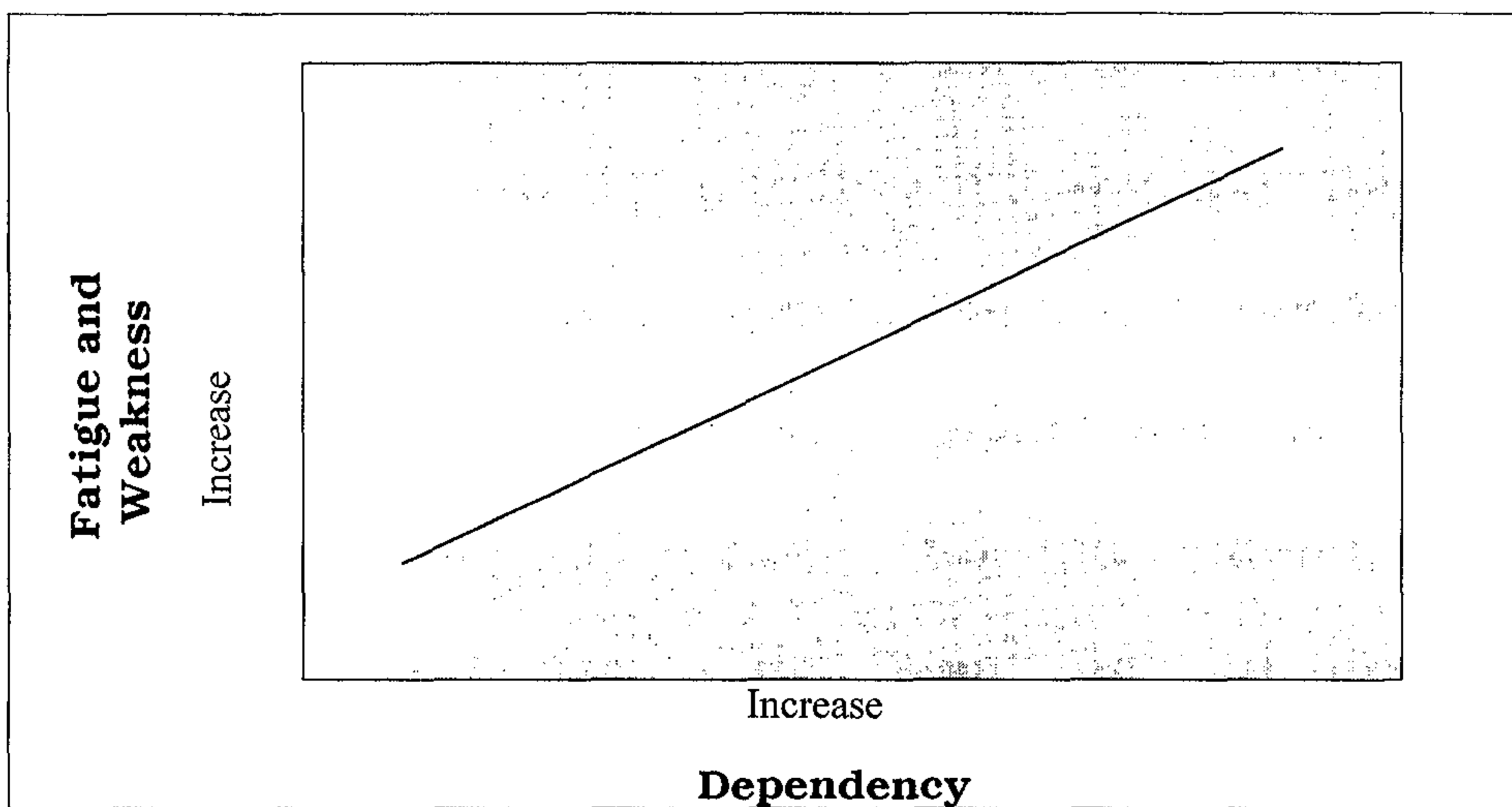
Figure 4: Fatigue, Weakness and Dependency

Figure 4 represents a positive correlation between fatigue, weakness and dependency. It suggests that an increase in fatigue and weakness results in an increase in dependency.

Figure 5: Fatigue, Weakness and Autonomy

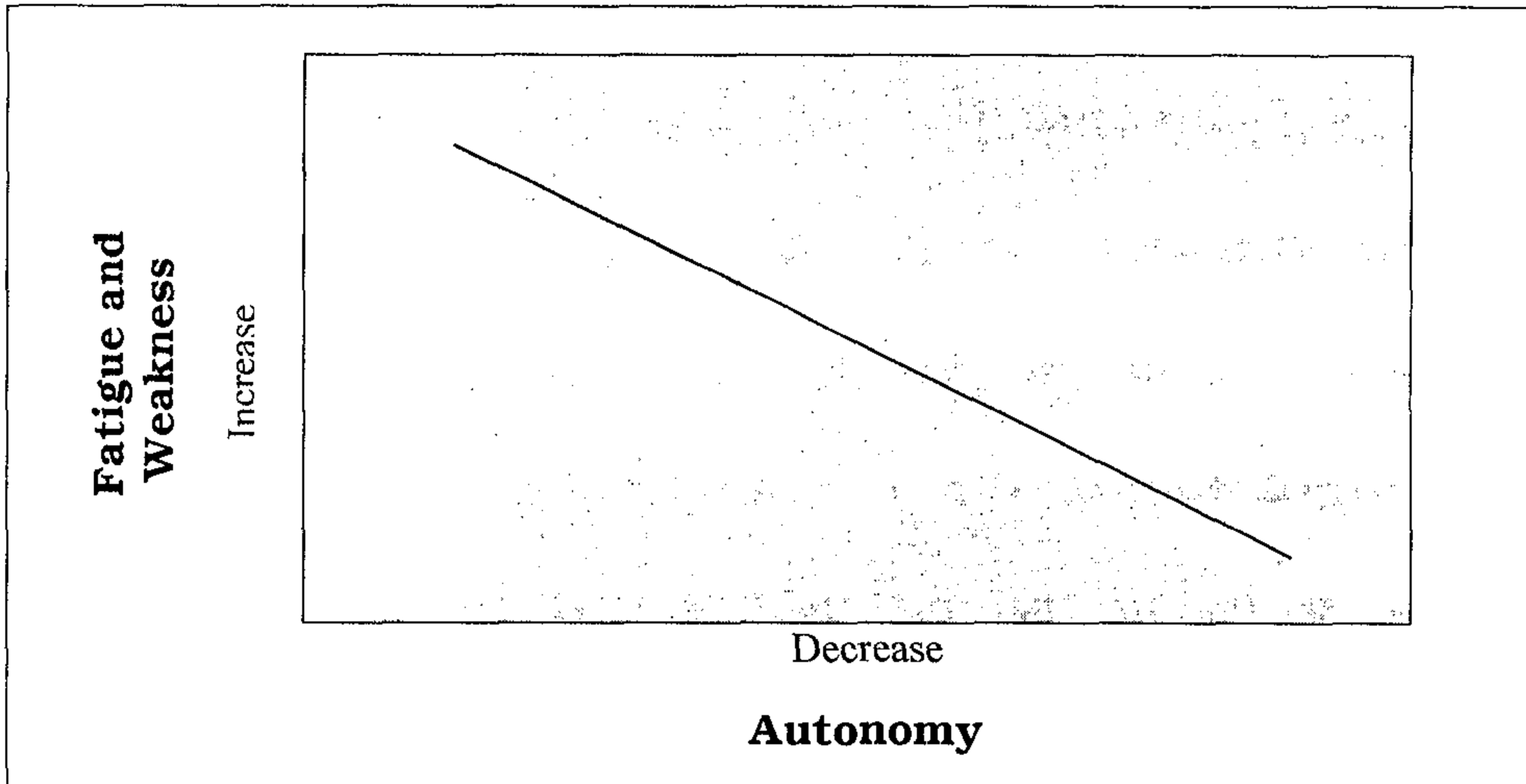


Figure 5 represents a negative correlation between fatigue, weakness and autonomy. An increase in the experience of fatigue and weakness results in a decrease in autonomy.

Figure 6: Dependency and Autonomy

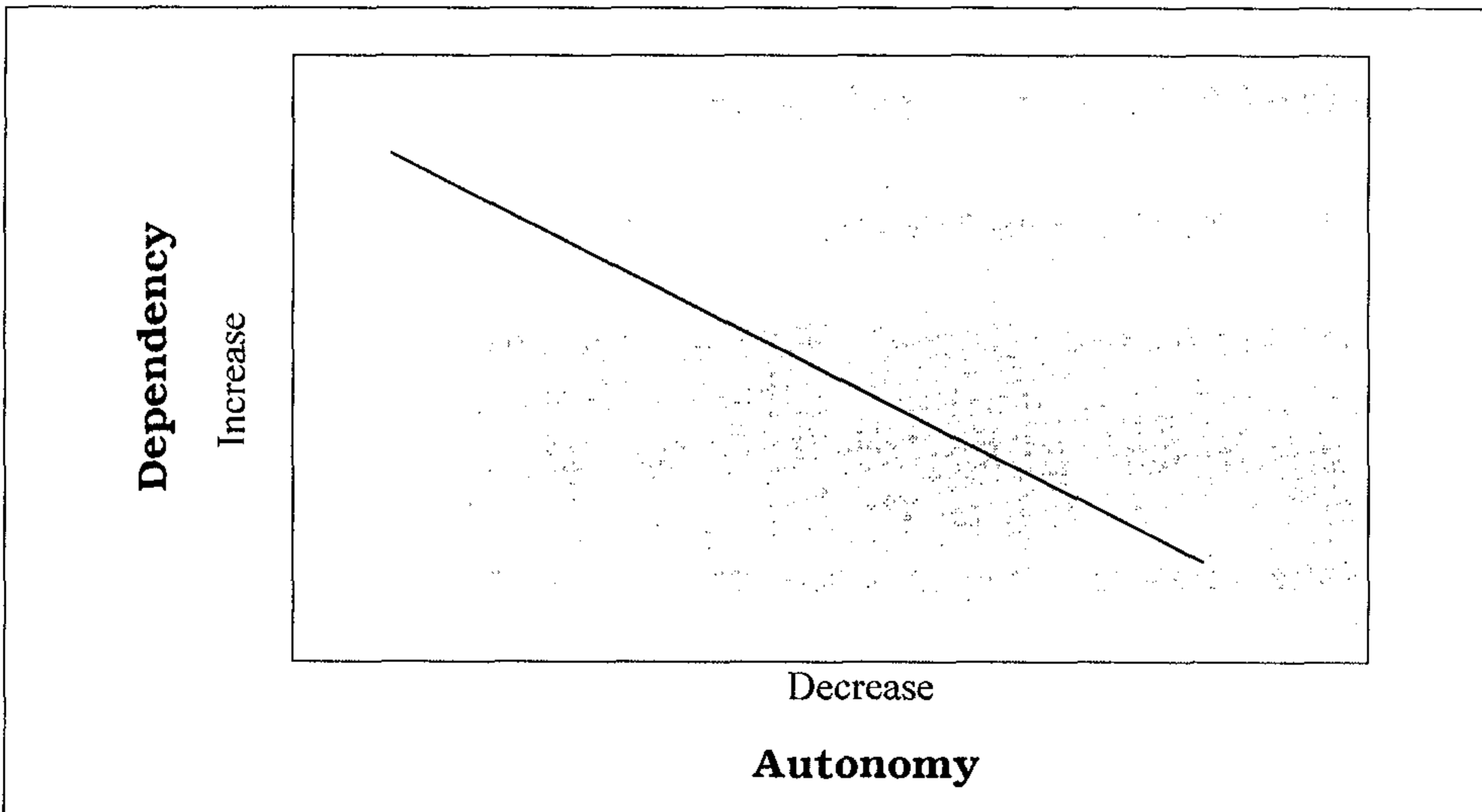
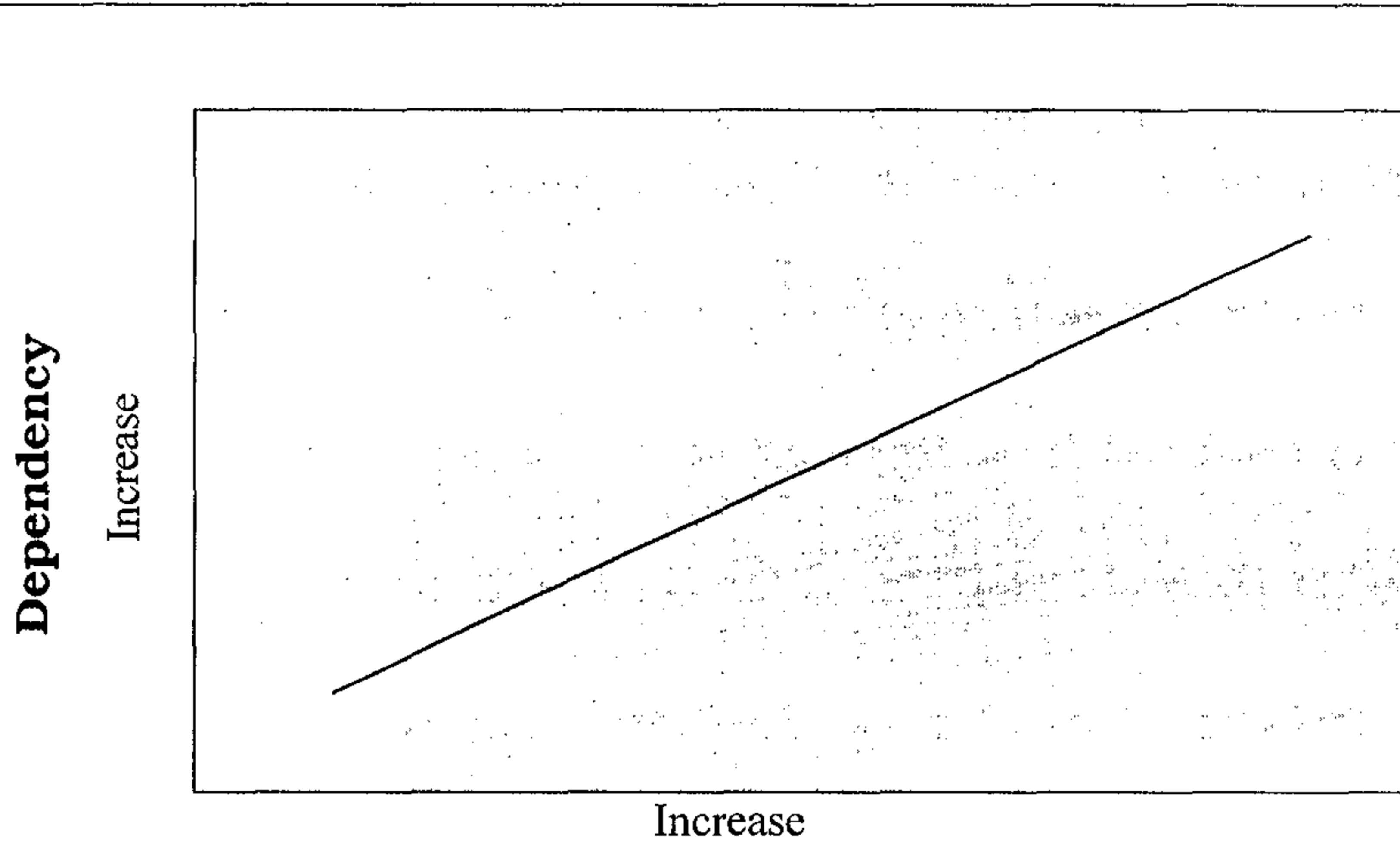


Figure 6 represents a negative correlation between dependency and autonomy. An increase in dependency results in a decrease in autonomy.

Figure 7: Dependency, feelings of Hopelessness and Helplessness



Feelings of Hopelessness and Helplessness

Figure 7 represents a positive correlation between dependency and feelings of hopelessness and helplessness. An increase in dependency results in an increase in feelings of hopelessness and helplessness.

ANNEXURE

B

The psychosocial experiences of patients diagnosed with acute leukemia during hospitalization

INFORMED CONSENT FORM

Research study

I _____ willingly agree to participate in this study which has been explained to me by _____. This research study is being conducted under the auspices of Pretoria Academic Hospital.

Purpose of the study

It has been explained to you that you have been diagnosed with _____. You have been invited to participate in this research study. This research study is attempting to better understand your experiences as a result of your disease and the hospitalization process.

Description of procedures

The study involves researching your experiences. To ensure that the results will be useful **patients diagnosed with acute leukemia** will be selected for the study. The method of obtaining information will be in the form of an interview. In this interview you will be asked to share your experiences as a result of your diagnosis and the hospitalization process. These experiences may include your feelings, thoughts, ideas, needs, wishes, concerns, behaviour, etc. Your identity will not be revealed to any reader of the research report or at any stage of the research.

Discomforts

Hopefully you will not be experiencing any discomfort regarding the interview, as you will be in control of what you want to disclose. If situations arise that will cause you to feel uncomfortable you can stop the process immediately. If needed you may request further counselling.

Benefits

The information obtained from participants will be utilized to:

- Understand the experiences of those diagnosed with Leukemia,
- Develop and offer quality supportive services to all diagnosed with Leukemia especially during the hospitalization process.

Voluntary participation

Participation is voluntary. Compensation will not be offered for your participation in the study. If you should decide **not** to participate in the study you **will not** incur any penalties or any loss of benefits.

Confidentiality

Your identity in participating in the study will not be revealed in the documentation or the discussion of the research findings.

Permission

I have read all the above. I had the opportunity to ask questions and received answers concerning areas I did not understand. I willingly give my consent to participate in the research study. Upon signing this form, I will receive a copy thereof.

Participant's signature

Date

Witness' signature

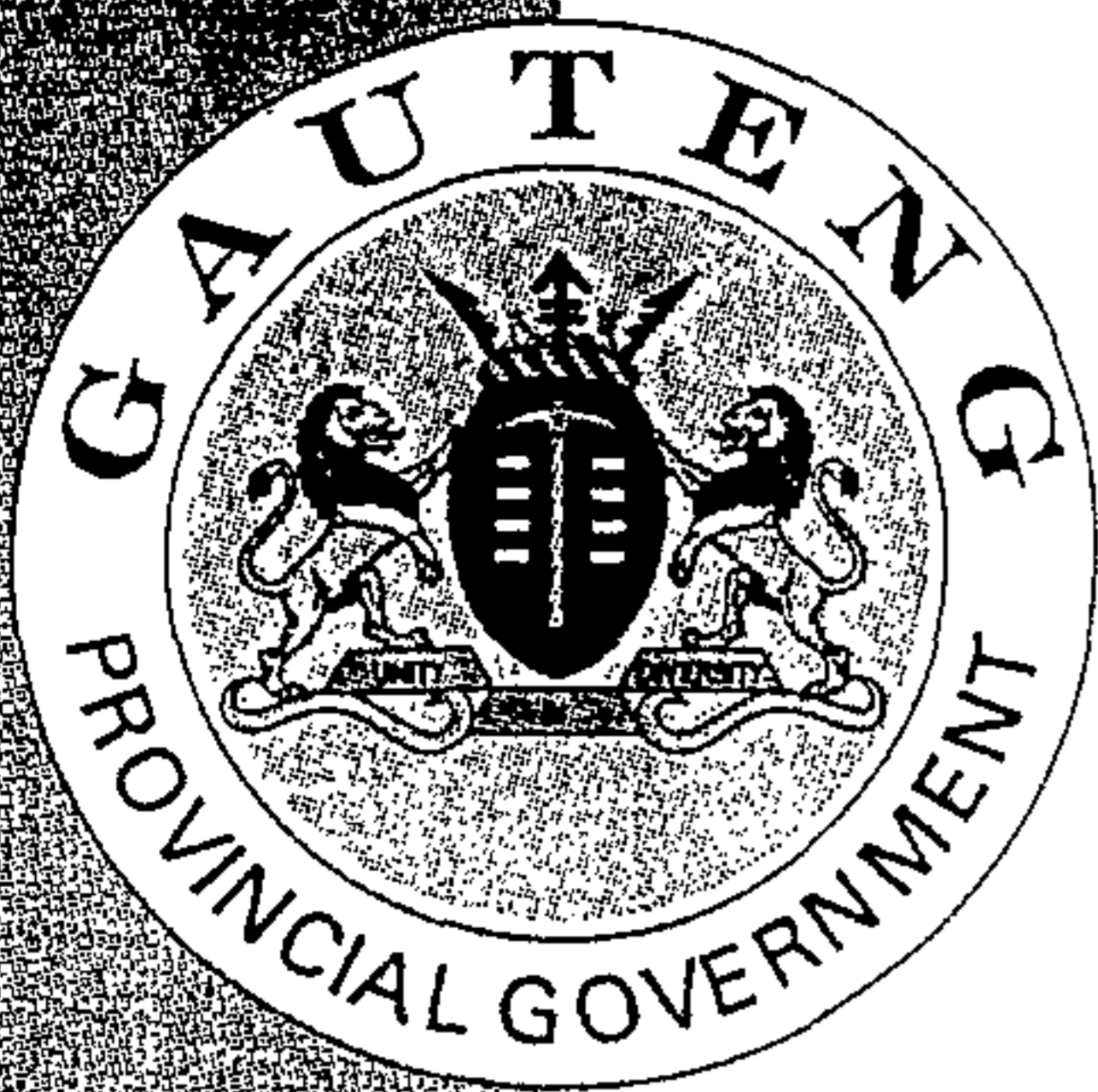
Date

Researcher's signature

Date

ANNEXURE

C



DEPARTMENT
OF
HEALTH

DEPARTEMENT
VAN
GESONDHEID

Tel: (012) 354 1560

Fax/Faks: (012) 354 1831

Ref/Verw: Ethics Committee

Enquiries/Navrae: Dr R Sommers

Ward 4 Room 19

Date : 18/08/2000

Number : S 87 / 2000

Title : The Psychosocial Experiences of patients diagnosed with acute leukaemia during hospitalisation.

Investigator : Laetitia Petersen; Department of Medical Oncology (Ward 19); Pretoria Academic Hospital; Pretoria.

This Protocol and Informed Consent has been considered by the Ethics Committee, Faculty of Medicine, Univ. of Pretoria and Pretoria Academic Hospitals on 16/08/2000 and found to be acceptable.

Dr J.E. Davel (female) MBChB: Hospital Superintendent
Prof A.P. du Toit BA; DipTheo; BA (Hons); MA; DPhil: Philosopher
Prof C.I. Falkson (female) MBChB; M.Med(Int); MD; Med. Oncologist
Prof G. Falkson CHAIRPERSON; MBChB; M.Med(Int); MD; OSG: Medical Oncologist
Mrs C. Gerber (female) BA(FineArts); Architectural Draughting (Boston House College Pta)
Prof S.V. Grey (female) BSc(Hons); MSc; DSc : Deputy Dean
Mrs R. Jooste (female) Dip. Pharm; M Pharm; Pharmacist.
Dr V.O.L. Karusseit MBChB; MFGP(SA); M.Med(Chir); FCS (SA): Surgeon
Dr S. Khan (female) MB.BCh.; Med. Adviser (Gauteng Dept. of Health).
Ms B.C.F. Magardie (female) BCur: Matron/Senior Nursing-Sister
Miss B. Mullins (female) BscHons; Teachers Diploma;
Dr P.Z. Njongwe (female) MBChB ; D.P.H.; DTMtH; DOH ; F.F.C.H(CM)
S.A. Chief Med. Super of Pretoria Academic Hospital.
Snr Sr J. Phatoli (female) BCur(Et.Ai) Senior Nursing-Sister.
Prof H.W. Pretorius MBChB; M.Med (Psych) MD: Psychiatrist
Prof P. Rheeder MBChB; MMed(Int); LKI(SA); MSc (KLIN.EPI): Specialist Physician
Prof M.M.S. Smuts (female) BVSc; DVSc
Prof J.R. Snyman MBChB, M.Pharm. Med: MD: Pharmacologist
Prof De K. Sommers BChB; HDD; MBChB; MD: Pharmacologist
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Prof FFW van Oosten BA; LLB ; LLD ; LLD ; Head of Department of Public Law and Prof in Criminal Law and Medical Law

Student Ethics Sub-Committee

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Dr R. Sommers SECRETARIAT (female) MBChB; M.med (Int); MPhar. Med;
Dr C. van der Westhuizen (female) D. Cur; M. Ed.

PROF G FALKSON;

MBChB; M.Med(Int); MD; OSG: Medical Oncologist
CHAIRPERSON of the Ethics Committee at Pretoria Academic Hospital,

PROF P RHEEDER;

BChB; MMed(Int); LKI(SA); MSc (KLIN.EPI): Specialist Physician
CHAIRPERSON of the Student Ethics Committee at P.A. H