

CHAPTER ONE: INTRODUCTION AND BACKGROUND: GROUNDING THE QUESTION

Introduction

In this thesis the level of agreement between cancer patients' understanding of their quality of life (QoL) and their nurses' perception of their QoL will be examined. This will be done by conducting a survey using a questionnaire followed by an interpretive approach to obtain an in-depth understanding of the similarities and differences of QoL perception by cancer patients and their nurses. The purpose of this chapter is to provide the background concerning the topic and to justify the significance of the research study in both the clinical and research areas.

To achieve this goal, the impact of cancer internationally will be discussed from a statistical point of view, looking particularly at Australia and especially South Australia (SA). The importance of situating cancer research in the context of QoL and its potential benefits for cancer patients, health care professionals, and policy makers is discussed. Having emphasised the importance of the direct assessment of cancer patients' QoL, the importance of other people's perceptions, particularly nurses' perceptions, is recounted. Following this, the process through which research questions were developed from the researcher's clinical experiences will be described and finally, an overview of the thesis will be given.

The significance of cancer

Cancer is a major global health issue. Kamangar, Dores and Anderson (2006) reported that in 2002 approximately 25 million persons lived with different kinds of cancer worldwide. They stated that in 2002 lung, breast, colon and rectum, stomach, prostate, liver, cervix, and oesophagus were amongst the eight most common cancers internationally. The World Health Organisation (WHO 2007) estimated that in 2005, 7.6 million (out of 58 million) deaths worldwide (13.1 %) occurred due to cancer. WHO also anticipated that cancer death rates globally will increase to around 9 and 11.4 million in 2015 and 2030, respectively. Other statistical information indicates

that people at no stage of their life can be rid of the risk of cancer; however, it is most likely that individuals in the age group 65 years and older will be affected by cancer (Yancik 2005).

The Australian Institute of Health and Welfare (AIHW 2007) and Australian Association of Cancer Registries (AACR 2007) state that in 2003, one in three men and one in four women would be directly affected by cancer before the age of 75. They also estimated that in 2006 cancer was responsible for the deaths of more than 39,200 people in Australia. This incidence can be identified from statistics presented by the Australian Bureau of Statistics (ABS) about Causes of Death in Australia in 2005. Malignant neoplasms, at 29.4%, were the main cause of death in Australia followed by ischemic heart disease, which was responsible for 18% of all deaths. While ischemic heart disease has been one of the main causes of death amongst Australian men and women, according to ABS (2007) death rates from ischemic heart disease have decreased from 23.7% in 1995 to 18.0% in 2005. However, the corresponding figure for malignant neoplasms has increased from 27.0% to 29.4% over the same period (ABS 2007). Cancer is now the number one killer of Australian men and women.

Cancer is a burden for both Australian males and females and can impact on all organs of the body. The ABS (2006) shows that from those reporting a neoplasm or tumour in 2004-05, 87% reported a malignant neoplasm (cancer). According to AIHW and AACR (2007) in 2003, prostate cancer was the most commonly diagnosed cancer among males, followed by colorectal cancer, melanoma and lung cancer. Breast cancer was the most common cancer among females in 2003, followed by colorectal cancer, melanoma and lung cancer (AIHW and AACR 2007).

The South Australian Department of Health (2004) has reported that cancer is the second major cause of death in South Australia (SA). In addition, one in three South Australians will be diagnosed with cancer at some time during their lives. While both men and women in SA share similar rates of cancers, prostate cancer is the most common for men at 29.2% whereas for women it is breast cancer (28.4%) (South Australian Cancer Registry 2004). Comparison between the SA and national statistics shows that they match each other in terms of incidence and the most

common cancers in men and women. However, cancer deaths in SA are marginally lower than the national figures.

The significance of QoL research in cancer care

Reviewing the oncological literature indicates that investigators have been paying particular attention to QoL, particularly in the last two decades. A range of QoL trials can be accessed involving various types of cancer, such as: prostate (Galalae et al. 2004; Gall 2004), lung (Bottomley et al. 2003), gastrointestinal (Cense et al. 2004; de Liano et al. 2003), breast (Bardwell et al. 2004; Bloom et al. 2004; Bottomley et al. 2005), colorectal (Efficace et al. 2004; Guren et al. 2003), head and neck (Ferlito et al. 2003; Funk et al. 2004), testis (Fossa et al. 2003; Miyake et al. 2004) and gynaecological cancer (Hawighorst-Knapstein et al. 2004; Lutgendorf et al. 2002). This indicates that many researchers consider that QoL is an important consideration when delivering care to cancer patients.

Although many of the QoL research studies conducted with cancer patients have provided useful information, there are publications in which QoL has not been measured with any rigour. Gill and Feinstein (1994), for example, state that there are many articles published under the QoL title that do not have a primary focus on QoL. Added to this there is some evidence of using (or misusing) QoL as a marketing tool, particularly by the pharmaceutical industry (Aaronson 1988). Researchers therefore need to distinguish this bulk of less reliable literature from the more informative studies. The large number of QoL research studies suggests that QoL is an important matter for patients and increasingly so for health care professionals and policy makers.

Cancer patients and QoL

There are many reasons why QoL is considered important for cancer patients. Cancer has a deleterious effect on all aspects of a person's life (MacDonald 2001). Based on the researcher's teaching responsibilities and clinical experiences with cancer patients (described later in this chapter), he recognises that having a cancer can be a catastrophic experience and challenges the individual's reality and, of course, their

QoL. The QoL concept is explained more fully in the next chapter. In brief, this is a concept used to emphasise that different aspects of individuals' lives such as physical, psychological, and emotional are important in determining the experience of living. Quality of life needs to be taken into the consideration by health care professionals when caring for those whose life is under threat.

Even when cancer patients have undergone cancer treatments for cure or to increase their chance of survival, their lives may be distorted further (Isikhan et al. 2001). In other words, in attempting to give years to the life of cancer patients, the life during these years or their QoL has frequently been compromised. Research studies which contribute to a greater understanding of the impact of cancer on the individual's life and subsequent alleviation of this problem are worthwhile.

Health care professionals, policy makers, and QoL

QoL is not only an important issue for individual cancer patients; it is also a matter of great importance for health care professionals and policy makers. QoL information can potentially be used extensively in clinical practice and this matter has been addressed in the literature. Higginson and Carr (2001) highlighted that QoL information can be used for screening and prioritising potential problems in different aspects of health status such as the patient's physical, psychological and social condition. QoL information can help to facilitate communication with patients and identify their preferences, for example, to select a specific treatment or care plan (Jacobsen, Davis & Cella 2002). Patients can communicate their problems and priorities by filling out a QoL questionnaire or through an interview. Issues like sex life, personal relationships and financial issues, for example, are amongst those important matters patients usually do not express explicitly unless they are questioned. QoL assessment can prompt the process of revealing hidden problems more appropriately and lead to more holistic care.

QoL information also has implications for training new staff, clinical auditing and in clinical management (Higginson & Carr 2001). By looking at outcomes of QoL questionnaires along with other complementary information, policy makers, for example, can identify which aspects of patients' care need more attention. This also

has implications for training health care professionals. Knowledge about QoL assessment can be incorporated into the curriculum of undergraduate and postgraduate. QoL information can also be used as an indicator for assessing the cost-effectiveness of different treatments (Hendry & McVittie 2004; Movsas 2003; Schwartz & Sprangers 2002). Two different treatments, for example, may have the same effect on patients' survival, but the treatment decision may be made in favour of one that has a better effect on patients' QoL. This research study will suggest implications for clinical practice and other related fields and therefore will be potentially very useful for health care professionals and policy makers. Potential implications of QoL information are further explained in Chapter Two.

Although QoL information may be important for health care professionals, there are some significant problems that come with this need. One of these is if health care professionals can assess patients' QoL on their own behalf or whether they need to assess it directly with patients. That is, can the carer act effectively as a proxy for the patient or must patients provide QoL information themselves?

Who can provide the best information about patients' QoL?

Health care professionals generally agree that asking patients is the ideal way to assess QoL because QoL is a subjective and personal experience (Fayers & Machin 2000; Movsas 2003; Rebollo et al. 2004; Schwartz & Sprangers 2002). It is always difficult for a health carer to know exactly what QoL means for their patient unless they assess it directly with the patient. However, this "should not imply a wholesale rejection of alternative sources of such information" (Sprangers & Aaronson 1992, p.744). There are situations in which health care professionals' perceptions about patients' QoL are important. For example, in cases where the patient is unable to be consulted a proxy assessment may become the only source of QoL information. Nurses are intimately involved with cancer patients and their perceptions of cancer patients' QoL may be vital.

Significance of nurses' perceptions of cancer patients' QoL

There are situations when nurses' perceptions about cancer patients' QoL are important. Firstly, in the clinical area nurses need to identify different physio-psycho-social needs of patients using a holistic approach (Rebollo et al. 2004; Tallis 2005). The philosophy of nursing invites nurses to nurture people to achieve holistic health and to adopt an approach that incorporates and integrates all aspects of their life into care decision-making (Erickson, Tomlin & Swain 1983). Focusing on QoL is consistent with the philosophy of a holistic approach in nursing (King et al. 2002). Perceptions that nurses form about patients' QoL, provide nurses with the best possible opportunity to identify needs, make decisions and select appropriate actions to be more therapeutic in their supportive roles and to improve patients' QoL (King 2006a). Conversely, without a full understanding of patients' QoL, decision-making about patient care could be potentially haphazard (King et al. 1995; Nekolaichuk et al. 1999; Pickard & Knight 2005).

Secondly, in the clinical area patients may try to show themselves favourably to clinicians and may not genuinely express their feelings (Fayers & Jones 1983). In these situations, an experienced nurse can gain the patients' confidence and hear any unpleasant comments about disease, care or treatment. Therefore, it is possible that nurses' perceptions about patients' QoL can closely reflect what is really going on in the patients' lives. Patients' situations including concerns, expectations and hopes, might be seen through nurses' eyes and perspectives more fully than other practitioners.

Thirdly, although other health care professionals make many treatment decisions about patients (Aaronson 1991), they usually have time constraints, particularly in outpatient oncology settings (Fisch et al. 2003; von Essen 2004). They may rely on nurses to convey to them information about patients' QoL (Parker 1997). In these situations nurses become a voice for their patients. Therefore, this voice needs to be accurate enough to convey to other health care professionals the broad spectrum of patients' problems, needs, and expectations. Despite ongoing debates on the privileged position of nurses in the research and practice with patients (Cheek 1996; Lawler 1997), it appears that nurses generally are more knowledgeable about the

patients compared with other health care professionals. Empirical evidence from a survey with a group of Canadian oncologists, for instance, revealed that more than half of them (54%) identified nurses as the best source of QoL information (Bezjak et al. 1998).

Finally, there are situations in which a direct QoL assessment with the patient is not possible or is very difficult, such as when patients experience cognitive impairments, communication deficits, have symptoms that really frustrated them, where QoL assessment is physically or emotionally too burdensome or patients are very old or very young (Addington-Hall & Kalra 2001; Chaboyer & Forrester 2000; Rebollo et al. 2004; Sneeuw et al. 1998; von Essen 2004) or where patients personally do not like to provide QoL information (Aaronson 1991; Blazeby et al. 1995; Epstein et al. 1989; Magaziner et al. 1988; Sneeuw et al. 1998). Nurses as proxies may form perceptions about QoL of this group of 'non-respondent' patients (King et al. 1995; Slevin et al. 1988; Sneeuw et al. 1999).

When somebody else other than the patient forms a perception about a patient's QoL and reports on it, they are referred to as patients' proxies (Phillips et al. 2003; Tamim, McCusker & Dendukuri 2002). Armstrong (1989, cited in Nelson et al. 1990) states that in 271 studies conducted on the aetiology of non-infectious diseases published between 1980 and 1985 in the *American Journal of Epidemiology*, proxies were used in 8.8% of studies. Stineman et al. (2004) stated about one third of the information from the National Health Interview Survey (NHIS) on QoL was proxy-provided. Part of the results of a review by Sneeuw (2002) between 1991-2000 revealed that nurses were selected in many QoL research studies to act as patients' proxies for non-respondent patients. Accordingly, findings of the research reported in this thesis may also be useful and relevant for researchers who are interested in knowing whether nurses can provide reliable information in proxy research studies.

Whatever the circumstances, a reasonable degree of agreement needs to exist between the patient's and nurse's perceptions of the patient's QoL. Given this, assessing the level of agreement between the patient and the nurse over the patient's QoL is considered important and worthy of investigation.

The gap in QoL research

The need for a research study comparing nurses' and patients' perceptions on QoL was further reinforced when it was identified that there is still a gap in the QoL research literature. Evidence from previous research studies focussing on 'proxy rating' identified several general trends. Proxies, for example, appear to have a better understanding of objective aspects of QoL, such as the physical aspect, rather than subjective aspects such as the psychological and social QoL (Becchi et al. 2004; Herrman, Hawthorne & Thomas 2002; Lobchuk & Degner 2002; Wilson et al. 2000). However, there are gaps or omissions in such research studies.

Firstly, research studies in which the perceived QoL of cancer patients is compared with that of nurses worldwide appear to be inconsistent in their outcomes. For example, nurses' perceptions of cancer patients' QoL are considered inaccurate in some research studies (Brunelli et al. 1998; Horton 2002; Slevin et al. 1988; Zhao et al. 2003) whereas others reported that such perceptions are reasonably correct (Fisch et al. 2003; Geddes et al. 1990; Sneeuw et al. 1999). Generally, researchers recommend further studies to compare proxies' ratings of patients' QoL with that of patients' own rating (Lampic & Sjoden 2000; McPherson & Addington-Hall 2003; Pickard et al. 2004; Tang & McCorkle 2002b).

Secondly, few research studies adequately address the influence of major factors affecting agreement between patients and proxies (Magaziner et al. 1988; Novella et al. 2001; Sands et al. 2004; Tang & McCorkle 2002b; von Essen 2004). As stated by several researchers (Lobchuk & Degner 2002; Sneeuw, Sprangers & Aaronson 2002) the findings of research studies have not been consistent and there is need for further research work. For example, in one research study, the degree of QoL agreement between patients and their proxies was influenced predominantly by the patients' performance status (Horton 2002). Another study yielded no evidence of such a relationship (Sneeuw et al. 1997). Further research is necessary to identify the different variables affecting QoL agreement (Lampic & Sjoden 2000; Tang & McCorkle 2002b; von Essen 2004) using more accurate statistical tests including multivariate analysis (see Chapter Five - results of the first phase).

Thirdly, the majority of QoL proxy research studies are empirical and data have been analysed by different statistical tests. These are mainly Bivariate tests (such as the Pearson correlation). There is a lack of interpretive research in this field. Such research studies can explore nurses' perceptions of cancer patients' QoL in greater depth and uncover factors that may influence nurses' perceptions of cancer patients' QoL. Further interpretive research studies comparing different perspectives should be conducted.

Finally, the literature search for the research reported here yielded no Australian research comparing nurses' rating of patients' QoL with cancer patients' rating of their QoL. A number of empirical research studies have been conducted, but they used QoL tools developed in other countries including the United States of America and United Kingdom rather than the cross-culturally developed tools such as the World Health Organisation's Quality of Life Brief Questionnaire (WHOQoL-BREF) which incorporates a broad spectrum of QoL issues (The WHO Group 1995). Outcomes of research studies in which the WHOQoL-BREF is used can better be generalised to other situations or countries (see Chapter Four).

The literature review shows that a research study comparing patients' and nurses' understanding of cancer patients' QoL, and identifying variables influencing agreement between these groups in Australia, would be useful. The study needs to adopt a QoL tool with strong external validity such as the WHOQoL-BREF questionnaire, use more robust statistical tests, and incorporate interpretive methodology.

The researcher's experience and background

This research study uses an interpretive approach to evaluating the experiences of cancer patients and nurses about cancer patients' QoL. It is therefore appropriate to consider the researcher's experiences and background, particularly in relation to cancer patients. These experiences began with working as a qualified nurse and developed further as the researcher worked as a clinical educator, university lecturer and PhD student.

The researcher has worked with cancer patients in different clinical situations, particularly chemotherapy and radiotherapy departments, for more than 10 years in his country of origin, Iran. The researcher began working with cancer patients at the end of the second year of his Bachelor of Science in Nursing. Due to hospital work demands, nursing students at a Bachelor level could apply for work after finishing the second year of study. The researcher therefore had a professional position for two years as a qualified nurse and worked with cancer patients as well as other medical-surgical patients across different non-specialist oncology wards during his study commitments. These experiences encouraged the researcher to begin thinking about the different physical-psycho-social needs of cancer patients and how health care professionals managed them.

Working as a qualified nurse coincided with the researcher's studies for the Master of Science in Medical-Surgical Nursing Education for three years. To complete this degree, the researcher investigated early side effects of radiotherapy in cancer patients undergoing radiotherapy after a self-care education program in Iran. The researcher saw many patients dealing with difficulties related to diagnosis of cancer and their life expectancy in specialist oncology wards. Patients were concerned about the symptoms of cancer, cancer treatment side effects, and the social and psychological problems associated with cancer along with their mortality. The researcher gradually developed a feeling that both 'quantity and quality' of life for cancer patients should be paid particular attention. It brought to his mind that for many people affected by cancer, life during and after therapy is not just concerned with how long they live, but how well they live. It was during these times that the researcher thought more deeply about psycho-social needs of cancer patients as well as physical ones.

By spending time reading oncology books and research papers and teaching nursing students in the hospitals, the researcher learned more about the importance of QoL research for cancer patients and nurses. The researcher developed a closer relationship with patients during patient care with nursing students in cancer departments, and these led to some valuable experiences. One of these experiences for example, concerned a patient with a malignant lymphoma in his abdomen. The patient was not told about his diagnosis but his family was. The clinician started

chemotherapy in order to decrease the size of the tumour and to facilitate its removal later by surgery. The clinician thought that he made the best medical choice for the patient and withheld the truth from the patient. The clinician thought that the patient would accept his diagnosis and comply with the treatment later. A couple of weeks later the patient experienced alopecia and noticed his diagnosis. The patient realised the truth of having cancer, became distressed, and did not follow through to the surgical treatment. The patient died later due to the very severe side effects of the aggressive chemotherapy that was required. This experience encouraged the researcher again to consider more deeply if health care professionals particularly nurses, have a holistic understanding of the needs, expectations, and desires of patients who live with cancer.

The researcher received a scholarship to continue his studies in Australia leading to a PhD. In the light of that knowledge related to QoL and this clinical experience with cancer patients, the researcher decided to investigate QoL with cancer patients. He reflected on his first experiences with cancer patients' QoL, discussed the issue with his colleagues and thought more deeply about how perceptions of health care professionals and even family members are similar or different from those of the patients. The researcher has also pondered over the possible reasons why these perceptions are similar or different and raised a further question as how perceptual differences might affect cancer patients. For example, the researcher was interested in how different treatments that patients receive (such as chemotherapy and radiotherapy) might affect nurses' perceptions of cancer patients' QoL. What will happen to patients if nurses do not understand the full spectrum of patients' needs and problems when they, for instance, undergo chemotherapy. What about nurses' factors like their experiences, gender and age? Do more experienced or older nurses have a better grasp of the patients' situation or their QoL or not?

The researcher also reflected on his own position as an international student who is doing this research study in Australia. Cultural differences might affect his interpretations, particularly in the interpretive phase of the research study and undermine the usefulness of the study for Australia. The researcher has tried to resolve this by engaging more in Australian society and through ongoing consultations with his supervisors, other Australian friends, and a few patients. On

the other hand, how can research outcomes in Australia be useful for his country of origin? This idea emerged because the researcher has always been personally interested in improving nursing care for cancer patients in Iran. This challenging question is addressed in the next section.

The significance of the research study for health care in Iran

How can the findings of this research study in Australia benefit and influence health care in Iran? Even though the research study is conducted in Australia, research outcomes will be still relevant to Iran for several reasons.

Firstly, cancer is also a major health problem in Iran. Unfortunately, obtaining reliable statistical information from Iran can be problematic. Based on the researcher's best knowledge, institutions or centres that are engaged in collecting or reporting cancer statistics and other relevant information are very limited in Iran compared with Australia.

As an international student it was surprising to see that in Australia different institutes or foundations are collecting and reporting critical statistical information about cancer separately or in relationship with each other. For example, the ABS collects information about cancer through the National Health Survey (NHS) but also uses complementary information from other sources including the Australian Institute of Health and Welfare (AIHW). AIHW works in conjunction with different centres, particularly those in their states in collecting, analysing and reporting health-related data. At the state level, Australia also benefits from the different government and non-government cancer related centres. The Cancer Council, for example, is a non-government institute and one of its main goals is to improve understanding and public knowledge of cancer in each state. Another major federal government centre working across government jurisdictions is the Australian Department of Health and Aging which is actively engaged in registering diagnosed cancers through a Cancer Registry.

Based on the researcher's knowledge, the only up-to-date information about cancer

in Iran has been reported by WHO (2006). It indicates that in 2005 cancer killed around 47000 people in the country. Cancer is the main cause of death (11.8%) in Iran after cardiovascular diseases and injuries. Other chronic diseases altogether constitute only 17.5% of deaths nation-wide. The rate of cancer death is projected to undergo a slight increase from 11.8% to 13.4% by 2030. In the WHO report on Iran, a general category is introduced as 'other malignant neoplasms' but it is not clear what kind of cancers fall into this category. In this report, stomach cancer and 'other malignant neoplasms' are the most common cancers in males in 2002. For females the situation changes in that 'other malignant neoplasms' are at the top of the list followed by stomach cancer.

Comparing available information about Iran with international figures indicates three points. The first is that general trends are only marginally less than the international statistics. For example, 13.1% of deaths worldwide are due to cancer and in Iran it is 11.8%. The second point is that the incidence of most diagnosed cancers in males and females in Iran varies slightly from the international statistics. In Australia, for instance, the most common cancers are breast cancer and prostate cancer in women and men, respectively. These cancers were ranked at the fourth and third category of most common cancers amongst Iranian men and women, respectively. The third point is that cancer trends in Iran might be closer to international figures if a more nation-wide data collection was conducted. It is therefore essential that this information require strategies to be planned, such as registration of diagnosed cancers in each province and then at the national level in Iran.

Secondly, the relevance of relating the research outcomes to Iran can more fully be recognised if the current research study is seen in the framework of a bigger research study that will be conducted by the researcher after finishing his PhD. In other words, outcomes of this research study can be beneficial by undertaking a comparative study in Iran in the near future. Comparing QoL data across different countries in the shape of cross-cultural research trials is one important line of research for investigators. This would help, for instance, to explore if cancer patients in a developed country like Australia have a better state of QoL compared with a developing country like Iran. Such research studies would be very useful in evaluating the underlying reasons for this and improving the health systems.

Thirdly, in the survey phase of the research study the WHOQoL-BREF questionnaire, discussed earlier, was chosen. The dimensions that are covered by this tool may be broad enough to cover many QoL issues that are relevant to Australia and Iran. Some empirical outcomes of the research study therefore might have external validity and applicable to Iran, but with necessary caveats.

Fourthly, the relative transferability of the qualitative data from this Australian-context to Iran is a relevant topic to discuss. Transferability of interpretive findings from one area to another relies on the similarity of contexts and there is some literature that has done this. For example, cancer patients in developing countries like Iran are suffering from many QoL issues that may occur in Australia. The major cancers in developing countries appear in an advanced state and given the notion that such countries do not have enough resources for treating them well, it is important to provide opportunities to prevent, palliate and improve their QoL (Olweny 1992). Chaturvedi et al. (1997) also stated that in most Asian countries, QoL activities were very diverse and in the early stages of development, except in Japan. They also concluded that QoL deserves greater recognition as a part of the general public health landscape. Their conclusions were based on pre-designed forms answered by representatives from different Asian nations including one representative from Australia. Studies with a mixed approach like this research study (see Chapter Three) can potentially create outcomes that might have better ‘inference transferability’ to other places and situations (Teddlie & Tashakkori 2003, p. 37).

The research questions

This research project will examine how accurately nurses perceive and report cancer patients’ QoL in the clinical area in an Australian population. The following main research questions will be answered:

1. What differences and/or similarities are there between cancer patients’ and nurses’ perceptions of cancer patients’ quality of life?
2. Why do differences and/or similarities exist between cancer patients’ and nurses’ perceptions?

It would be ideal to undertake a research study involving all key persons who are engaged in caring for cancer patients such as other health care professionals and significant others as well as nurses. However, nurses are intimately involved with cancer patients more than other health care professionals and their understanding of cancer patients' QoL is important. Moreover, inclusion of other health care professionals or significant others was beyond the resources available and therefore the scope of this study.

The research study utilised rigorous methods to comprehensively compare nurses' understanding of cancer patients' QoL with that of patients' own perceptions.

Methodology

The research study was underpinned by a mixed approach. The first phase was based on an empirical methodology and utilised the WHOQoL-BREF questionnaire. The aim was to assess the level of agreement between patients and nurses about cancer patients' QoL and identify variables influencing agreement. The second phase of the study was founded on the principles of grounded theory. The aim of this phase was to include an interpretive perspective and explore reasons why patients and nurses may differ in their perceptions using semi-structured interviews. More details of the methodology and methods can be seen in Chapter Three (methodology chapter), Chapter Four (methods of the first phase), and Chapter Six (methods of the second phase).

Thesis structure

The thesis consists of nine chapters. Chapter One provides an introduction to the whole project and discusses the significance of the research topic. Chapter Two concerns a review of the literature which serves as the basis for generating the research questions.

Chapter Three describes the methodology and explains the philosophical issues underpinning each phase of the research study. This chapter emphasises the role of

the mixed research approach.

Chapter Four outlines the method of the first phase and the results of this are presented in the next chapter, Chapter Five.

In Chapter Six and Chapter Seven, respectively, methods and results of the second phase are fully described.

In Chapter Eight, the discussion chapter, all the key information drawn from the two phases of the research study is summarised and discussed with reference to the research questions and findings. Limitations of the research approach are discussed at the end of the chapter.

Chapter Nine provides the conclusion and discusses the implications arising from comparing patients' and nurses' perceptions about cancer patients' QoL.

Conclusion

The importance of the QoL concept, particularly in the clinical area of cancer patients, has been considered. The key issue is that patients, while they can provide the best source of information about their own QoL, may not be able to provide this data. In the meantime, nurses also form perceptions about cancer patients' QoL. They may need to act on such perceptions to support their clinical decision-making, especially where patients cannot provide such information. Other health care professionals and researchers may also rely on nurses to provide them with proxy QoL information about patients. It is useful to determine the extent to which nurses' understanding of cancer patients' QoL agrees with that of patients themselves. The motivation for this study arises from the researcher's knowledge and experience as a qualified nurse and a nursing clinical educator and the need to improve the adequacy and accuracy of nurses' assessment of patients QoL.

In the next chapter, the literature that has been published on general and more specific aspects of the QoL concept (such as QoL development, definitions,

dimensions, and implications) will be reviewed. Furthermore, the key variables related to the level of agreement between cancer patients and nurses about cancer patients' QoL and how these variables may influence the level of agreement between the parties will be reviewed. This discussion will provide the basis for formulating the research questions.

CHAPTER TWO: LITERATURE REVIEW: SITUATING THE STUDY IN RELATION TO OTHER RESEARCH AND ASSOCIATED THEORY

Introduction

Chapter One argued that QoL research with cancer patients has potential benefits for cancer patients, health care professionals and policy makers. Another justification for conducting this research study was that the findings from comparing nurses' perceptions about cancer patients' QoL with that of patients' own perceptions will add new knowledge to the current literature.

The purpose of this chapter is to relate this research study to the most common issues and debates in the literature about nurses' perceptions of cancer patients' QoL. Although this research study has a mixed approach, most of the literature reviewed in this chapter is empirical in nature and this helps to establish a rationale for the research questions. A few existing interpretive studies are also reviewed in this chapter. Another literature search was conducted at the conclusion of the interpretive phase, focussing on the specific categories that emerged.

Concept of Quality of Life (QoL)

Understanding the concept of QoL is essential for this research project and it can be stated at the outset that this concept is the result of lengthy debate and discussions.

Development of the QoL concept

In the following historical survey, the development of the QoL concept has been divided into three stages: early times, 1940s-1960s, and 1960s-present. This narrative framework has been chosen because it reflects the relative quantity and nature of discussions that appeared during these eras.

Early times

The expression QoL is fairly new in academic literature (Szalai 1980) but the themes it dealt with were nonetheless familiar to some people. Strain (1990) and King (2003), for example, highlighted that people have always expressed concerns regarding having a good life particularly after their basic needs have been met. Some researchers believe that concepts such as human happiness and satisfaction have been given particular attention over a long period of time. Richardson Lear (2004), for instance, stated that the historical development of the QoL concept goes back millennia and possibly originated in the time of Aristotle in ancient Athens. Aristotle was one of the great Western philosophers who articulated about concepts such as happiness. In the book *Introduction to Aristotle* (McKeon, 1947), one single chapter focuses on issues concerning happiness. Consider, for example, the following extract:

...what is the highest of all goods achievable by action. Verbally there is very general agreement; for both the general run of men and people of superior refinement say that it is happiness, and identify living well and doing well with being happy; but with regard to what happiness is they differ...For the former think it is some plain and obvious thing, like pleasure, wealth, or honour....Now some thought that apart from these many goods there is another which is self-subsistent and causes the goodness of all these as well. (Aristotle, cited in McKeon 1947, p. 311)

Aristotle explained that happiness has different meanings for individuals but there should be an ultimate kind of happiness that satisfies all people. Despite this general interest about issues like happiness and pleasure, it appears that until recent decades there was less conceptualisation and clarification about QoL.

From the late 1940s to the 1960s

Several important publications can be identified indicating that in the late 1940s a shift in the conceptualisation about health and evaluating medical interventions occurred. Karnofsky and Burchenal (1949), for example, introduced the idea that in evaluating chemotherapeutic agents in cancer, both quantitative (such as survival rate) and qualitative (such as performance status, well-being) factors should be given particular attention. They described performance status as an important criterion indicating how patients can independently conduct their daily living activities or how much they rely on medical care. Karnofsky and Burchenal were pioneers in the

medical field and introduced a scale that emphasised the importance of measuring the performance status of patients rather than attempting to accurately determine patients' prognosis (Spitzer 1987). Similarly, the Index of Activities of Daily Living was developed by Katz et al. (1963); this instrument assessed patients' physical functioning. However, it can be argued that these measures are generally uni-dimensional in character and focus mainly on physical aspects. These publications marked a significant turning point in the discussion of QoL.

A similar conceptualisation about health can also be seen in the WHO definition of health that was released in 1948. WHO's constitution (1946, p.1315) defined health as "a state of complete physical, social and mental well-being, and not merely the absence of disease or infirmity". De Haes and van Knippenberg (1985) stated that psychological and social needs, as well as materialistic goals, become more apparent in the literature during the 1960s and 1970s. The period between the 1940s and 1960s witnessed a greater focus on health and a holistic approach to understanding one's health. This can be considered as an introductory phase to the formal introduction of the QoL concept that emerged later.

From the 1960s to the present

Szalai (1980) stated that the term QoL was used for the first time during the late 1950s or early 1960s in popular discussions or general publications like newspapers and magazines. This period saw the development of a number of QoL definitions, refined to the point in 1993 when WHO explicitly stated that all individuals have a right to psycho-social care for an adequate QoL in addition to physical care (World Health Organization 1993). Based on QoL definitions, a number of QoL tools were also created including those developed by WHO (WHOQoL-BREF and WHOQoL-100). The advantages and disadvantages of QoL tools are explained in more detail in the following chapters, particularly Chapter Four.

Nowadays the QoL concept is a very well-known concept though it continues to generate considerable discussion and debate. There are several key themes present in the literature concerning QoL and to some extent these can help us to identify the principal elements and issues surrounding it. The most common themes in the

literature, particularly recently, include:

1. Quality and/or quantity (Chancellor, Coyle & Drummond 1997; McVilly, Burton & Davidson 2000; Steel, Geller & Carr 2005; Tang & McCorkle 2002a). In other words, when considering individuals, not only is the number of years of life important but also the way that a person lives during those years. There might be people who live for a longer time but have not fulfilled their potential in all those years. Conversely, a number of individuals have shorter lives than others but are quite happy and satisfied during these years.
2. QoL assessment along with other measurements like survival, tumour control, treatment toxicity, performance status, mortality and morbidity (Bottomley 2002; Costantini et al. 2000; Cox 2003; Garratt et al. 2002; O'Carroll et al. 2000; Roila & Cortesi 2001). While criteria like survival or mortality rate are important and might reflect patients' QoL, these criteria cannot adequately describe the impact of a disease on all aspects of individuals' lives. Conversely, a QoL assessment takes into account a range of important physical, psychological, and social issues particularly during the course of a disease like cancer.
3. QoL assessment as a means to consider both subjective and objective parts of health status (Bottomley 2002; Giesler 2000; McVilly, Burton & Davidson 2000; Skevington, Lotfy & O'Connell 2004; Testa & Simonson 1996). The focus of a QoL assessment is not only on objective (measurable) factors like nutritional status, sleep patterns, and physical activities. It must also take into account subjective aspects of experience like individuals' satisfaction with their family, community, society, and other relationships.

In summary, it is not clear when and who exactly created the concept of QoL. However, it did gain importance in the literature during the 1960s. QoL has been developed further since that time through the introduction of specific QoL definitions and tools. QoL assessment can potentially lead to a better understanding of the patient as a whole and their health status and provides a parameter by which various domains of health status, such as physical, psychological, and social, can be assessed or evaluated.

This research study is conducted in the oncology field and therefore it is important to understand that QoL has implications for this area of expertise specifically.

Development of QoL concept in cancer care

Oncology is one of the main fields in which QoL began. Aaronson (1989) identified several reasons for QoL being developed in the oncology area:

1. The patient's needs and choices need to be considered before making treatment decisions.

Aaronson argues that cancer has been a long-term and not always curable disease. He concluded that it was quite important that in the selection of treatment choices and care strategies, patients can receive particular attention. In addition, before introducing the QoL concept, it was common for health care professionals to select a treatment choice for a cancer patient without any consideration of what patients wanted.

2. The need to identify less toxic treatments.

Despite significant advances in improving the survival of cancer patients and introducing a number of cancer treatments, Aaronson describes the concerns to identify less toxic cancer treatments. According to him, toxicities related to treatments can affect the QoL of cancer patients, and QoL assessment was a way to identify better treatments with less toxicity.

The implication of Aaronson's view is that cancer patients will benefit. For example, a specific group of cancer patients can potentially receive a chemotherapy or radiotherapy regimen as a treatment. Through QoL assessment patients might express, for example, that a radiotherapy regimen has a better impact on their QoL than chemotherapy. So it might be helpful for health care professionals to realise that the radiotherapy regimen has less treatment toxicities for patients and they continue with that treatment.

3. The need to consider patients' rights.

According to Aaronson, much more attention was paid to the concepts of

patients' rights and especially formal consent. These rights enable patients to be informed and QoL assessment was a unique way to translate medical information into understandable concepts for patients.

This movement as explained by Aaronson has been beneficial to cancer patients. For example, it became quite important that patients have a right to make choices about their treatments, how they let health care professionals treat them, and even they can say 'No' to a treatment if they think that they cannot or will not tolerate it. Health care professionals can provide cancer patients with a QoL tool, through which patients can understand a number of issues and have this opportunity to convey to the health care professionals their expectations and needs.

4. The need to approach treatment more holistically.

Finally, Aaronson describes the way in which more emphasis was put on treating cancer patients with a holistic approach. In fact, in cancer treatments both psychological and physical toxicities are important. QoL assessment was a useful approach, which increased awareness that with treatments, both the patient's physical and psychological toxicities should receive particular attention.

Aaronson suggests that when a patient is receiving a chemotherapy regimen, for instance, they are faced with a range of physical toxicities (e.g. stomatitis and diarrhoea) and psychological and emotional toxicities (e.g. a sense of isolation and body image disturbances) and all of them need to be taken into consideration. A health care professional cannot provide effective care and treatment to a patient experiencing stomatitis, for example, with a chemical component which provides only pain relief and comfort in the oral cavity but forget the preceding anxiety associated with it or the fear of recurrent stomatitis. The researcher's experience suggests that when managing a stomatitis, a broad range of concerns can be explored; a small window to the holistic care of clients.

Altogether, the development of the concept of QoL concept is a response to patients who believe that they are not only physical bodies but also human beings who want to live and have personal needs and interests. QoL to this day continues to be a controversial concept and its definition has been a contested field.

QoL definitions

Several researchers (Cella & Tulsky 1990; Varricchio 1990) on the issue of QoL research in a clinical area like oncology have insisted on the need for a workable definition. This is a difficult task as there is no universally accepted definition and many debates exist (Bottomley 2002; Fayers & Machin 2000; Hendry & McVittie 2004; King et al. 1997). There are several reasons why there is a lack of consensus about the definition of QoL. Firstly, this concept has a highly individual nature related to one's personal values (Anderson & Burckhardt 1999; Carr, Gibson & Robinson 2001; Holmes & Dickerson 2003; King et al. 2002; Mast 1995; Zhan 1992). It is "a vague and ethereal entity, something that many people talk about, but which nobody very clearly knows what to do about" (Campbell, Converse & Rodgers 1976, p. 471). Assessment of QoL includes "the measurement of practically anything of interest to anybody" (Andrews & Withey 1976, p.6). A concept that is so highly subjective will inevitably make it difficult to offer a definition acceptable to all because it constitutes issues that are experienced by a broad range of people.

Secondly, the definition of QoL is often related to who is involved and from what perspective. For example, many philosophers emphasised that QoL is related to personal happiness (Holmes 1989). Chinese philosophers believe that quality of life is achieved if there is a balance between Yin and Yang (Zhan 1992). Economists define QoL as being associated with the allocation of resources to achieve aims (Anderson & Burckhardt 1999). So, different disciplines have different approaches to QoL definition.

Thirdly, some similarities can be observed between this concept and others such as health, well-being, and life satisfaction, to name a few, which makes it even more difficult to introduce an exact and consensual definition of QoL (Anderson & Burckhardt 1999; King et al. 1997; Zhan 1992). People, for example, may think that

life satisfaction is with the same as QoL, while others will argue that it is just a part of it which only takes into the account the subjective aspects of QoL (King 2003).

Due to these ambiguities, different definitions have been proposed. Some common definitions of QoL are as follows:

1. individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (World Health Organisation 1996, p.6);
2. a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her (Ferrans & Powers 1992, p.29);
3. subjective evaluation of the positiveness or negativeness of attributes that characterize one's life (Padilla et al. 1990, p.108).

Despite different definitions, some important characteristics emerge from such definitions of QoL. Firstly, QoL is an individual experience. No two persons can be assumed to have the same level of QoL before it can be assessed (Hinds & King 2003). Further, comparing two persons who appear to have the same level of QoL as a means of assessing one's QoL is problematic because the perception of QoL varies amongst individuals.

Secondly, QoL is a subjective judgement; a perception or sense. Even though there are some objective measures that can show individuals' perceptions of QoL (King 2003), no outsider can claim that one can truly assess somebody else's QoL based only on such measures. For example, daily living activities of patients, as an objective criterion, can be used to assess how patients are physically independent. While it may be logical to assume that patients who are more independent in their daily activities have higher levels of QoL, this would be an incomplete evaluation unless other subjective issues and concerns are also considered.

Finally, the level of QoL is related to different things in individuals' lives such as expectations, important life goals and chosen activities. In other words, achieving an appropriate level of QoL for a specific person depends on meeting different needs that are priorities for that person.

This current research study is mainly based on the first definition (above) developed by the WHO. The WHO definition supports the study because it includes all of the above mentioned factors (individuality, subjectivity, and breadth). In other words, in this research study QoL is considered as being the patients' perception, which is individual and subjective. It is acknowledged that the patient is the most important source of QoL information and other perceptions about patients' QoL need to be compared on that basis. This thesis also accepts the notion that QoL consists of different aspects that constitute a person's QoL. These are usually called QoL domains or dimensions. Research studies related to QoL need to clarify what QoL domains will be considered.

Quality of Life domains

Like QoL definitions, disagreements exist as what domains exactly contribute to individuals' QoL. This is not surprising because the domains are based on the QoL definitions. The terms QoL domain, QoL dimension, and QoL aspect are used interchangeably (Gill & Feinstein 1994; Glaus 1993; Trompenaars et al. 2005). In this research study these terms (QoL aspects, QoL domains, and QoL dimensions) are used interchangeably. Quality of life domains are considered to be "a set of elements to which a variable is limited, or the range over which the concept of QoL extends" (Schalock 2004, p.205). A QoL domain consists for particular components (Gill & Feinstein 1994). Generally speaking, there is not general consensus about the range of domains or aspects of QoL (Draper 1992; Ferrans & Powers 1985; Schumacher, Olschewski & Schulgen 1991).

While in the past only one QoL domain - such as physical - has been measured, most experts would agree that QoL consists of at least the physical, psychological and social domains (Boling, Fouladi & Basen-engquist 2003; Cox 2003; Tallis 2005). Additional domains have also been identified such as the functional (Brunelli et al. 1998; Cella et al. 2002; Fallowfield 2002; Wilson et al. 2000), emotional (Cella et al. 2002; Fallowfield 2002; Movsas 2003; Schumacher, Olschewski & Schulgen 1991), spiritual (Bonomi et al. 2000; Ferrell Dow & Grant 1995; King et al. 1997), family (Ferrans & Powers 1992), illness (Hawthorne, Richardson & Osborne 1999), independent living (Bonomi et al. 2000; Hawthorne, Richardson & Osborne 1999),

symptoms and side effects (King et al. 1997; Lindley 1992) and environmental domains (Bonomi et al. 2000).

It is important to consider what QoL domains are suggested by the WHO. Based on the WHO definition of QoL, QoL must be assessed across six domains. They are: physical health; psychological health; level of independence; social relationships; environment; and spirituality. In order to address these QoL domains, WHO constructed a QoL tool named WHOQoL-100 (The WHO Group 1998a).

The WHO later developed another QoL tool named the WHOQoL-BREF questionnaire. This tool is a short version of the WHOQoL-100, which is useful for assessing QoL in the clinical area. It assesses QoL across four domains: physical, psychological, social relationship, and environmental (World Health Organisation 1998). The domains concerning spirituality and the level of independence appearing in the original tool were merged into other domains. In the survey (first) phase of this research study, QoL is assessed across four domains as recommended by the WHOQoL-BREF questionnaire. More details about this tool and other QoL tools can be seen in Chapter Four.

Even though the WHOQoL-BREF questionnaire is generally an appropriate tool for use in clinical contexts, some criticism exists. For example, it has been emphasised that items in the social aspect of the tool may not be comprehensive enough to assess this domain (O'Carroll et al. 2000). So this research study will help to determine the appropriateness of this tool further by addressing one of its main psychometric properties, namely reliability, and through interpretive analyses, which emerge in the second phase of the research study. The critique of the WHOQoL-BREF questionnaire is discussed in Chapter Nine. QoL domains of the WHOQoL-BREF questionnaire and their related facets are demonstrated in Table 2-1. In this table, each facet is defined as a behaviour, state of being, a capacity or potential, or a subjective perception or experience (The WHOQOL Group 1994).

Table 2-1: Description of aspects of the WHOQoL-BREF questionnaire expressed as domains and facets of QoL

Domain	Facets incorporated within domains
1. Physical health	Activities of daily living Dependence on medicinal substances and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work Capacity
2. Psychological	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality / Religion / Personal beliefs Thinking, learning, memory and concentration
3. Social relationships	Personal relationships Social support Sexual activity
4. Environment	Financial resources Freedom, physical safety and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation / leisure activities Physical environment (pollution / noise / traffic / climate) Transport

Source: World Health Organisation (1996, p.7)

To conclude, QoL is a broadly defined concept and located in multiple domains. In the survey phase, this research study uses the WHOQoL-BREF questionnaire. It assesses QoL across four domains as recommended by the WHOQoL-BREF questionnaire: physical, psychological, social relationship, and environmental. This research study acknowledges the very personal nature of the QoL concept and for

this reason incorporates a more in-depth assessment of QoL during the interpretive phase of the research study.

When QoL research is conducted in the clinical area, it is also important to make a decision whether to use the term QoL or Health Related Quality of Life (HRQoL). This includes domains that are suitable for the clinical area but is again a debatable issue that will need to be considered further in the next section.

Differences between Quality of Life (QoL) and Health Related Quality of Life (HRQoL)

Similar to debates about QoL definitions and domains, an ambiguity can also be observed in the literature about the difference between QoL and HRQoL. Some researchers (Boling, Fouladi & Basen-engquist 2003; Fayers & Machin 2000; Movsas 2003) believe that the term QoL is used in a variety of fields, but the term HRQoL is often used to indicate quality of life in relation to diseases and therapeutic interventions and argue that it is a more suitable term in clinical research trials and in the medical field. Boling et al. (2003) also indicated that HRQoL differs from the general concept of QoL, in that it usually includes the psychological, physical, and social functioning of patients, but excludes perceptions of environment, housing, or other external domains.

Hunt (1997) in an editorial paper, critically reviewed QoL definitions and domains and pointed out that the term HRQoL has been inserted to solve some criticisms related to the QoL concept. However, separating effects or problems related to health from those simultaneous issues related to finance, friendship, family life, responsibilities, expectations, occupation and aging is in reality not a well considered distinction to make when one takes into account the overlap between them. Family problems, for example, may worsen the process of patients' recovery whereas those patients with a more supportive family might receive better care and therefore more rapid improvement in their health status. Guyatt et al. (1993) also indicated HRQoL is a suitable term as a means of emphasising those aspects of QoL related to health. However, when a patient is so ill, all aspects of life such as income, freedom, and environmental issues not directly related to health, should be regarded as health-

related matters.

To address this ambiguity, in many research or review articles (Allison, Guichard & Gilain 2000; Bezjak et al. 2001; Cella, DF 1996; Dancey et al. 1997; Fayers et al. 1997; Stavem et al. 2000; Stephens et al. 1997; Trompenaars et al. 2005) both terms QoL and HRQoL have been used though without any rationale as to why. It also appears that even the WHO did not make a clear distinction between these two terms and prefers to define the term QoL. The reason might be that domains introduced by the WHO are comprehensive enough to consider any issues important in the clinical area or under other circumstances. So the WHO definition of QoL might imply that such a distinction between QoL and HRQoL may not be appropriate. A review study on 75 QoL articles was conducted by Gill and Feinstein (1994) to evaluate how well QoL is being measured in the medical literature. Results revealed no article differentiated 'overall' QoL from HRQoL (Gill & Feinstein 1994). It is also interesting to note that QoL and HRQoL are also considered to be synonymous terms in some websites (Phoenix 5 2002).

It can be concluded that while both terms, QoL and HRQoL, have been used extensively and interchangeably in this field, the term QoL is more suitable for this study. The reason is that the term QoL is an easier term to follow compared with HRQoL. It is a holistic concept because this research study was based on the WHO definition of QoL and QoL domains might be comprehensive enough to include all issues that might be important for individuals.

Implications of QoL information

The literature generally describes implicitly or explicitly the reasons behind assessing QoL (Aaronson 1989; Fayers & Machin 2000) and in the oncology area specifically (Jacobsen, Davis & Cella 2002; Roila & Cortesi 2001; Wright et al. 2003). Fayers and Machin (2000, pp.7-14) described seven subdivisions where QoL assessment existed in randomised clinical trials:

- 1) clinical trials of treatment with curative intent;
- 2) clinical trials of treatment with palliative intent;

- 3) improving symptom relief, care or rehabilitation;
- 4) facilitating communication with patients;
- 5) patient preferences;
- 6) late problems of psychological adaptation;
- 7) medical decision-making.

In the following pages these subdivisions will be discussed more fully with some examples from oncology and non-oncology literature used to clarify the importance and value of QoL data. While QoL implications are discussed in separate sections, overlap exists between these implications. For example, while a research study is conducted with the aim of improving care or communication with patients, it can also help researchers to identify patients' preferences. Another research study, for instance, might be conducted with a curative purpose but outcomes can also be useful for better care.

1-Clinical trials of treatment with curative intent

Several authors (Cella 1995; Gridelli, Cortesi & Roila 2001; McMillan 1996) state in many cancer cases, such as malignant lymphoma or testicular cancer, the goal of therapy is to cure and to remove disease but even in these examples, there are treatment side effects. In this context, QoL can be affected and should be considered. Regarding another example, where two treatment options have equal impact on the survival rate, the final decision in choosing the best option, may be in favour of the one with better impact on QoL (de Haes & van Knippenberg 1985; Litwin et al. 1999; Maguire & Selby 1989; Strain 1990).

For example, Testa et al. (1993, cited in Fayers & Machin 2000), in their study on an evaluation of two anti-hypertensive drugs, found that the effect of drugs on the sampling population was the same in the terms of efficacy and safety, but QoL scores were different. The results were useful for selecting one drug. This research study is similar in its purpose with another one conducted by Palmer et al. (1980). In this research study, researchers aimed to select one chemotherapy regimen (one drug versus five drugs) suitable for breast cancer survival with metastasis. Patients reported worsened QoL related to multi-drug chemotherapy so it was useful for

selecting a one drug regimen.

In a study on 224 locally advanced breast cancer survivors, the effect of two chemotherapy regimens (systemic standard chemotherapy versus dose-intensified chemotherapy) on QoL was measured so as to select one regimen. Research findings showed in a three-month period, intensified treatment had a worse effect on QoL than the standard one, but the QoL scores were the same after 12 months. The authors concluded that dose-intensive treatment has a temporary impact on QoL and needs more research to assess this regimen (Bottomley et al. 2005).

In another study, two kinds of treatments (amputation plus chemotherapy versus limb-sparing surgery plus radiation therapy plus chemotherapy) were compared in their effect on QoL in 26 patients with soft tissue sarcoma. Research findings revealed that the QoL scores of patients under limb-sparing surgery plus radiation were not higher than those under amputation as researchers had assumed it would be (Sugarbaker et al. 1982). This can show how perceptions of other people about patients' QoL vary with that of patients' own perceptions.

In the above cases the selection of one treatment from two groups is relatively easy to identify as the impact of two treatments on the survival rate is relatively equal, but one treatment can lead to a better or worse QoL. However, when one treatment leads to an increase in survival but decreases the QoL or, vice versa, improves the QoL but decreases survival, selecting one treatment from the two is more difficult (Roila & Cortesi 2001). In these situations, there are two solutions. The first solution is to consult with patients about all positive and negative effects of different treatment choices and consider the patient's preferences. This option gives more weight to patients' perspectives and places the patients central to decision making. The importance of patients' preferences will be discussed further in this chapter. The second solution is to use measures in which quality and quantity (duration of survival) combined together like Quality Adjusted Life Years (QALY) and Quality-Adjusted Time Without Symptoms and Toxicity (Q-TWIST) (Mandelblatt & Eisenberg 1995; Roila & Cortesi 2001). In this option the attention is given to both patients' and health care professionals' perspectives; patients' perspectives about their QoL are assessed using utility QoL tools. Chapter Four will elaborate on the

types of QoL tools that exist.

One of the most common measures of combining the quantity with quality is the QALY (Mandelblatt & Eisenberg 1995). The basis of this approach is that if two options are offered to individuals to choose either a longer life with serious problems or to have a shorter but more healthy and satisfactory life, a rational person would choose the second option (Hunt 1997). For a patient, for example, conducting a chemotherapy regimen might improve the survival rate up to 10 years but the associated quality of life using a utility tool might be 0.5 due to severe chemotherapy toxicities and the QALY of the patient is only five years ($10 \times 0.5 = 5$ QALY). This chemotherapy might be superior to another treatment with the utility of 0.4 due to more toxicities but with a survival of 11 years ($11 \times 0.4 = 4.4$ QALY) (Giesler 2000).

Q-TWIST is another extension of the QALY in which time and the patients' preferences are considered together (Mosconi et al. 2001). Giesler (2000) suggests that in order to calculate the Q-TWIST, survival time needs to be divided into three health states: (a) a period of time that patients experience toxic effects of therapy (TOX); (b) a period of time after completion of therapy without symptoms or toxicities (TWIST); and (c) a period of time after the relapse (REL). QoL during these times (except TWIST) are measured using a utility tool. TWIST receives a maximal utility of 1 and then Q-TWIST is calculated based on the following formula:

$$\text{Q-TWIST} = (\text{utility value during the TOX} \times \text{TOX}) + \text{TWIST} + (\text{utility value during the TOX} \times \text{REL})$$

It can be concluded that QoL information has important implications for choosing a treatment option. Even so, other criteria such as survival or treatment side effects are also important; QoL information arising from patients is central to such decision-making. It is therefore essential to get patients' perspectives about their QoL because it can reflect their treatment choices. The situation is similar when the decision is made for palliative purposes.

2-Clinical trials of treatment with palliative intent

The cited QoL studies so far have had a curative purpose; however, for many

patients, particularly those with advanced cancers, the goal of therapy is palliation and not to prolong survival or produce a cure (Gridelli, Cortesi & Roila 2001; Horton 2002; Mandelblatt & Eisenberg 1995; McMillan 1996; Moinpour et al. 2000; Payne 1992; Perez et al. 1997; Slevin et al. 1988). The aim of treatment is to palliate symptoms or to prolong the time without symptoms and in these situations QoL is considered as an outcome for symptom evaluation and management (Brunelli et al.; McMillan 1996; Michael & Tannock 1998; Schipper & Levitt 1985). Many research studies exist that show how outcomes of QoL research studies are useful for choosing a palliative treatment.

In a study by Osoba (1999), the effect of two kinds of drug regimens (prednisone alone versus mitoxantrone plus prednisone) was used to measure pain and QoL endpoints of metastatic prostate cancer patients. Results identified that treatment with mitoxantrone plus prednisone compared with only prednisone was associated with lower levels of pain and better QoL in several QoL domains.

Coates et al. (1987) did research on metastatic breast cancer patients to compare two kinds of chemotherapy regimens (continuous chemotherapy versus intermittent therapy) with non-curative purposes. The outcomes, surprisingly, found patients under continuous chemotherapy have better QoL and better palliative results than those with intermittent chemotherapy. For such a cancer the goal of treatment is not curative. Therefore in this research the important criterion for selection was the better scores of one regimen on physical well-being, mood, pain, and appetite and a quality-of-life index.

In a study of chemotherapy as palliative treatment by Earl et al. (1991), 300 small-cell lung cancer patients were selected and randomised to receive either regular 'planned' or 'as required' chemotherapy. The chemotherapy regimen was the same in both groups. The planned group received chemotherapy on a regular basis and the 'as required' group received it based on factors such as disease symptoms. QoL and symptom assessment measurements were conducted for both groups. Despite the fact that 'as required' chemotherapy is considered by health care professionals as a unique way of using chemotherapy for palliative purposes, patients receiving this treatment assessed their QoL lower and experienced more severe symptoms than

patients receiving ‘planned’ treatment. It was concluded that ‘as required’ chemotherapy is a less satisfactory treatment compared with planned chemotherapy for palliative purposes.

In another research study, Tannock et al. (1988) selected a chemotherapy regimen for metastatic breast cancer patients and used two different doses, initially using the low dose and for those patients failing to respond to this, a higher-dose was used. QoL was measured using linear analogue self-assessment scales. While, higher-dose chemotherapy made more toxicity immediately after treatment, the QoL of patients generally improved after this period. This trial suggests that using a full-dose chemotherapy regimen can improve QoL of patients and is useful for palliative purposes.

These cases mentioned above indicate how patients’ ideas about QoL may be considered when a plan is made to palliate patients. Often patients’ palliative choices differ from routinely used care plans.

3-Improving symptom relief, care or rehabilitation

In many cases QoL data was used to provide useful information to relieve specific symptom(s) such as fatigue, dyspnoea, pain, nausea, vomiting and to improve care and rehabilitation (Fayers, Curran & Machin 1998; Isikhan et al. 2001; Jacobsen, Davis & Cella 2002; Movsas 2003; Osoba 2000).

Langendijk et al. (2000) conducted research with the aim to assess QoL and respiratory symptom change in a group of 65 patients with metastatic non-small-cell lung carcinoma (NSCLC) before and after three episodes of thoracic radiotherapy. Patients reported the following QoL response rates: 1-excellent for haemoptysis (79%); 2-good for arm/shoulder pain (56%) chest wall pain (53%) and cough (49%); 3-moderate for dyspnoea (39%); and minimal for the general symptoms fatigue (22%) and appetite loss (11%). Global QoL improved in 37% of the cases. This study confirmed that the radiotherapy regimen was useful for palliation of respiratory symptoms and could improve QoL in this patient population.

QoL information can also be used by health care professionals involved in patient care or rehabilitation, for a wide range of issues including assessing physical and psychological problems or morbidities and to plan, evaluate and modify a specific program of care (Grant et al. 1990; Wright et al. 2003). For example, results of recent research study demonstrate that lung cancer patients benefit from psychological support at the beginning of their treatment, due to the disease's impact on the social and emotional part of their QoL (Lheureux et al. 2004). Consequently, it is clear that QoL assessment has implications for the development of a suitable psychological support program for lung cancer patients.

Results of a longitudinal research study by Sweed et al. (2002) on oesophageal cancer patients before and after oesophagectomy revealed that global QoL decreased slightly over time and the intensity of several symptoms including hoarseness, reflux and diarrhoea after oesophagectomy increased and led to a gradual decrease in the QoL scores. They also concluded that where a decrease in symptom intensity is observed, it is very important to institute measures to increase QoL and nursing care plays a major role in this effort. Another study conducted by He and Liu (2005) on nasopharyngeal cancer patients revealed that such patients benefited from education about the side effects of radiation therapy and needed to be supported in the use of appropriate coping styles by nurses.

Another study by Deschler et al. (1999) compared QoL assessment scores between cancer patients and their primary lay caregiver (spouse, child or friend) before head and neck surgery. Research findings identified that, except for some areas of differences, such as pain and general health, there was agreement between patients and the primary lay caregiver in several aspects of a given QoL tool. The researchers concluded that such concordance has implications for outpatient rehabilitation of cancer patients by their relatives.

4-Facilitating communication with patients

Fayer (2000) stated that the aim of QoL assessment in some situations is to provide information to be used in caring for future patients. Meyerowitz (1993) mentioned that QoL information indirectly informs physicians and nurses about the common

concerns and psychological reactions of patients and this knowledge can be used to anticipate the problems, to communicate better or to discuss issues further that otherwise may be overlooked when caring for this group of patients. Such information can be collected by filling out a QoL questionnaire when patients, for example, are waiting to see a doctor or questionnaires can be completed easily through a computer (Schwartz & Sprangers 2002).

Jacobsen, Davis and Cella (2002) also agree that QoL assessment can be helpful to identify problems that staff may be reluctant to ask patients about or patients may be hesitant to express directly to staff, such as sexual concerns. While health care professionals are constantly being challenged in communication with cancer patients to tell the truth about having a cancer in order to maximise patients' QoL, results of QoL assessment before and after cancer diagnosis on two groups revealed that, generally, knowledge about the cancer and its treatment does not significantly affect patients' QoL (Montazeri et al. 2004).

Velikova et al. (2004) explored the effects of regular assessment and use of QoL assessment in an oncology area on the process of care and patient well-being. From 286 cancer patients, a number were randomly classified into three groups. The first group consisted of those who completed QoL assessment and other relevant forms by computer and gave the results to oncologists. The second group completed the questionnaires but did not provide any feedback and finally there was a control group for whom no questionnaire was filled in. They concluded that routine assessment of cancer patients' QoL can improve communication between physicians and patients and is beneficial, particularly for patients who, as a result, had better QoL and emotional functioning.

5-Patient preferences

Perspectives, expectations, attitudes and preferences of patients in some situations may differ from those judgements by health care workers such as physicians or nurses and even from other groups of patients or healthy persons (Belcher 1990; Tamburini 2001; von Essen 2004). For this reason, QoL assessment can provide an opportunity to understand these differences more clearly.

Some research findings identified that many cancer patients rated their QoL relatively highly and they were generally satisfied with their lives (Bush et al. 1995; Rustoen et al. 1999; Waldron et al. 1999). Staff and relatives, on the other hand, tended to underestimate the patients' psychological problems, exaggerated physical symptoms, misjudged the patients' trade off between quantity and quality and underestimated the patients' QoL (King et al. 1995; Molzahn, Northcott & Dossetor 1997; Tamim, McCusker & Dendukuri 2002). In a study conducted by Slevin et al. (1990), for example, findings revealed that cancer patients generally accepted positively an intensive chemotherapy regimen with less benefit than did healthy people or attending staff such as doctors and nurses.

A study was carried out by Montazeri et al. (2003) to better understand QoL of lung cancer patients using three types of QoL questionnaires before and after diagnosis and between cancer patients who received the treatment and those who did not. This research study reported on different kinds of health problems that this group of cancer patients experienced after diagnosis of cancer. It was concluded that QoL information can enhance our understanding of cancer patients' experiences of their treatment.

Another study (Koller et al. 2000) where 55 cancer patients under radiotherapy were assessed to understand the relationship between therapy expectations and global QoL before and after radiotherapy, revealed three kinds of expectations including: (a) pain/emotional control; (b) healing; and (c) tumour/symptom control. Nineteen patients had curative treatment but 35 patients reported "healing" as an expectation. The more expectation there was of healing, the better QoL was observed. In the group as a whole, radiotherapy decreased patients' QoL only a little, but it substantially worsened the QoL of those patients who had an expectation of healing but perceived that this had failed. These findings indicate that in cancer patients, the expectation of healing is one major component of a good global QoL, whereas more limited expectations (pain control, tumour control) relate to lower QoL. Further research about patients' expectations and how it can improve the patients' care and rating of their own QoL was recommended.

An interpretive phenomenological study was conducted by McGrath (2004) to

uncover positive spiritual outcomes for survivors of haematological malignancies. Results revealed that those patients who gain successful treatment results and are well supported can experience positive outcomes such as greater confidence and independence, better capability to express their personal needs, being more informed of body needs, and being less judgmental. In general, such patients were mindful that the treatment was the gift of extra life. They wanted to experience life at the fullest level and to be able to do those things they were interested in doing. McGrath (2004) noted that during the cancer journey, patients also experienced a heightened sense of family togetherness, awareness of reliable friends and family members, respect from others, and changes in work values. These changes were associated with an overall improvement in QoL.

6- Late problems of psychological adaptation

Many of the physical and psychological problems for patients surviving cancer may be similar to those experienced by patients with chronic diseases and will be found to exist over a long period of time (Aziz 2002; Movsas 2003). QoL information may help health care staff to understand these problems more clearly (Schwartz & Sprangers 2002; Thapa & Rowland 1989). QoL assessment may lead to better understanding of some aspects of patients' QoL, including psychosocial problems and pain intensity, if patients' QoL can be followed up over longer time periods by caregivers (Byar, Eilers & Nuss 2005). For example, an eleven year follow-up of long-term survivors of testicular cancer was undertaken in order to evaluate their QoL using two QoL tools and to assess social problems. A comparison was made between this group (case group) and a healthy control group. Generally speaking, no significant difference was identified between QoL scores of the case and the control groups. The study also revealed that, except for patients' sexuality problems, patients generally did not have a greater range of associated health problems than the 'healthy' population.

Bush et al. (1995) conducted research to assess the QoL and the health problems of 125 adults surviving 6–18 years after bone marrow transplantation. Research findings revealed that, except for a very small proportion, long-term survivors generally reported full and meaningful lives, with no major continuous

complications, and viewed themselves as cured and well.

7-Medical decision making

QoL information is valuable when making medical decisions (Belcher 1990; Strain 1990). For example, QoL scores in cancer patients can be a strong predictor of survival (Blazeby, Brookes & Alderson 2001; Butow, Coates & Dunn 1999; Montazeri, Gillis & McEwen 1998; Montazeri et al. 2001; Osoba 1999; Schwartz & Sprangers 2002; Shadbolt, Barresi & Craft 2002; Sprangers 2002), particularly the physical aspect of QoL assessment, which has been a major predictor of survival in cancer patients (Arraras et al. 2002; Cassileth et al. 1985; Cassileth, Walsh & Lusk 1988; Chang et al. 1998; Vigano et al. 2004).

There are many documents that emphasise the strong relationship between QoL scores, irrespective of other values, with survival rate. For example, a study conducted by Coates, Porzsolt and Osoba (1997) assessed the prognostic value of QoL scores in a group of advanced cancer patients. Results revealed that QoL scores carry prognostic information independent of other recorded factors. The value of QoL scores as a predictive factor for survival was also confirmed for breast cancer patients after disease relapse (Coates et al. 2000), with metastatic malignant melanoma (Coates et al. 1993), lung cancer (Ruckdeschel & Piantadosi 1994) and colorectal liver metastasis (Earlam et al. 1996). Therefore, QoL information arising from research studies has several implications. Such data will be useful in selecting an efficacious treatment incorporating curative and palliative intentions, and in improving communication with patients and understanding of their preferences.

This study also assesses the influence of some important variables on the nurses' understanding of patients' QoL. This is an important aspect of exploring why patients and nurses may differ in their perceptions. Research studies in which the influence of variables on the level of agreement on QoL were assessed are very limited, particularly those with nurses as proxies, oncology patients, and with interpretive methodologies. The relevant literature therefore was reviewed to address this issue.

Variables influencing agreement between patients and nurses about cancer patients' QoL

It is important to recognise that nurses' perceptions of cancer patients' QoL may differ from patients' own perceptions for a number of reasons. Important variables might be related to patients (such as age, sex, and education), proxies (such as age, sex, education, and time spent with subjects) and other general issues (such as QoL domains, QoL assessment) (Addington-Hall & Kalra 2001). These important issues affecting the level of QoL agreement will be explored further in the following subsections.

Patients' and proxies' demographics

It might seem obvious that different variables such as age, gender, marital status, and educational level might influence agreement between patients and proxies (McPherson & Addington-Hall 2003). However, previous research findings led to inconsistent outcomes when effects of such characteristics on agreement were explored.

For example, variables including age, gender, socioeconomic status, and marital status of patients have no effect on the level of agreement between patients and proxies about QoL (Epstein et al. 1989; McCusker & Stoddard 1984). Both Epstein et al. and McCusker and Stoddard used QoL tools other than the WHOQoL-BREF questionnaire and sample populations were less than 100, which is generally considered to be a small sample size. Larsson, von Essen and Sjoden (1998) compared the perceptions of seventeen patients with endocrine cancer and their staff by using the European Organization for Research and Treatment of Cancer (EORTC) QoL questionnaire. Findings from their study revealed that no specific pattern for the effect of patients' and staff members' demographic variables regarding agreement could be identified.

The same outcomes emerged when QoL of 103 cancer patients was compared with QoL perception of their significant others using the EORTC QoL questionnaire. No significant relationship was found between a range of patients' and proxies' background characteristics (such as age, gender, proxies' relationship with the

patient, and the living arrangement in relation to the patient) and the level of agreement between them (Sneeuw et al. 1997).

Brunelli et al. (1998) also conducted a research study to measure agreement between 159 terminal cancer patients and proxies using the Therapy Impact Questionnaire (TIQ). They demonstrated that none of the demographic factors for patients or proxies have a statistically significant effect on the level of QoL agreement between the two. Even though the patient sample size is not small, they do not state how many proxies took part in the study. However, other studies have led to conflicting results. In Sneeuw et al.'s (1998) analysis, the extent of agreement between 307 cancer patients and 224 proxies was compared using the EORTC QLQ questionnaire. In this research study several demographic variables of cancer patients and their significant others were found to be associated with the level of agreement. However, using multivariate analysis these factors together explained only less than 15% of the variance in patient-proxy differences (Sneeuw et al. 1998). This research study used a large sample size for both patients and proxies and had more precision to identify the influence of several variables on agreement.

Another research study was conducted by Kristjanson et al. (1998) in an Australian population. The two main objectives were to assess the level of agreement between terminal cancer patients and family caregivers about symptom distress and to identify the effect of demographic and disease and treatment related variables on the level of agreement. 78 dyads of patients and caregivers agreed to participate in the study. The outcomes identified a reasonable agreement between proxies' ratings of symptom distress and cancer patients' rating. These results have also been reported to be similar to those of a Canadian research study conducted by Lobchuk et al. (1997) and confirm that family members may provide reasonable proxy ratings of advanced cancer patients' symptom distress. A few demographic variables, such as marital status, gender of the patient, age of the family caregiver, the relationship between the patient and family caregiver and family income, were also identified to affect the level of agreement. This research study assessed agreement on a part of QoL (symptom distress) and was conducted on a small sample.

Relatively similar outcomes were explored in another research study in which cancer

patients' and caregivers' (a family member or a nurse) assessment of symptom distress were compared with each other. While no statistically significant relationships of patients' demographics of sex, age and education level and agreement were found, non-statistically significant tendencies were found for some caregiver demographics such as education, professional experience, and family caregiver burden (Broberger, Tishelman & von Essen 2005).

The influence of educational level was also identified in another proxy research study conducted by Muhlenkamp (1986). In this research study, agreement between 30 hospitalised arthritis patients and 26 registered nurses on affective states (hostility, anxiety, and depression) was assessed. One of the main findings of the study was that agreement was better when nurses had a higher level of education. In another study, the level of agreement between 231 elderly patients and their primary care givers was assessed using the Euro QoL (EQ) questionnaire. Amongst the demographic variables, greater agreement was found between patients and proxies when the proxy's native language was English (Tamim, McCusker & Dendukuri 2002).

Research conducted to explore the influence of demographic variables on the level of agreement about QoL suggests that outcomes are varied and at times contradictory. No general trend can be identified that shows that particular variables influence the level of agreement in a specific direction. It appears that effects of such variables need to be explored further, particularly using larger sample sizes. An important issue is that a small sample size can lead to biased outcomes (von Essen 2004), particularly when samples are about 50 or less in each group of patients and proxies (Sneeuw, Sprangers & Aaronson 2002).

Patients' health status

The effect of patients' health status on patient-proxy QoL agreement is also an area of debate (McPherson & Addington-Hall 2003). In some studies looking at proxy rating of cancer patients, the degree of QoL agreement was influenced by the clinical and performance status of the patient as an indicator of health status. For example, a research study was conducted to evaluate the QoL rating amongst 90 cancer patients

and their significant others, physicians and nurses on a given QoL tool. Part of the outcomes indicated that agreement was better when patients have a very good or poor performance status (Sneeuw et al. 1999). Performance status using Eastern Cooperative Oncology Group (ECOG) shows how the disease is progressing, how it is affecting the daily living abilities of the patient, and determines appropriate treatment and prognosis. However, in another study no relationship was found between cancer patients' and significant others' agreement and overall performance status of patients (Sneeuw et al. 1997). So it is still necessary to investigate how indicators of patients' health status like patients' performance status can influence the level of agreement between patients and proxies.

Contact time between patients and proxies

It is generally accepted that more contact time between the proxy and the patient, results in better agreement in QoL ratings (Lobchuk & Degner 2002; Magaziner et al. 1988; Tamim, McCusker & Dendukuri 2002; Tang & McCorkle 2002b; von Essen 2004).

Steel, Geller and Carr (2005) found that agreement between cancer patients and caregivers including a family member or a physician was generally better after three months compared with the baseline assessment. Proxies had more contact with patients during this period of time and could better monitor changes in the patients' QoL. This effect can also be identified in another research study in which agreement between patients and proxies was better in a four month follow-up compared with the baseline due to spending more time with patients (Tamim, McCusker & Dendukuri 2002).

While the duration of contact between patients and nurses is a key issue in agreement, how proxies use their time in getting to know the patient may be most important. For example, a proxy research study was conducted by Broberger, Tishelman and von Essen (2005) to explore discrepancies between lung cancer patients and their caregivers (nurses and family caregivers) in assessment of symptom distress and symptom occurrence. Thirty three patient–nurse dyads and 54 patient–family caregiver dyads assessed patients' symptom distress and symptom

occurrence. In this research study, instead of asking about the length of time the proxy had known the patient as an indicator, nurses were asked to answer the question “How well do you know this patient?” Results demonstrated that nurses knew two patients very well, 26 patients well or fairly well, and five patients not at all. The result indicates that caregivers, including nurses, might spend a period of time with patients but not know them in-depth or well.

Another issue is that spending more time with patients might also lead to disagreement in some situations. In Magaziner et al.’s (1988) research study, agreement between 361 elderly hip fracture patients and their proxies was assessed on measures of patient health and functional status. The outcomes indicated that proxies with more contact with patients had better agreement with patients but when they did disagree with each other, proxies with the greatest patient contact tended to overestimate patient disability (Magaziner et al. 1988).

It can be concluded that when nurses spend enough time with patients they may better understand patients’ QoL. In this research study, the effect of the time each nurse spends with cancer patients on their understanding of patients’ QoL was examined.

Proxies’ burden

As proxies usually are in a close relationship with patients, they are susceptible to many stressor burdens that can affect and disrupt their own QoL (Edwards & Ung 2002; Ergun, Oran & Bender 2005; Meyerowitz 1993; Tang & McCorkle 2002b). It is argued that such stressors in turn can influence their evaluation of the patient’s QoL. For example, Sneeuw et al. (1998) found that QoL disagreement between cancer patients and significant others increased when caregivers had a higher level of intensity in their care-giving function.

In another research study, the effect of some demographic and clinical factors related to terminally ill cancer patients and family caregivers on the level of agreement in their rating of patients’ QoL was assessed. As a part of the research study the care-giving burden was calculated using the amount of care needed and the impact of care

giving on the caregiver's health. The results indicated that the care-giving burden has a negative influence on the level of agreement between patients and families about cancer patients' QoL (Tang 2006). This is an outcome that was present in another study where the level of agreement between 91 patients with dementia and their family caregivers about patients' QoL was assessed. Caregivers who reported higher levels of burden rated patients' QoL lower than did patients in all five domains of QoL (Sands et al. 2004).

Altogether it appears that nurses' assessment of their own QoL and other related issues, like their burden of care, can influence their understanding of patients' QoL. In this research study, nurses' QoL was assessed and then the influence of nurses' assessment of their own QoL on the level of agreement between cancer patients and nurses about patients' QoL was examined.

QoL domain

It is stated by many researchers that there is better QoL agreement between patients and proxies about patients' QoL when more concrete, objective and less private aspects of the QoL assessment such as the physical domain are explored (Addington-Hall & Kalra 2001; Broberger, Tishelman & von Essen 2005; Clipp & George 1992; Dorman et al. 1997; Lobchuk & Degner 2002; Magaziner et al. 1988; Magaziner et al. 1997; McPherson & Addington-Hall 2003; Pickard et al. 2004; Sneeuw et al. 1999; Tamim, McCusker & Dendukuri 2002; Tang & McCorkle 2002b; von Essen 2004; Wilson et al. 2000). Care providers usually focus more on the physical problems of patients and they have less accurate information concerning the psychosocial and social aspects of patients' QoL, like personal relationships (Brunelli et al. 1998; Stromgren et al. 2001). This research study assessed QoL across four domains and it is interesting to consider the extent to which the findings support this trend.

In summary, the outcomes of the literature review in relation to variables influencing the level of agreement between patients and proxies about QoL identified several issues. Firstly, the majority of research studies were empirical and assessed the influence of only a limited number of patients' and nurses' demographic and clinical

variables on the level of agreement. Because variables influencing agreement are potentially very diverse, more complementary interpretive approaches are necessary to explore the whole range of possible variables. Interpretive research studies can also provide a more in-depth understanding as to why these variables are important in nurses' understanding of cancer patients' QoL.

Secondly, outcomes of the empirical studies in which the effect of clinical and demographic variables on the level of agreement have been tested generally show different and diverse outcomes. This means that the effect of these variables on the level of agreement still needs to be explored further. Finally, empirical research studies in which the influence of nurses' variables on the level of agreement was examined are quite limited. An improved understanding of the ways in which nurses' characteristics might facilitate nurses' understanding of cancer patients' QoL would be potentially very useful.

Conclusion

In this chapter, the main historical and developmental phases or characteristics of the QoL concept were described, and how the QoL is defined in terms of various domains/dimensions. While different QoL definitions have been identified, it is clear that QoL is an individual and broad concept. It is argued that while some commentators recommend using the HRQoL assessment in the medical area, full assessment of QoL is a more suitable approach and will be used in this research study. QoL has been introduced into the oncology area as a way to pay attention to patients' rights and preferences and to ensure that health care professionals consider all aspects of individuals' situation when planning their care, including physical and psychological parts.

QoL information has many applications in the clinical area. For example, QoL information can be useful for determining if a curative or palliative treatment is most suitable for patients. QoL information is very useful in: understanding specific symptom(s) and enhancing care and rehabilitation; improving communication with patients; providing a better understanding of patients' preferences; identifying longer

term problems of patients; and in supporting better decisions about patients' care plans. The next chapter details the methodological and philosophical issues underpinning the research process.

CHAPTER THREE: METHODOLOGY

Introduction

In the previous chapter, the literature in relation to nurses' perceptions about cancer patients' QoL was reviewed. It was emphasised that if nurses can accurately assess cancer patients' QoL, it can potentially lead to useful intervention, particularly for the clinical area. However, a number of variables (such as age and marital status) might influence the level of agreement between cancer patients and nurses about cancer patients' QoL which will be examined in the first phase. Other factors (such as how participants understand the meaning of QoL concept) can also influence nurses' understanding of cancer patients' QoL and will be explored in the second phase.

The purpose of this chapter is to present the philosophical and theoretical issues that underpin this research study comparing nurses' and patients' perceptions about cancer patients' QoL. This discussion, in turn, underpins the methods chosen for the study. These philosophical and theoretical issues are also known as a 'paradigm' which mainly consists of methodology, epistemology and ontology (Finlay 2006). While the concept of 'paradigm' is used widely, it is considered as an unclear and ambiguous term by some commentators (Wainwright 1997). Conversely, the term 'worldview' is an easier term to understand (Weaver & Olson 2006) and therefore is preferred for this research study. Because different meanings and interpretations have been suggested about the concepts of ontology, epistemology, and methodology, it is very important to know what these concepts mean more precisely in the context of this thesis.

Guba (1990, p.18) highlighted the notion that ontology is about "what is the nature of the knowable?" or "what is the nature of reality?", epistemology is about "what is the nature of relationship between the knower (the inquirer) and the known (or knowable)?" and methodology focuses on "the best means for gaining knowledge about the world". Therefore, choosing a methodology means that researchers take into consideration both questions of epistemology which talks about how the

knowledge will be created and ontology which demonstrate the way we think about the nature of the world and of our being.

Ontology is relevant to choosing a suitable methodology or perspective for the research project because if researchers assume a reality ‘out there’ (realism), they might choose an empirical approach which allows them to focus on the reality as precisely as possible by controlling possible confounding variables (Guba & Lincoln 1994). Conversely, researchers with a relativist ontological view accept different meanings and interpretations about reality and therefore might adopt an interpretive perspective.

Similarly, epistemological positions that researchers bring to the research endeavour influence the selection of methodology (Weaver & Olson 2006). Reality might seem to be out there and quantifiable (objectivism) compared with those who believe that separation of meanings from objectives is impossible (subjectivism). The former might select an empirical methodology whereas the latter would adopt an interpretive approach (Guba & Lincoln 1994). More discussion about the ontology and epistemology and their relationship with the methodology can be found later in this chapter.

The thesis as a whole has a mixed approach which incorporates empirical and interpretive ideas in two different phases. Therefore, this chapter explains why these two perspectives are used together and what this can add to the strength and usefulness of the research study. The methodology and related ontology and epistemology underpinning the first phase are discussed. For the second phase, why an interpretive approach is used will be justified and then why, from a variety of options within this approach, a grounded theory approach was chosen.

The methodology of the whole thesis: a mixed research approach

Given that several terms have been used to name research studies with mixed methodologies or mixed methods (Creswell 2003; Sandelowski 2000a; Teddlie & Tashakkori 2003), the term ‘mixed research approach’ was developed. It was

concluded that this term is more useful and can include either a study that is mixed at a method level or at a methodological level. The terms ‘mixed method’ or ‘mixed methods (with plural s)’ which are suggested in the literature seem to be confusing for the researcher because they imply that the combination is only at the method level.

There are several reasons why a mixed research approach was chosen as a framework for the research. Firstly, a number of precursor empirical research studies assessed the level of agreement between cancer patients and proxies about cancer patients’ QoL and explored variables influencing this agreement (Sands et al. 2004; Schwenk et al. 2004). However, the outcomes of research studies assessing the level of agreement vary across studies and the variables that have been investigated are very diverse. Moreover, some of the empirical studies that consider variables influencing the level of agreement between patients and proxies are limited because they do not canvass all important variables.

It was concluded that an empirical study needs to be conducted to verify or confirm the relationship(s) between the level of agreement between cancer patients and nurses in an Australian context. In addition, an exploratory research study was required to explore in depth the interactions between cancer patients and nurses that might result in differences in nurses’ perceptions of cancer patients’ QoL. A mixed research approach is very useful in such situations because it allows different kinds of questions to be addressed. Teddlie and Tashakkori (2003, p.15) suggested that a mixed research approach is very useful when researchers want to “simultaneously answer confirmatory and exploratory questions and therefore verify and generate theory in the same study”. This research study has both confirmatory (the level of agreement between patients and nurses about cancer patients’ QoL) and exploratory questions (why perceptual differences exist).

The second reason why a mixed research approach was chosen is that this study deals with the complex issue of QoL. Nurses’ perceptions of cancer patients’ QoL is a complex issue and in this study such perceptions are seen from different perspectives using empirical and interpretive approaches. Empirical enquiries usually gather the information from a large number of participants and make interpretations

of quantifiable data. Conversely, interpretive enquires usually deal with experiences of a limited number of participants in order to have a richer understanding of the phenomenon. These enquiries together can increase the breath and depth of the research study. Therefore, it is most likely that complexities of QoL perception will be understood more fully. Sandelowski (2000a) also argues that a mixed research approach allows researchers to better understand the complex issues like health or QoL.

The final reason for choosing a mixed research approach is that conclusions made from such studies may have more generalisations compared with those emerging from either qualitative or quantitative data alone. The reason is that experiences of participants related to nurses' understanding of cancer patients' QoL in response to the WHOQoL-BREF questionnaire, are compared with their subjective experiences determined through their responses to interview questions. Therefore, it is most likely that more consistent outcomes can be revealed by comparing quantifiable and qualitative data that are also useful and applicable to other situations and contexts. Teddlie and Tashakkori (2003, p.37) suggested the term "inference transferability" in mixed research approaches that covers both the quantitative term of "external validity" and the qualitative term of "transferability". Teddlie and Tashakkori (2003, p.42) opined that mixed research approaches can potentially lead to more 'inference transferability' due to "the *gestalt principle* that the whole is bigger than the sum of its parts" (Teddlie & Tashakkori 2003, p.42).

To be precise, a mixed research approach provides researchers with this opportunity to get an in-depth understanding of complex issues and questions (Williams-Cox 2004) and potentially can lead to more rigorous findings (Smith & Biley 1997). The researcher would suggest that other researchers, particularly nursing PhD students, deal with complex issues related to health by incorporating mixed research approaches into their research studies.

Despite the importance of studies with a mixed approach, a number of debates exist as to what philosophical and theoretical issues underpin a study with mixed approach. Teddlie and Tashakkori (2003, pp.17-22) mentioned that previous researchers using mixed research approaches, have taken the following main

positions. The first position adopted is by those researchers who believe that mixed research approaches do not need to justify their worldview. A research study can be conducted provided that methods are chosen that best answer the research questions. Another option is introduced by those researchers who argue that conducting mixed research approaches are not possible because researchers cannot adopt two different perspectives or worldviews in one study. This option has been criticised by others arguing that different worldviews can be used in the same research study and even researchers might welcome opposite worldviews in one research study. Finally, there are researchers who are of the idea that a mixed study can use only one worldview. These latter ones mainly proposed the pragmatic worldview because mixed research studies can find practical answers for research questions.

Having considered the above options, it can be argued that like many other research studies, this research study uses two different worldviews in two separate phases of the research study. A single worldview did not select for this research study because while investigating the theoretical and methodological issues, no phase was dominant over another. Therefore, because each phase of the research study has its own theoretical and philosophical issues, in the following sections the theoretical and philosophical issues of each phase of this study are discussed separately.

The methodology and the philosophical issues underpinning the first phase

In the first phase of the research study, the main aim was to understand the degree or level of agreement between patients and nurses about cancer patients' QoL. It was realised that numerous empirical studies measuring this agreement in a population other than Australia needs to be extended into the Australian context due to the importance of QoL perceptions. Given that QoL is a culturally bonded concept, this could provide a number of Australian patients and nurses with the opportunity to reflect on their experiences and further empirical comparisons amongst such experiences can be made.

When this study began the researcher reflected on his worldview and recognised that he only conducted empirical studies and he is more or less an 'empirical person'. In

other words, he was a person who saw the reality out there as being more quantifiable and objective. However, he also acknowledged that there might be other meanings and interpretations of reality and therefore he was interested in changing his worldview to a more balanced view gradually. This required the researcher to explore alternative methodologies.

The researcher was also new to the research environment and starting with an empirical study allowed him to become more familiar with the research area, participants and constructing the research questions for the interpretive phase. Creswell et al. (2003, p.277) argue that conducting an empirical study followed by an interpretive one can be potentially very useful for “quantitative researchers” who are unfamiliar with interpretive research studies. They stated that the quantitative phase allow researchers to familiarise themselves with interpretive studies while they start the empirical phase.

Therefore, in the first phase an empirical study was conducted which is based on the principles of a positivist worldview. It is quite important to consider this worldview in more detail to see on what grounds the first phase of the research study has been established.

Positivism

The first phase of the research study was based on the positivist view of knowledge. It is quite a rigorous worldview for research studies and has been developed over a long period of time (Lincoln & Guba 2000).

The first generation of positivists can be traced back to the 18th and 19th centuries when peoples’ thinking about life moved away from traditional religious interpretations and focused on human experiences (Crossan 2003). Comte, the French philosopher, for instance, used the word ‘positivist’ for the first time and influenced social research in the twentieth century (Lewes 1853). As a result of this generation, more attention was given to the importance of investigation based on evidence, particularly that emerging from direct observation and away from the oppressive authority of religious belief systems. The second generation is related to

many philosophers in the early 20th century who are collectively named the Vienna Circle (Crossan 2003). These philosophers believed that experience is the only source of knowledge but such experience needs to be studied using logical inductive thinking (Suppe 2001). Logical inductive thinking will help researchers to draw meaningful and less speculative conclusions from data particularly when researchers study complex concepts associated with human health like QoL.

The next generation was developed by Karl Hempel in the post-war period (Crossan 2003). Hempel (1965) preferred to use the term empiricists for himself and similar philosophers rather than positivist and suggested that researchers need to have a focus on reasoning based on logical conclusions through deductive thinking rather than pre-accepted assumptions. The major feature of this generation appears to be that researchers use general principles to predict relationships between facts and then conduct research studies to see if these predictions are correct or not.

In brief, these generations of positivist thinkers developed important concepts including evidence-based inquiry, inductive and deductive thinking that can be used in this research study. However, these important aspects or figures of the positivist worldview can also be classified in another way. For example, the well-known classification is that the positivist approach focuses on realism in ontology, objectivism in epistemology, and is experimental regarding methodology (Guba & Lincoln 1994). In the following sections, these major elements of the positivist approach will be explained in more detail. While issues related to positivism are open to debate, the major characteristics of positivism are adapted from an often cited publication written by Lincoln and Guba (2000).

Positivism and the issue of realism

The ontology of the first phase of the research study is based on realism because patients and nurses will report on their experiences by answering a QoL survey tool that translates the internal state of QoL to QoL scores. The researcher assumes that this reflects the real state of QoL. Lincoln and Guba (2000) point out that in the positivist view, the reality is out there and the role of researchers is to find that truth. They mention that the knowledge emerging from such findings will be summarised

in the form of time and context free generalisations that can be used to predict and control natural phenomena. In other words, in this worldview reality is seen as being external to researchers (Grbich 1999) and in fact things are experienced as they exist (Wainwright 1997).

Positivism and the issue of objectivism

The epistemology of the first phase of the research study is based on objectivism because the state of QoL has been measured by a QoL tool leading to quantifiable data which is then analysed by statistical tests. The assumption here is that QoL is accessible from the “outside” of a person when the inner experience is operationalised. Lincoln and Guba (2000) highlight that in a positivist worldview researchers stand in a distant position and see the natural situation without altering it, which can potentially exclude any confounding or biasing variables from the process of questioning. In other words, this epistemology accepts the possibility of making objective observations or measurements (Gerber & Moyle 2004).

Positivism and the issue of experimentalism

The methodology of the first phase is derived from the ontological and epistemological assumptions described above. An objectivist/positivist approach requires tools that allow accurate measurement of an empirical reality. This led to the choice of empirical experimentalism where patients and nurses were invited to answer a QoL questionnaire with prepared QoL questions to assess the state of QoL. Moreover, in order to control the situation (another feature of empirical experimentalism), there are inclusion and exclusion criteria. For example, participants are confined to only adult patients and nurses and they are asked to report on their QoL scores based on their experiences over the last two weeks. Guba and Lincoln (1994) assert that while researchers try to ask questions and to exclude any confounding variables, it is possible for them to be biased because nature is complex and tends to be confounded. Therefore, researchers prepare their questions in advance in a propositional form and nature also carefully verifies the hypothesis or to replicate findings.

In summary, the positivist worldview underpinning the first phase of the research

study is based on acceptance of the fact that knowledge has the following characteristics:

- is discovered, i.e. universal and external truths are grasped and justified
- arises from empirical processes which are reductionist, value neutral, quantifiable, objective and operationalizable statements are valid only if publicly verifiable by sense data.

(Higgs & Llewellyn 1998, p.61)

Given the fact that this thesis uses a complementary approach, the philosophical issues underpinning the second phase of the research study are discussed below.

The methodology and philosophical issues underpinning the second phase

An empirical study based on principles of a positivist approach is useful in guiding the first phase of the research study because it allows a large number of participants to report on QoL questions that express their internal state of QoL. However, the researcher was also interested in providing more opportunity to participants to give meanings and interpretations to QoL issues. This was done in the second phase of the research study using an interpretive study. Liamputtong and Ezzy (2005) emphasise that in contrast to the empirical studies that might test a specific theory or verify relationship between variables, in interpretive studies participants interpret and give meaning to events and things.

As well as participants' interpretations, the researcher also wanted to have in-depth descriptions of QoL issues all through the data collection and analysis rather than making interpretations of final data as it can be identified in empirical studies. In other words, an interpretive approach allowed the researcher to take a more active role and interpret experiences of participants as he was conducting interviews. This does not mean making interpretations that are not rooted in the actual data but rather to interpret the data more deeply. DePoy and Gitlin (1998) suggest that in interpretive studies, investigators work from the beginning to the end of the study process in a very active way to find the truth in natural situations.

Consequently, knowledge arising from the interpretive worldview underpinning the second phase of the research study has the following characteristics:

- comprises constructions arising from the minds of knowing, conscious and feeling beings
- is generated through a search for meaning, beliefs and values, and through looking for wholes and relationships with other wholes.

(Higgs & Llewellyn 1998, p.61)

Interpretive studies have a varied range of methodologies such as ethnography, grounded theory, and phenomenology. A couple of more recent methodologies also emerged in nursing named under titles such as ‘descriptive, exploratory’ (Annells 2007), ‘descriptive’ (Sandelowski 2000b), and ‘interpretive descriptive’ (Thorne, Kirkham & MacDonald-Emes 1997). It is important to reflect on the difficulties the researcher experienced in determining the best methodology to use. There is overlap between and divergent ideas and even definitions that are used by researchers when they describe methodology. For example, a researcher might label a research study as a grounded theory study whereas another might call it descriptive, interpretive, or descriptive-exploratory. It is not surprising to see these divergent views and controversies because interpretive studies are still in the early stages of development. Jeon (2004) also highlights that finding an interpretive methodology that can best answer the research question is difficult.

However, the researcher decided to base the second phase of the research study on the principles of grounded theory method, more specifically a classical version of it. The following section justifies the methodology chosen to underpin the second phase.

The rationales for choosing processes and principles of grounded theory

The following reasons are offered to justify why this research study was based on the principles of grounded theory.

1-Finding conceptual categories that inform practice

The researcher used ‘the principles of grounded theory’ to show that it is a modified version of grounded theory. This study presents only descriptions and a conceptual ordering and not an explanatory schema. In other words, this thesis is not concerned with developing a theory as has been done in other grounded theory studies. Annells

(2007) pointed out that many researchers in different areas of nursing have used grounded theory methods at two levels of analysis, being description and conceptual ordering, rather than seeking to develop a substantive theory about action and interaction.

The aim of this thesis is to obtain a fundamental understanding and description of the experience of QoL and differences between patients and nurses. Annells (2003) suggested that researchers might use some aspects of grounded theory, like coding up to a conceptual ordering level, and this is helpful in obtaining a basic understanding of the research area. Strauss and Corbin (1998, p.288) in their response to students' questions also point out that researchers can use some of their procedures in the studies aiming for "description, conceptual ordering, or discovery of categories to build measurement scales" rather than to build a theory. However, it can be argued that grounded theory studies with coding up to a conceptual ordering level are also useful for those researchers who are not able to develop a full theory due to their time limitation and availability of resources – both of which were factors in the current research project.

2-Lack of knowledge about the reasons, outcomes, and implications of agreement

Review on the literature identified that generally there is a lack of research in which nurses' perceptions about cancer patients' QoL have been explored in depth. Grounded theory is especially very useful for understanding those situations involving people about which very little is known (Jeon 2004; Stanley 2006). Other interpretive approaches are also helpful to uncover knowledge but they might open the door for interpretations that are less supported by the actual data. A research study based on a grounded theory approach, particularly a classical version of it, tries to develop knowledge on the basis of information gathered from exploring the issues with participants (Auerbach & Silverstein 2003). Grounded theory then requires the researcher to rigorously link interpretive conclusions with the actual data.

3-Focus of the research study on patients-nurses interactions

The main aim of the study is to know how nurses perceive cancer patients' QoL

when they interact with cancer patients in the oncology wards. What is going on between cancer patients and nurses that makes a difference in QoL perceptions? It is consistent with a grounded theory approach because it also focuses on actions and reactions (Annells 2006). Grounded theory is based “on the process of social interactions by which individuals make sense of the world” (Stanley 2006, p.64). It is quite important to briefly review interactionism because it is the main philosophy underpinning grounded theory and in turn the second phase of the research study.

Interactionism

The history of interactionism can be traced back to the American social psychologist George Herbert Mead who taught this concept at the University of Chicago (Morris 1977). Mead was in a close relationship with pragmatists like Dewey and he was greatly influenced by pragmatists (Morris 1962). Pragmatists generally think that individuals need to adapt themselves to social changes and the human mind makes this process possible (Jeon 2004). In other words, individuals through purposeful thinking can find suitable ways to answer their research questions or solve their problems. Creswell (2003) expresses his idea that pragmatism will give individuals a sense of freedom for choosing alternatives that meet their needs or expectations. Thinking in a pragmatic way can be seen in Mead’s later publications in which he highlighted the importance of the mind.

In the introduction to Mead’s *Mind, Self and Society*, Morris (1962) clarified Mead’s beliefs. Morris points out that “mind and self are, without remainder, generated in a social process, and he [Mead] has for the first time isolated the mechanism of this genesis” (p. xv). This implies that the self can be understood only in interaction with other people and society because nobody lives in isolation. As individuals communicate with each other, they might accept that other people’s beliefs and attitudes about them are correct and relevant. These attitudes and beliefs might shape how people think about themselves and in turn they might reflect in a certain way.

Similar interpretations of Mead’s view about the relationship between the self and society have been made by other researchers. For example, Annells (1996) pointed out that the main point of Mead’s thinking was “the essential defining of self through social roles, expectations, and perspectives cast on self by society and by those

within society. He argued that humans come to understand collective social definitions through a socializing process” (pp. 380-381). In other words, as individuals are in a continuous interaction with each other in the context of a complex society, they learn about their social roles and mutually they can also influence the society.

Mead’s beliefs about the social process, the importance of self and mind were titled symbolic interactionism by one of his students (Blumer 1969). According to Blumer “what makes human beings unique is their symbolic ability to define their situations and shape their actions” (Wilson & Hutchinson 1991, p.267). So, in each society individuals develop a number of symbols such as words either for speaking or writing and non-verbals cues like gestures which are meaningful for them and facilitate interactions between them.

Although symbolic interactionism influenced a number of fields such as philosophy, psychology and sociology, one of the major goals of Blumer in developing Mead’s philosophical work and creating the symbolic interactionism approach was to improve research practice (Blumer 1969). Wilson and Hutchinson (1991, p.267) argue that “research based on symbolic interactionism emphasises how people view their circumstances, how they interact, and how these processes change. One such research strategy is termed grounded theory methodology”.

In summary, symbolic interactionism is based on the notion that meaning can be established through people’s interaction. This is quite a supportive statement for choosing grounded theory as a methodological basis for this research study because nurses make perceptions about cancer patients’ QoL when they interact with patients. Patients’ signs and symptoms, verbal and non-verbal cues will help nurses to develop perceptions about patients as they interact with them. Nurses’ perceptions about patients’ QoL are also meaningful for patients and even might influence the way patients think about their own QoL. Any issues that influence patient-nurse interactions in the workplace can also affect nurses’ understanding of patients’ QoL and need to be taken into consideration. Symbolic interactionism provides a framework for understanding these aspects of the nurse-patient relationship.

4-To incorporate findings of the first phase into the construction of the second phase

Another advantage of using a grounded theory approach is that it allows researchers to incorporate empirical data from the first phase into the development of findings of the second phase. Grounded theory allows any form of collected data including survey, experiment, and case study to be combined and integrated (Glaser 1978). If researchers choose an interpretive approach that is not congruent with the empirical one and does not accept the quantitative data, it is most likely that researchers feel frustrated and can not synthesise any ideas from the divergent data. Conversely, two methodologies agreeing with each other provides researchers with more consistency in inferences and the conclusions they make. Annells (2006, p.59) also highlighted that without congruency in approaches that researchers choose, they may feel frustrated and “becoming lost in multiple fractures which would inevitably occur when trying to do the research”.

5- Researcher’s philosophical view and background

The more the researcher read and reflected he found that his views reflected a more realistic and objective perspective. In the ontology’s continuum ranging from realist to relativist (Lincoln & Guba 2000), the researcher’s view was near to the end of the continuum of the realist aiming to move toward the relativist. In the epistemology’s continuum ranging from objectivist to subjectivist (Lincoln & Guba 2000), the researcher placed himself near to the objectivist aiming to move toward subjectivist.

On more reflection, as also identified by others (Sandelowski 2000b), the researcher realised after a while that it is not easy to exchange his strong belief system from a positivist view to a completely different worldview such as constructivism. In contrast to more dialectical and subjectivist modes of an interpretive worldview such as phenomenology, a research study based on principles of grounded theory, especially a classical mode, was closer to the researcher’s worldview. While the research question needs to be one that grounded theory can answer, the researcher’s worldview is also important (Annells 1996, p.379). Finlay (2006, p.14) is of the following opinion:

However, your preferences count too. You have to adopt a methodology to

which you can relate. To identify and clarify your preferences, you might find it useful to reflect on your values, beliefs and interests; your goals; your resources and opportunities; your skills and knowledge; and any academic/disciplinary demands that influence you.

Altogether, it seems that a research study based on principles of a classical mode of grounded theory methodology is more congruent and fits better with the researcher's worldview. Grounded theory allows researchers to move from empirical studies to interpretive ones more easily (Smith & Biley 1997). It is important to review different modes of grounded theory in more detail to see the differences that exist between modes of grounded theory in terms of their ontology and epistemology and why the classical mode of grounded theory was chosen as a base for this research study.

Different modes of grounded theory

The classical form of grounded theory method was introduced by the collaborative work of Barney Glaser and Anselm Strauss in 1967 (Annells 1997). Glaser had a more positivist background working in Columbia University whereas Strauss had more experience with fieldwork, symbolic interactionism and pragmatic philosophy at University of Chicago (Charmaz 2000).

The major concern of Glaser and Strauss leading to the development of grounded theory was that many social sciences research studies were more empirical, with fewer field work efforts, and a division between the theory and empirical research (Glaser & Strauss 1967). Before grounded theory was introduced, there was a tendency to develop a theory and then gather the data to verify it (Dey 1999, cited in Walker & Myrick 2006). The grounded theory method in fact originated from Glaser and Strauss's motivation to address the gap between theory and practice that:

had not been bridged by studies using logical deductive reasoning as the method of inquiry....Grounded theory is an approach for generating theory that is grounded in and systematically derived from data, with an emphasis on the comparative method of constant, concurrent data collection and analysis. (Jeon 2004, pp. 251-252)

The theory they were trying to generate was dependent on data coming from field work and in order to bridge the theory-practice gap, a "middle range" theory

emerged (Charmaz 2000, p.510). Glaser and Strauss (1967, pp. 32-33) point out that such a middle range theory sits between the “minor working hypothesis” of every day life and “all-inclusive” grand theories. In other words, in contrast to grand theories (Bringer, Johnston & Brackenridge 2004), middle range theories try to conceptualise the “first hand-experiences” of people (Wilson, Hutchinson & Holzemer 2002, p.1313) and are very useful in practical situations.

Annells (1996) states that critical realism is the ontology of this mode of grounded theory that accepts that “the social and natural worlds have differing realities, but that both forms of reality are probabilistically apprehensible, albeit imperfectly”. She also asserts that the epistemology of this version presents “a discernable post positivist suggestion that the method is independent of the researcher and has separate existence. This can be identified as a modified objectivist epistemological view about the nature of the relationship between the knower and what can be known”. Finally, the methodology of this mode, as emphasised by Annells, is based on “theory discovery and generation in a detailed qualitative research process rather than logico-deductive a priori assumptions, which comprise the first step of positivist research” (1996, pp. 385-387). As a result of a grounded theory research using the classical approach, researchers can interpret the data but it also offers researchers the means and methods of thinking and analysing so that interpretations do not veer to far from the actual data. Altogether, the ontology and epistemology of the classical mode of grounded theory is very close to a positivist approach chosen for the first phase of this study.

Another mode of grounded theory was published in 1990 by Strauss and Corbin. The major difference between this mode and the classical one is the “suggestion of a conditional matrix” in the data analysis (Annells 1996, p.386). Strauss and Corbin (1998, pp.181-182) are of the opinion that a phenomenon needs to be located “contextually or within the full range of macro and micro conditions in which it is embedded and tracing out the relationships of subsequent actions/interactions through to their consequences”. Such approaches to data analysis were criticised as forcing data and therefore deviating from the basics of the grounded theory method (Walker & Myrick 2006). However, in Strauss and Corbin’s version of grounded theory it is not clear what exactly constitutes the macro and micro conditions in the

context of a research study and how different consequences of action/interaction can be identified. Therefore using such a matrix is not necessary and instead emerging conceptual categories from data are mainly dependent on researchers allowing the data to tell the story.

This research study is mainly based on the concepts developed by Glaser and Strauss (1967). These features consist of following items: theoretical sampling, theoretical sensitivity and issue of theoretical saturation; comparative data analysis; memo writing; and coding and identification of the core category. As stated earlier, these methods keep the researcher very close to the data and interpretations made through this process are most likely to be grounded in actual experiences of participants. While these features are interwoven, they have been considered as methods and discussed in the relevant sections in the method chapter of the second phase (Chapter Six). If there is any modification to these features, they are also addressed in those sections. The crucial thing is that if any modification to this methodology is made, they need to be addressed by researchers (Jeon 2004).

In summary, the interpretive phase of the research study was based on the principles of a grounded theory methodology in which the focus is mainly on patient-nurse interactions in order to make conceptual categories to inform the practice.

Conclusion

This research study as a whole has a mixed approach that is very helpful to deal with complex issues like QoL and the results should have greater generalisation to, and validity in, other situations and contexts. The first phase is an empirical study based on principles of a positivist view of knowledge. The second phase is an interpretive study based on principles of a classical mode of grounded theory. The researcher believes that philosophical issues underpinning grounded theory (mainly interactionism and pragmatism) are very supportive for the interpretive phase of this research study because the study has a focus on interactions between patients and nurses in order to develop conceptual categories to help the caring practice. Moreover, philosophical issues of grounded theory appear to be more congruent with

the researcher's philosophical view and background at this time. Finally, the researcher also found that methods suggested in grounded theory (comparative data analysis, memo writing, and theoretical sampling) are very useful because they constantly remind the researcher to stay with the data and avoid making interpretations that are not supported by the actual data.

Having clarified the methodology and philosophical issues underpinning this thesis, the methods and results of each phase are addressed separately in the following chapters. Chapter Four focuses on the methods while Chapter Five examines the results of the first phase. Chapters Six and Seven discuss the methods and results of the second phase, respectively.

CHAPTER 4: METHODS OF THE FIRST PHASE

Introduction

In the previous chapter, it was explained that this research study has a mixed approach. The first phase has an empirical approach in which QoL perceptions of patients and nurses are translated to QoL scores that are quantifiable and objective. To do justice to the complex nature of the concept of QoL, a range of statistical tools will be used in this phase to better understand the multi-dimensional nature of the QoL concept. The second phase of this study continues to acknowledge the multi-dimensional construct of QoL and includes subjective experiences of participants to provide richer interpretations of QoL perceptual differences. These two approaches together will increase the breath and depth of the research study.

This chapter describes and justifies the quantitative methods used in the first phase of this study. While the methodology is related to philosophical issues underpinning the research, methods relate to the techniques used to gather and analyse data (Wainwright 1997). Furthermore the specific aims of the first phase are introduced. After a brief introduction about different QoL tools, it will be argued why the WHOQoL-BREF questionnaire is an appropriate tool in this study. Then the actual procedure used for the data collection is introduced. A justification of the appropriateness of the sample size in the first phase of the research study is made at the end of the chapter.

Aims of the first phase

In Chapter One, two research questions for the whole project were presented enquiring about the level of agreement between patients and nurses about cancer patients' QoL and why QoL perceptual differences exist. In order to answer these questions, this phase sought to address the following specific aims:

1. to determine the reliability of cancer patients' and nurses' QoL scores on the WHOQoL-BREF questionnaire using an internal consistency test (Cronbach alpha coefficient);

2. to explore the structure of domains of the WHOQoL-BREF questionnaire completed by cancer patients using exploratory factor analysis;
3. to investigate the level of agreement between patients' and nurses' QoL scores on the WHOQoL-BREF questionnaire using different statistical tests (Pearson correlation, IntraClass Correlation Coefficient, Bland-Altman test, Proportion of exact agreement, Paired t-test);
4. to establish the association between the level of agreement between patients' and nurses' QoL scores on the WHOQoL-BREF questionnaire and patients' level of QoL using Bland-Altman test; and
5. to investigate the influence of patients' and nurses' demographic and clinical variables on the level of agreement between patients' and nurses' QoL scores on the WHOQoL-BREF questionnaire using Bivariate (Pearson Correlation) and Multivariate (Multiple regression) tests.

It is not the intention of the research study to explore for statistically significant relationships between clinical and demographic variables of patients and nurses and QoL scores given by patients and nurses separately but to identify if these variables influence the level of QoL agreement between these two chosen groups.

Having considered these specific aims, statistical procedures that were used to answer the above research questions will be explained.

Research Design and procedure

Instrument

The WHOQoL-BREF questionnaire used in this research study is classified as a generic health profile QoL tool. It is relevant to explain the classification of QoL tools to see what characteristics generally differentiate the WHOQoL-BREF questionnaire from other QoL tools.

Classification of the WHOQoL-BREF questionnaire

QoL tools have been classified in two major divisions: generic (or general) and specific tools (Soni & Cella 2002). Specific QoL instruments focus on problems that

are applicable only to a certain disease or population (for example cancer) a certain dimension of QoL (psychological) or a given condition (pain) or a specific treatment modality (Cella & Nowinski 2002). These instruments are usually more responsive than generic QoL tools, but often are not comprehensive and cannot be used to compare responses across different diseases or conditions (Fayers & Machin 2000).

The generic QoL instrument, on the other hand, is designed to measure the complete spectrum of dimensions relevant to QoL and can be used to compare results across different patients and may also be used for healthy people (Cella & Nowinski 2002; Movsas 2003). The two types of generic instruments are utility measures and health profiles (Movsas 2003). With utility instruments, QoL is measured as a single number along a continuum ranging from death (0) to full health (10) (Giesler 2000). In other words, such measures integrate multidimensional information related to QoL into only a single comprehensive item; it shows how patients value the state of their health.

Conversely, health profiles are single instruments that measure different aspects of QoL with different items (Fayers & Machin 2000). For example, the WHOQoL-BREF questionnaire as a health profile QoL tool uses 26 items or questions which assess the QoL across four domains including physical (seven items), psychological (six items), social relationship (three items), and environmental (eight items) domains and two items measuring overall quality of life and general health. All 26 items are rated on a five-point Likert-type scale (e.g. ranging from very poor, to poor, to neither poor nor good, to good, and to very good) (The WHO Group 1998a).

The aim of this research study was to compare patients' and nurses' perceptions about cancer patients' QoL across different domains. Moreover, the cancer patients who were selected in this research study had different types of cancer. So a generic QoL tool like the WHOQoL-BREF questionnaire was chosen because it might better do a comprehensive comparison between patients and nurses about cancer patients' QoL.

Patient and proxy versions of the WHOQoL-BREF questionnaire and instructions

The WHOQoL-BREF questionnaire was used by both the patient and nurse groups. The questionnaire for nurses (proxy version) was similar to that of patients with only small modifications made to QoL items as recommended by Hays et al. (1995). For example, the item ‘how satisfied are you with your health?’ in the patient version was modified in the proxy version to ‘how satisfied is the patient with his (her) health?’

Participants also needed to be instructed as to how to complete the WHOQoL-BREF questionnaire. Patients were instructed to complete the questionnaire to reflect how they felt about their quality of life. The purpose of giving instructions to the proxy is different across research studies. For example in some QoL studies the proxy was asked to respond as they thought the subject would (Sneeuw et al. 1997) or try to view the situation from the patients’ perspective (Sneeuw et al. 1998) while in other proxy studies (Dorman et al. 1997; Horton 2002; McVilly, Burton & Davidson 2000; Moinpour et al. 2000; Nekolaichuk et al. 1999; Wilson et al. 2000) no such statements were made. In this research study, in the instruction part of the proxy version, nurses were instructed to complete the survey specifically about the patient and the quality of life (QoL) they believe this patient has.

Given the fact that numerous QoL tools exist, a justification for choosing a specific QoL tool needs to be presented (Gill & Feinstein 1994). This is discussed in the next section.

Rationales for selecting the WHOQoL-BREF questionnaire

The literature review shows that many QoL tools exist. One article on the QoL of lung cancer patients, for example, stated that more than 50 instruments were actually used to assess QoL (Montazeri, Gillis & McEwen 1998). In another study that reviewed 75 articles about usage of QoL tools, 159 QoL tools were identified (Gill & Feinstein 1994). Salek (1998) compiled a compendium of 160 QoL instruments and stated that a large number of QoL measures are available. This number of QoL tools might indicate that generally there is no need to develop more QoL tools. Spilker et

al. (1990) also stated that having numerous QoL tools can show that QoL instruments probably have reached or are close to reaching the maximum number. Garratt et al. (2002) found that in some areas there are numerous QoL tools and recommendations for the selection of such tools are needed. Therefore, in this research study a decision was made not to develop any new QoL tool, but use one of the existing QoL tools and make some recommendations about how to use it in the clinical area.

Having a large number of QoL tools can also bring with it the difficulty of making a choice for several reasons. Firstly, each QoL tool might have some advantages and disadvantages. Verma (1997) commented that every QoL tool has its own strengths and weaknesses and as other researchers have stated (Cella 1996; Ganiats et al. 1997; Hawthorne, Richardson & Day 2001; Sloan et al. 2002), no QoL tool can claim to be the ideal one. In fact, when researchers tried to compare some QoL tools, the results showed that no one instrument generally could be replaced by others in the assessment of QoL (Kemmler et al. 1999; King, Dobson & Harnett 1996; Kopp et al. 2000).

Secondly, previous researchers have not always provided reasons for their selection. Such rationales can be beneficial for researchers who choose to conduct similar research. For example, a literature review conducted by Efficace, Bottomley and van Andel (2003) on a number of data bases from 1980 to 2001 showed that rationales for using a specific QoL tool were provided in only 44% of studies. The findings of Gill and Feinstein (1994) about QoL in the medical field also revealed that having reasons for selecting a QoL tool was addressed in only 36% of articles they studied. In a similar vein, when reviewing 265 QoL articles, only 15% of them provided a rationale for selecting the specific instrument (Kong & Gandhi 1997).

Having discussed these general issues with regard to the selection of a QoL tool for use in this study, there are several reasons why the WHOQoL-BREF questionnaire has initially been chosen for this research study from generic QoL tools.

1-It possesses good psychometric properties

One important issue during the process of assessing a QoL tool is to what extent

responses to a given tool are truthful (Giesler 2000). To maximise this, there is a psychometric validation process (Mystakidou et al. 2004). If a QoL tool has poor psychometric properties, this can compromise the outcomes of QoL assessment in clinical trials (McKenna & Doward 2004). Before introducing the psychometric properties of the WHOQoL-BREF questionnaire specifically, it is relevant to explain the main psychometric properties of QoL tools further. The most important psychometric properties of a QoL tool consist of validity and reliability

A valid tool must measure what it claims to measure (Boling, Fouladi & Basen-engquist 2003). In fact, a valid tool helps to define the degree of confidence that a researcher can have in the scores derived from the instrument (McMillan 1996). For example, a valid QoL tool must measure QoL and not any other construct. The most important aspects of validity consist of criterion, content, and construct validity.

Criterion validity searches for a correlation between one tool and another instrument, particularly one which is assumed to be superior (Grant et al. 1990). There is no QoL tool that can claim to have superiority over other tools or questionnaires or to be the gold standard (Aaronson 1989). Therefore, other existing QoL tools can be chosen for making a correlation (Giesler 2000). For example, a new QoL tool can have criterion validity provided that a correlation between this tool and a previous existing QoL tool can be observed. Content validity indicates whether or not the items in the tool are representative of the domain it is intended to assess and adequately samples the content area (Boling, Fouladi & Basen-engquist 2003). For instance, the physical domain of a QoL tool must include items to measure exactly that and not contain items from other domains, otherwise it would be deemed as having poor validity.

Construct validity indicates to what extent a tool is related to other tools based on a series of hypotheses about the variables that the tools are intended to assess (Boling, Fouladi & Basen-engquist 2003). Two most common types of construct validity consist of convergent validity (positive relation with a related measure) and discriminate/divergent validity (evidence of less correlation with a measure of other constructs) (Boling, Fouladi & Basen-engquist 2003). For example, we might find a positive relationship and therefore a convergent validity between a QoL tool and a tool that claims to measure health satisfaction. In this case both constructs of QoL

and health satisfaction share similar characteristics. On the other hand, a QoL tool might have divergent validity if it does not have a significant relationship with a tool that measures, for example 'job seeking behaviours'.

Reliability is another important psychometric property of a measure that indicates to what extent the scores obtained by the instrument can be reproduced between one administration of the instrument to another time (McMillan 1996). When scores are unreliable, the researcher or clinician cannot rely on the accuracy of the scores in representing the phenomenon of interest. The two common forms of measuring reliability are internal reliability and test-re-test reliability (Boling, Fouladi & Basen-engquist 2003; Giesler 2000). Internal reliability or internal consistency indicates whether the items in the questionnaire measure the same concept and to what extent the hypothesised scale is free of random error (Aaronson 1989; Boling, Fouladi & Basen-engquist 2003). In test-re-test reliability, correlation between scores of a given tool in two points of time will be calculated (Giesler 2000).

Unfortunately, there is a lack of information related to psychometric properties of different QoL tools. For example, in a review of 14 QoL tools by Grant et al. (1990), their results revealed that while in many instances psychometric tests were reported, test-retest and internal consistency were cited in less than half of the measures and content validity indices in only one measure. In a similar work on 265 QoL articles, the reliability and validity of instruments were reported in 23.8% and 21.5% of cases, respectively (Kong & Gandhi 1997).

However, the psychometric properties of the WHOQoL-BREF questionnaire are very clear. As the WHO group (1998a) stated, high correlations exist between QoL domains of the WHOQoL-BREF questionnaire with the original long tool WHOQoL-100. The internal consistency of the WHOQoL-BREF ranges from 0.66 in the social relationship domain to 0.84 in the physical domain and test-retest reliability of the tool is 0.75 for all domains. All above correlations fall within intervals 0.61-0.80 and 0.81-1.00, which indicate almost substantial and perfect associations respectively (Landis & Koch 1977).

The WHOQoL-BREF questionnaire is therefore considered to be a psychometrically

robust tool for measuring the level of agreement between patients and nurses about cancer patients' QoL.

2-The tool is appropriate for use in the clinical area

Even though the WHOQoL-BREF questionnaire is a generic QoL tool, it can also be used in clinical studies. The WHO Group (1998a, 1998b) pointed out that the WHOQoL-BREF questionnaire is considered suitable by the WHO to best assess QoL for such areas as routine clinical work, epidemiological studies and clinical trials. In the clinical area the issue of time for completion of a QoL tool is important not only for patients but also for health care professionals. Although a number of generic QoL tools are lengthy and difficult to use for seriously ill patients (Salek 1998), the WHOQoL-BREF questionnaire takes about five minutes to be completed by well-literate people in the self-administrated mode (Department of Psychiatry of the University of Melbourne 2000). Note, however, that longer completion times have been reported (Phungrassami et al. 2004).

Sloan (1998) suggests using a minimalist approach in selecting a QoL tool for clinical studies and argues that a QoL tool having fewer but more critical questions is preferable to a long one, because it does not put too much burden on patients to complete it. It was also pointed out by Barofsky (1997) that a long QoL questionnaire may not be suitable because it has a higher drop-out rate of patients and therefore has a deleterious effect on the QoL data. Moinpour et al. (1990), basing their work on recommendations by the Southwest Oncology Group, also emphasised the use of brief QoL tools. It is important to select a QoL tool that takes no more than 10 to 15 minutes to complete, particularly for patients undergoing palliative therapy (Cella 1995).

3- It can be used in cross-cultural studies

The WHOQoL-BREF questionnaire is also suitable for conducting cross-cultural research studies. While researchers are faced with many QoL tools, most of them have been developed in the United States and United Kingdom and suitable only for those countries (The WHO Group 1995). As the WHO clarified, the two main reasons for creating the WHO quality of life tools were its commitment to health with a holistic approach as well as having a QoL tool with much more consensus

between researchers engaged in cross-cultural research studies (The WHO Group 1995). The WHOQoL-BREF was developed through an international process and consists of a broad range of aspects or dimensions which are applicable to different countries and cultures (Skevington, Lotfy & O'Connell 2004).

For example, the WHOQoL-BREF questionnaire has been culturally adjusted for Australian people which in turn maximises the reliability for measuring QoL (Herrman, Hawthorne & Thomas 2002). The researcher also wishes to do a similar or trans-cultural research in the near future with Iranian cancer patients and make a comparison between the two countries. There is also a Farsi (Persian) version of this QoL tool available for this purpose. A culturally-sensitive QoL questionnaire provides researchers with the means to carry out multi-centre or multi-country QoL assessment with a comparative approach (Saxena et al. 2001).

However, according to Ecosse et al. (2005) even the results of cross-cultural research studies with the WHOQoL tools should be considered with caution. In fact, they analysed the longer WHOQoL-100 questionnaire with the RASCH model (named after Georg Rasch who developed the model) to construct a brief tool with a single score and suitable for cross-cultural studies. Results have identified that just 25 items out of 100 QoL items were culturally equivalent across the six countries under consideration.

4-QoL tool development is based on both experts' and individuals' views

Criticisms have been presented about some QoL tools that were created by people or organisations for private or commercial reasons (Hunt 1997) and developed from experts' consensus without consulting individual patients (Carr & Higginson 2001). Another reason to use the WHOQoL-BREF questionnaire in this research study is that the WHOQoL tool was developed by the WHO with collaboration from researchers, clinicians and scientists (Skevington & Suzanne 2002). Moreover, the WHOQoL-BREF tool is one of those few QoL tools which are based on a theoretical framework which includes the perceptions of healthy people and patients (Carr & Higginson 2001).

Accordingly, the WHOQoL-BREF questionnaire was used in this research because:

(1) it provides a broad assessment of QoL; (2) is not overbearing for patients and health care professionals who may be asked to complete the questionnaire; and (3) is culturally suitable to be used in Australia.

Data Collection

The collection of data for the first phase was completed between July 2005 and February 2007. The research study was conducted in three major hospitals and in different wards including two specialist oncology wards, five non-specialist oncology wards, three outpatient chemotherapy units, one radiotherapy centre and one palliative care area. Therefore, the procedures for data collection were modified based on how the research study can be conducted better in different wards. Having gained appropriate clearance from the relevant ethical committees, two methods were used for data collection.

In 18 cases, there were some practical issues that limited a direct access to the cancer patients, mainly in the palliative setting or in the outpatient wards. In these cases, all forms and questionnaires related to one case (patient-nurse) were put in an envelope and placed in a specific area in the ward. In each envelope, a step-by-step guide was provided for nurses on how to collect the data. Any registered nurse who provided nursing care for a cancer patient, had knowledge of that patient, and was happy to take part in the study gave the patient a 'Participant Information Sheet' that introduced the project to them. If the patient verbally indicated an interest in participating in the research, the nurse completed the 'Patient Characteristics Form', which obtained information including patient's age, gender, marital status, educational level, first language, current cancer diagnosis, most common current treatment, treatment setting and patient performance status. After this the nurse gave the 'WHOQoL-BREF questionnaire to be completed by patients to the patient and separately filled out the 'WHOQoL-BREF questionnaire-to be completed by the nurse about the patient. After that, another form ('Nurses Characteristic Form') that recorded characteristics of nurses such as age, gender, first language, marital status, and educational level, approximate contact time with patients, clinical experience and nurse's quality of life, was also completed by the nurse. All the above completed forms and questionnaires were then collected by the nurse and put into one envelope.

These nurses were informed to complete the questionnaires alone without asking patients any questions and without looking at the patients' questionnaires. The step-by-step guide for nurses and relevant questionnaires and forms can be observed in **Appendices B, C, D, E, F, G and H.**

The second method of collecting data was conducted by the researcher. Here the researcher went to the wards and first talked with the nurse manager in order to select the patient suitable for the study based on inclusion criteria and to identify the primary nurse of patient. Then the researcher talked with the primary nurse to see if the nurse was happy to take part in the research and if they knew the patient. If the nurse was satisfied, then the researcher talked with the patient about the research and gave the patient the 'Participant Information Sheet'. When the patient verbally indicated his or her consent, then the researcher gave the relevant forms and questionnaires to the patient and the nurse and after their completion separately, he picked them up and put them in the envelope which was allocated for that patient-nurse pair. This process facilitated the response rate.

To maximise the reliability of the data, orientation sessions were conducted by the researcher for nurses along with the Clinical Nurse Consultant (CNC) of the wards so that they could be well informed and instructed about the research project. A few individual sessions were also implemented as nurses requested. The questionnaire was generally completed by nurses on the same day at a time suitable for them based on their perceptions of cancer patients' QoL. However, there were a few limited cases (less than 10) where nurses filled out the forms next day due to a busy schedule. The nurses were not allowed to ask the patients any questions specific to the questionnaire before filling out their own questionnaire. Instead, they had to refer to the medical or nursing records.

Inclusion and exclusion criteria for the participants

The research study involved cancer patients as well as their attending nurses at three main public hospitals in Adelaide, South Australia. The selection was based on the following inclusion criteria.

Patients were eligible for inclusion in the study if they had confirmed diagnosis of any kind of cancer; reached the age of 18 years or older; and had the ability to read and write in English to be able to respond to the questionnaire appropriately; and agreed to participate in the study. Patients were selected from all inpatient and outpatient oncology centres and differed in their health status, disease severity and treatment modalities. This increases the variability in QoL ratings and allows outcomes of the study to be generalised to a wider group of patients (Sneeuw et al. 1997).

All registered nurses who provided nursing care for a patient were eligible to take part if they stated that they knew the patient and consented to take part in the study.

Ethical considerations

1. Undertaking of the first phase of the research study was approved by three Human Research Ethics Committees.
2. A letter confirming participant indemnity was provided by Flinders University.
3. Permission letters were obtained from the Director of the Nursing Division of the different hospitals.
4. Letters of approval from the Director of Medical Oncology Unit at the participating hospitals and the relevant subcommittee of the Palliative Care Unit were obtained.
5. There was no need for patients or nurses to write their name on the questionnaires or forms. Instead, the same number was recorded on the upper right-hand corner of all questionnaires and forms related to patients and nurses, and all of them put in an envelope. This allowed information to be properly matched and participant anonymity was assured.
6. The research data were stored according to The National Health and Medical Research Council (NHMRC) policy on research data storage. For example, original questionnaire forms were stored in a locked filing cabinet in the researcher's office. The original data will be kept up to 5 years in a secure research archive after which they will be destroyed. The coded data were entered into a password protected computer and will be archived as well.

7. In order to deal with patients' possible emotional distress in the process of completion of QoL tools, supportive care was negotiated with the Clinical Nurse Consultant on different wards so that health care professionals could help the patient if required. Nurses were not expected to experience any emotional distress by filling out a QoL questionnaire for patients. Fortunately, there was no report of such distress from patients and nurses.

Data sampling

One of the most important things in QoL research studies is to obtain a proper sample size based on all information available (Julious et al. 1997). For the purpose of estimating the necessary sample sizes, a consultation was made with a statistical consultant as well as the relevant WHO group involved with the development of the WHOQoL-BREF questionnaire. Based on previous relevant literature (McPherson & Addington-Hall 2003; Sneeuw et al. 1997), the comparisons between patients' and nurses' perceptions about cancer patients' QoL are done at two levels: individual and group level. Therefore, the minimum sample size was calculated in a way that these two levels of comparison were possible.

At the individual level, the research aim was to have a sample size that could estimate the proportion of exact agreement (see the next chapter for more details) between patients and nurses. Therefore, the following assumptions were made:

1. it was assumed that the desired significance level would be 0.05, which is the probability of the researchers making a Type I error ($\alpha = 0.05$; i.e. concluding there is a difference when there really is no difference); i.e. there is a 1/20 chance of committing a type I error. In clinical research it is usual to proceed with $\alpha = 0.05$ (Cella 1996).
2. it was assumed that the proportion of exact agreement between patients and nurses in the WHOQoL-BREF items is 0.6 (60%). The researcher referred to previous studies (Fisch et al. 2003; Sneeuw et al. 1997) that stated that proxies had an exact agreement of about 60% with QoL responses of cancer patients. The proportion of exact agreement is explained in details in the next chapter.

3. it was assumed that the delta value (margin of error) would be 0.08 (8%) which is the proportion of error that can be expected around the exact agreement of 60%.

4. based on the above assumptions, at the individual level a minimum of 160 cases in each study cohort (patients and nurses) was needed. This sample size was estimated, using the normal approximation to the binomial distribution.

At the group level, for calculating the sample size the following assumptions were made:

1. a comparison between patients and nurses could be made between the mean scores on the four WHOQoL-BREF domains. The calculation was based on the average difference in domain mean scores across all four domains, arising from the two studies with a sample of people with psychosis (Herrman, Hawthorne & Thomas 2002) and schizophrenia (Becchi et al. 2004). These research studies reported mean and standard deviation (columns three, four, six, and seven, respectively) for each domain of the WHOQoL-BREF questionnaire and can be seen in Table 4-1.
2. the standard deviations of the difference scores for the quality of life subscales in the two research studies above were calculated by a statistical consultant stating that they range from 1 to 1.5 (not reported in the above table). A 3-point difference in QoL mean domain scores between the two groups of patients and proxies on any subscale therefore corresponds to a minimally interesting effect size of 2. This large effect size is detectable in a paired t-test with a sample size of only 5 (significance level 5%, power 80%).
4. based on the calculation of a statistical consultant, a sample of 160 patients (and relevant nurse-pairs), was required for agreement analysis at the individual patient level, which gave a detectable difference of 0.2 - 0.3 units between QoL mean domain scores of patients and nurses.

Table 4-1: Estimating means and standard deviations (ignoring the sign of the differences) for calculating the sample size

Research studies	Domains	Mean scores			Standard deviations		
		Cases	Proxies	Differences	Cases	Proxies	Mean
Becchi et al. (2004)	Physical	57.3	54.0	3.3	16.3	15.2	15.8
	Psychological	52.1	48.9	3.2	18.9	17.3	18.1
	Social	50.7	46.1	4.6	20.3	16.5	18.4
	Environment	55.4	55.8	0.4	14.6	14.9	14.8
Herrman et al. (2002)	Physical	60.7	57.0	3.7	15.4	12.5	14.0
	Psychological	56.8	51.1	5.7	17.4	13.0	15.2
	Social	51.3	43.4	7.9	20.3	18.8	19.6
	Environment	61.1	55.4	5.7	13.8	13.5	13.7

Generally speaking the sample size of 160 is enough for the purposes of this study for individual and group level comparisons. The recruitment of participants proved to be difficult as is often the case with clinical populations. Increasing the sample size was not possible with the resources available at the time.

Conclusion

The main aim of this research study was to identify the level of agreement between patients and nurses about cancer patients' QoL. As QoL is a multi-dimensional construct, a range of quantitative statistical tools were used to better understand the complex nature of QoL. In this chapter details in relation to the method of the first phase were discussed. Despite the difficulties in relation to the best choice of the QoL tool, the WHOQoL-BREF questionnaire was selected as an appropriate tool for this research study. A proxy version of the WHOQoL-BREF questionnaire was also developed by making small modifications to the original one. The WHOQoL-BREF questionnaire has acceptable psychometric properties and has been developed across different countries and cultures. This tool might be broad enough to assess QoL for different cancer patients with a variety of health status. However, the appropriateness of the WHOQoL-BREF questionnaire tool for patients and nurses was tested further in this research study. An explanation of how the WHOQoL-BREF questionnaire was used to collect data from patients and nurses across three major hospitals was also provided. Finally, the sample size at individual and group levels was justified. The following chapter the results of the first phase are described.

CHAPTER FIVE: RESULTS OF THE FIRST PHASE

Introduction

In the previous chapter it was argued that the WHOQoL-BREF questionnaire is an appropriate tool for the first phase of the research study. Then, methods related to data collection of the first phase were introduced and a justification for selection of the sample size was provided.

This chapter outlines the statistical tests used in order to analyse patients' and nurses' QoL scores and report on the outcomes. The statistical tests consist of assessments of the level of agreement between individuals; between each patient-nurse score (Proportion of exact agreement; Pearson correlation; Intraclass Correlation Coefficient; and Bland-Altman test), and an assessment of the level of agreement at the group level (paired-t test). However, the Bland-Altman test was also used to assess the association between the level of agreement (the difference between each patient-nurse QoL score) and the patient's level of QoL. The influence of patients' and nurses' demographic and clinical variables on the level of agreement (the difference between patients' and nurses' QoL scores) was also assessed using Bivariate (Pearson correlation) and Multivariate analysis (Standard multiple regression).

As well as these statistical tests in relation to the major aim of the study (measuring the level of agreement), other statistical tests were used including: descriptive statistical tests concerning patients' and nurses' demographic and clinical variables; descriptive statistical tests related to the amount of missing data; test of the reliability of the WHOQoL-BREF questionnaire; and exploratory factor analysis to explore the complex structure of domains of the WHOQoL-BREF questionnaire. It was beyond the scope of this research study to explore the effect of patients' and nurses' demographic and clinical variables on the QoL mean domain scores of patients and nurses separately.

Firstly, this chapter describes the Statistical Package for the Social Sciences (SPSS)

data file that was used in this research. Results will then be presented in different sections using illustrative tables or figures. The statistical tests used in this research study (introduced above) are explained in more detail at the beginning of each section before reporting the actual results.

Preparing the SPSS file

The quantitative data were entered into the SPSS version 12 software using syntax as recommended by the WHO for this specific questionnaire (The Australian Centre for Posttraumatic Mental Health 2003).

QoL survey items in the questionnaire(s) have specific labels and are classified into four domains: physical, psychological, social relationship, and environmental. Because three questions (three, four, and 26) out of the 26 questions were constructed in a negative form, their scores were reversed. Then, the QoL mean domain scores (MD1=Physical, MD2=Psychological, MD3=Social relationship, and MD4=Environmental) calculated. While the following steps are not obligatory but recommended in the syntax, QoL mean domains were then multiplied by four. The reason for this is that the WHOQoL-100 consists of 24 facets, each of which consists of four items. Only one item of each facet was used to construct the WHOQoL-BREF questionnaire. The WHOQoL-BREF also consists of 26 items but two items (general health and overall QoL) are not included in the scoring (Skevington, S.M., Lotfy & O'Connell 2004). Therefore, multiplication by four allows the WHOQoL-BREF questionnaire to be directly comparable with scores derived from the WHOQoL-100, giving domain scores ranging from four to 20. The same process was used for nurses, leading to four QoL mean domain scores (nMD1=Physical, nMD2=Psychological, nMD3=Social relationship, and nMD4=Environmental). Refer to **Appendix I** for further information.

The WHOQoL domain scores were then transformed to a 0 to 100 scale by the recommended syntax. This latest information was only reserved on the research data file and has the potential usage in the future for purposes of comparison of data with other validated instrument tools and with published community norms. As this

research study did not aim to compare the results with other tools or norms, QoL main domain scores were used on the bases of 4-20 rather than 0-100.

Each item in the WHOQoL-BREF questionnaire used a Likert-type scale (e.g. ranging from very poor, to poor, to neither poor nor good, to good, and to very good) and are categorical in nature. However, as real numbers are allocated to these categorical responses (e.g. 1 for very poor, 2 for poor, 3 for neither poor nor good, 4 for good, and 5 for very good) they can be deemed as continuous variables (Ferrell et al. 1992). Tabachnick and Fidell (2001) argue that making a distinction between categorical and continuous variables is not always a straightforward task. However, as recommended by the WHO and applied in previous QoL research studies, the items in the questionnaire were considered as continuous (not categorical) variables and analysed accordingly.

Data analysis and results

Parametric tests (such as Pearson correlation) were selected. Generally speaking, parametric tests tend to be considered superior to non-parametric tests as they use continuous data which in fact are more informative than categorical data (Story 2004). For example, for categorical variables (like sex or marital status) it does not make sense to calculate summary statistics like mean, median or standard deviation whereas for continuous variables (like age) it does (Greenwood 2004). Pallant (2004) points out that parametric tests are more powerful than non-parametric tests when it comes to identifying the differences between groups provided that conditions such as normal distribution and large sample size have been satisfied.

The assumption of normality was assessed at the beginning of data checking which generally was satisfactory. For example, different QoL mean domain scores for both patients and nurses groups appeared to be reasonably distributed as shown by a bell-shape pattern in the histogram. It is also suggested that when the sample size is large (greater than 100), the assumption of normal distribution is met (Katz, MH 2006). The sample size of 166 was also considered large enough for purposes of the study. No specific criterion exists to identify a large sample size. However, as a general

guide, precision tends to increase steadily up to sample sizes of 150 to 200; after that there are only small gains of accuracy deriving from increasing sample sizes (Fowler 1988).

However, in order to be on the safe side results identified from parametric tests were also checked using non-parametric tests. Since the results were nearly similar, only the parametric results are reported. Story (2004) comments that it is a good strategy to use both parametric and non-parametric tests when researchers do not want to check the assumptions of the parametric tests or parametric assumptions are doubtful. If the results of non-parametric tests are consistent with parametric ones, then only the latter are reported.

Outcomes of descriptive tests relating to missing data

It is common to have a proportion of missing data particularly when human beings are involved in the research study (Pallant 2004). Such missing data can also occur in QoL research studies (Ratcliffe et al. 2005; Tang & McCorkle 2002b). Two kinds of missing data in QoL research studies have been stated by Movsas (2003). One that is generally less important refers to situations when a QoL questionnaire is not filled in completely and can be managed by mean substitution. In this research study, for example, missing data related to questionnaire items were managed using a procedure that was recommended in the WHO data management. Where there were intermittent missing data in patient and nurse questionnaire items, the missing values were imputed using horizontal mean substitution (Department of Psychiatry of the University of Melbourne 2007). In other words, QoL missing items were substituted by the mean of other QoL items on that domain within-subject. No action was taken for missing data related to patients' and nurses' clinical and demographic variables.

The second important kind of missing data is called 'non-ignorable' missing data. In this scenario, a whole questionnaire is missed due to the patient's death or poor health condition. Such problems can lead to biased findings. Steel et al. (2005) suggested that missing data in QoL studies range between 2% and 46%. For example, as reported by Ballatori (2001) about 12% of cancer patients did not fill in their questionnaire. Ganz et al. (1988) found that in patients with metastatic lung

cancer, 13% did not fill out the QoL tool in the baseline assessment. While no universally accepted solution can be suggested for the second cause of missing data, the use of a proxy might be helpful (Bernhard et al. 1998; Bush et al. 1995; Tamim, McCusker & Dendukuri 2002; Tang & McCorkle 2002b). Outcomes of this research study can show if nurses can reliably substitute missing data arising from non-respondent patients or not. Tables 5-1, 5-2 and 5-3 show the number of missing data related to 26 items of the questionnaire and for patients' and nurses' clinical and demographic variables.

Table 5-1 description: The number of missing data based on QoL items of the questionnaire for patients and nurses. The items ‘Negative feelings’ (with 6 cases) and ‘Sex life’ (with 9 cases) have the highest number of missing data for patients and nurses, respectively.

Table 5-1: The number of missing data based on QoL items of the WHOQoL-BREF questionnaire for patients and nurses

Domains	Patients (N)		Nurses (N)	
	Valid	Missing	Valid	Missing
Physical				
"Pain prevents doing"	165	1	166	0
"Need medical treatment"	161	5	163	3
"Energy for daily life"	165	1	166	0
"Able to get around"	164	2	166	0
"Sleep"	164	2	166	0
"Daily living activities"	165	1	166	0
"Capacity for work"	164	2	166	0
Psychological				
"Enjoy life"	166	0	166	0
"Life is meaningful"	166	0	166	0
"Concentrate"	166	0	166	0
"Accept bodily appearance"	166	0	166	0
"Satisfied with yourself"	166	0	166	0
"Negative feelings"	160	6	158	8
Social relationship				
"Sex life"	162	4	157	9
"Friends"	163	3	162	4
"Personal relationship"	161	5	159	7
Environmental				
"Safe in your daily life"	166	0	165	1
"Healthy physical environment"	166	0	165	1
"Money to meet needs"	166	0	165	1
"Information available"	166	0	166	0
"Opportunity for leisure activity"	166	0	166	0
"Conditions of living place"	166	0	165	1
"Access to health services"	166	0	165	1
"Transportation"	166	0	165	1
Overall items				
"Rate QoL"	161	5	165	1
"Health satisfaction"	161	5	163	3

Table 5-2 description: The number of missing data based on patients’ demographic and clinical variables. The highest number of missing data (15 cases) refers to patients’ highest level of education.

Table 5-2: The number of missing data based on patients’ demographic and clinical variables

Characteristics	N	
	Valid	Missing
Patient's gender	165	1
Patient's first language	160	6
Patient's marital status	161	5
Patient's highest level of education	151	15
Patient's current cancer diagnosis	154	12
Patient's current treatment	156	10
Patient's treatment setting	164	2
Patient's performance status	161	5
Patient's age	156	10

Table 5-3 description: The number of missing data based on nurses’ demographic and clinical variables. The highest number of missing data (23 cases) relates to the time the nurse believes he/she spends with the patients/shift.

Table 5-3: The number of missing data based on nurses’ demographic and clinical variables

Characteristics	N	
	Valid	Missing
Nurse' quality of life	160	6
Nurse's age	160	6
Nurse's educational level	162	4
Nurse's gender	165	1
Nurse's language	162	4
Nurse's marital status	159	7
Nurse clinical experience	161	5
Nurse clinical experience with cancer patients	158	8
Time nurse spends with patients/shift	143	23

Outcomes of descriptive tests related to patients' demographic and clinical variables

Figures 5-1 to 5-8 and Table 5-4 summarise the descriptive statistics about patients' variables.

Figure 5-1 description: The number of patients involved based on their gender. These data show that 88 patients (53.3%) were males and 77 patients (46.7%) were females.

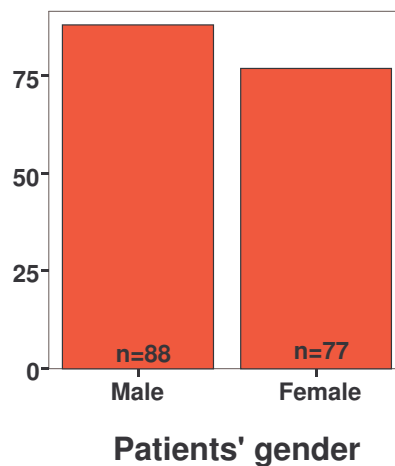


Figure 5-1: The number of patients involved based on their gender

Figure 5-2 description: The number of patients involved based on their first language. These data show that 145 patients (90.6%) used English as their first language and 15 patients (9.40%) spoke a non-English language.

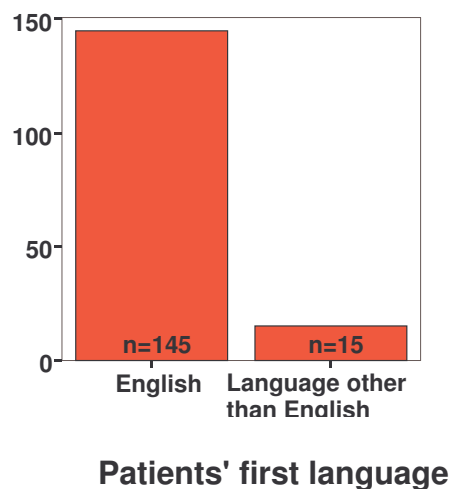


Figure 5-2: The number of patients involved based on their first language use

Figure 5-3 description: The number of patients involved based on their marital status. These data show that the majority of patients 101 (62.7%) were married.

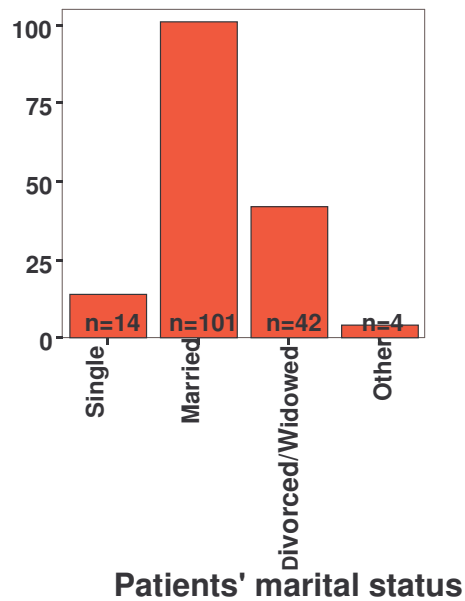


Figure 5-3: The number of patients involved based on their marital status

Figure 5-4 description: The number of patients involved based on their highest level of education. It is evident that the highest number of patients 101 (66.9%) had secondary school as their highest level of education.

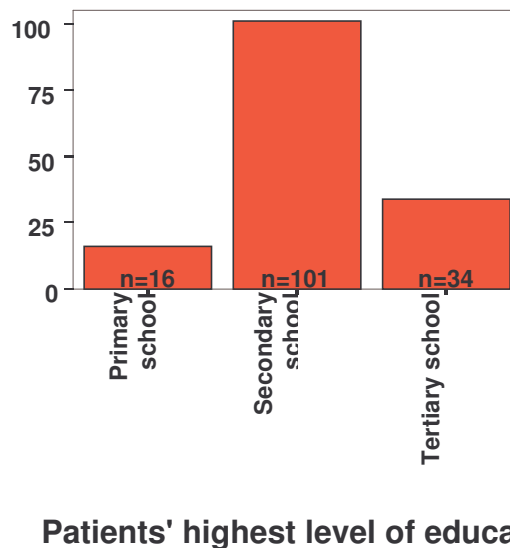


Figure 5-4: The number of patients involved based on their highest level of education

Figure 5-5 description: The number of patients involved based on their current treatment. These data reveal that the highest number of patients 86 (55.1%) received chemotherapy as their current treatment.

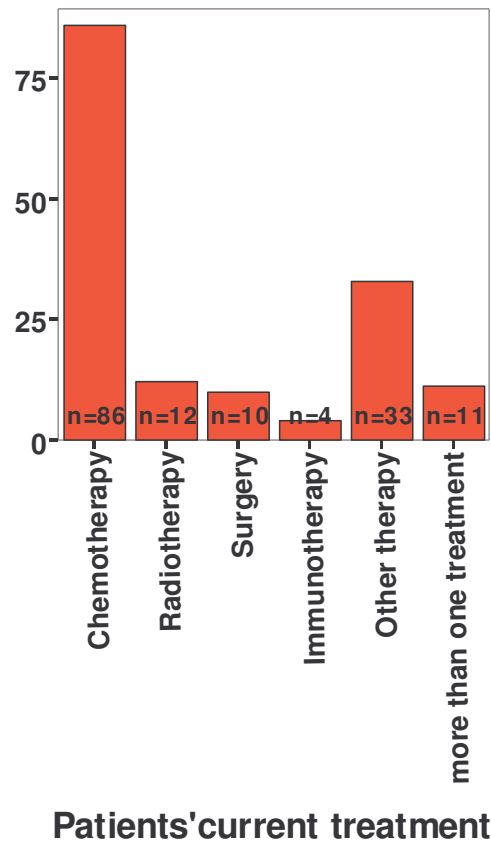
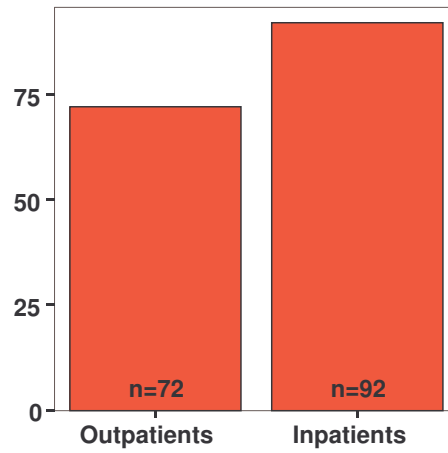


Figure 5-5: The number of patients involved based on their current treatment

Figure 5-6 description: The number of patients involved based on their treatment setting. It is indicated that 72 (43.9%) and 92 (56.1%) patients were treated in outpatient and inpatient wards, respectively.



Patients' treatment setting

Figure 5-6: The number of patients involved based on their treatment setting

Figure 5-7 description: The number of patients involved based on patients' performance status*. The highest number of patients 59 (36.6%) were "Restricted but ambulatory" in their performance status.

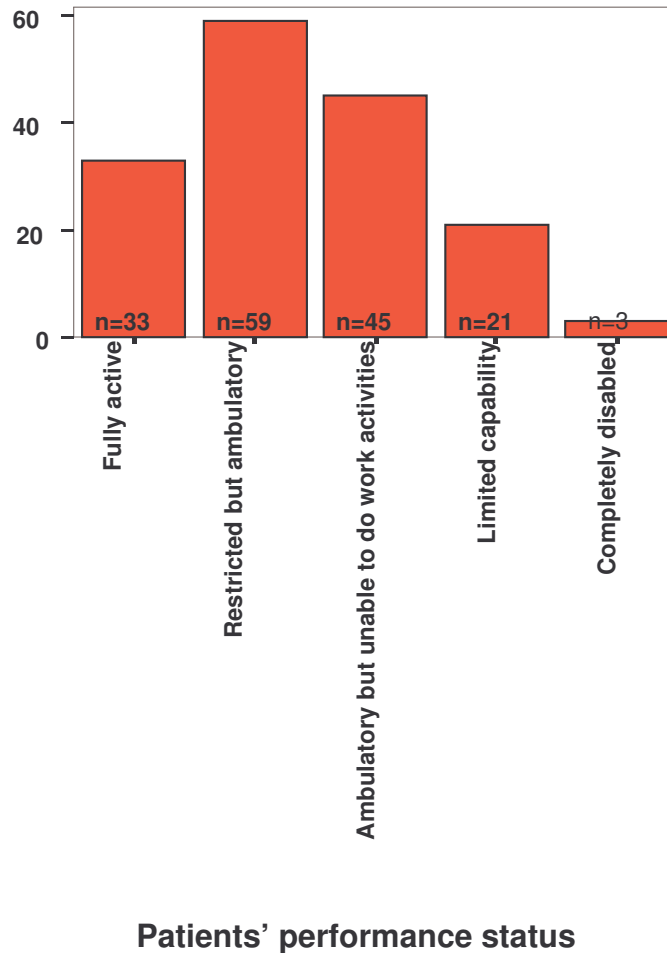


Figure 5-7: The number of patients involved based on patients' performance status

*The patient's performance status was rated using the Eastern Cooperative Oncology Group (ECOG) performance status scale, ranging from 0 (fully active) to 4 (completely disabled). This scale is used by doctors and researchers to assess how a patient's disease is progressing, assess how the disease affects the daily living abilities of the patient, and determine appropriate treatment and prognosis (Eastern Cooperative Oncology Group (ECOG) Performance Status).

Figure 5-8 description: The number of patients involved based on their cancer diagnosis*. The most common kind of cancer was revealed to be breast cancer (25 patients, 17%).

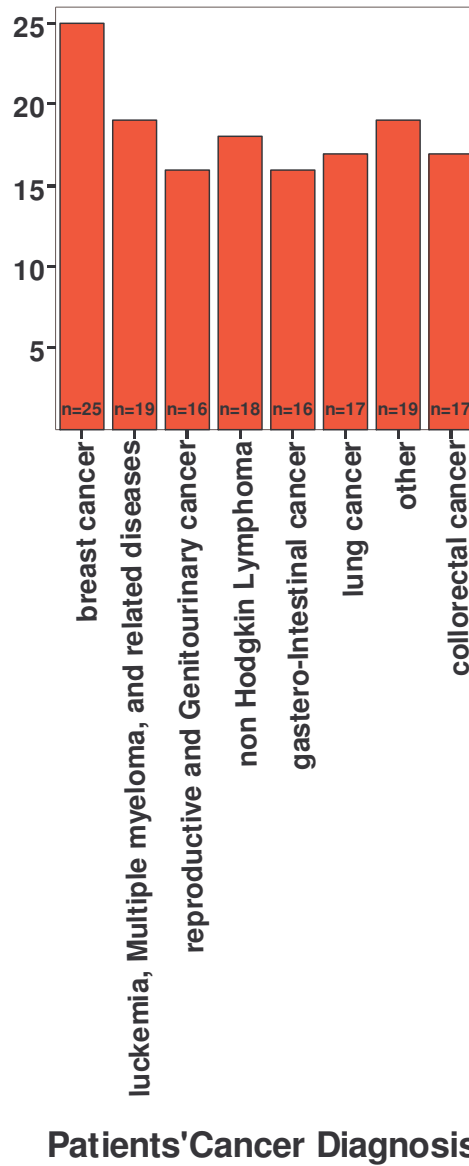


Figure 5-8: The number of patients involved based on their cancer diagnosis

*Cancer patients had a variety of diagnoses (26 types). However for purposes of more efficient reporting they were recoded into eight categories.

Table 5-4 description: Distribution of patients based on their number and their age. These data show that 166 cancer patients took part in the study with the average age of 63.7 (± 15.9 SD) ranging from 18-92.

Table 5-4: Distribution of patients based on their number and their age

Characteristics	Patients
Number	166
Age (Years)	
Mean	63.7
Standard Deviation (SD)	15.9
Range	18-92

Outcomes of descriptive tests related to nurses’ responses based on their clinical and demographic variables

Figures 5-9 to 5-13 and Table 5-5 summarise the descriptive statistics concerning nurses’ responses based on their demographic and clinical variables. Descriptive statistics related to nurses' clinical and demographic variables were calculated based on all responses to the nurses’ questionnaire, and therefore some nurses are included in the sample more than once. On average, one nurse completed two survey questionnaires.

Figure 5-9 description: The number of nurses’ responses in this study based on their gender. The overwhelming majority of responses 159 (96.4%) was made by female nurses and only 6 (3.6%) responses were made by male nurses.

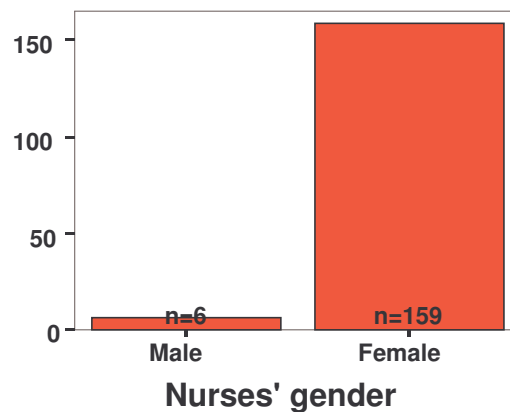


Figure 5-9: The number of nurses’ responses based on their gender

Figure 5-10 description: The number of nurses' responses based on their first language. These data show that 146 (90.1%) responses were made by nurses who had English as their first language and 16 (9.9%) responses were by those nurses who spoke a non-English language.

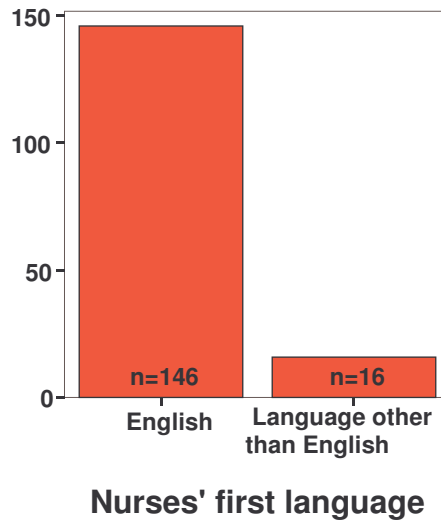


Figure 5-10: The number of nurses' responses based on their first language

Figure 5-11 description: The number of nurses' responses based on their marital status. These data show that the highest number of nurses' responses, 97 (61.0%), were made by those who were married.

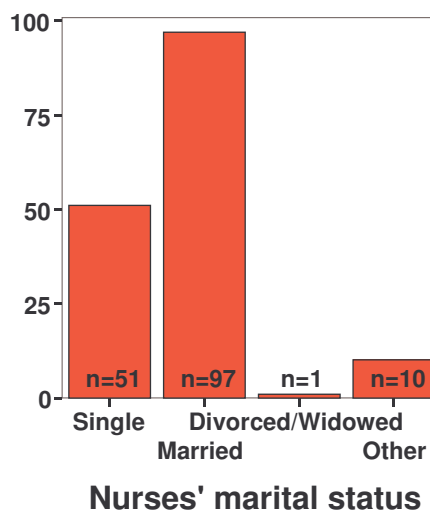


Figure 5-11: The number of nurses' responses based on their marital status

Figure 5-12 description: The number of nurses' responses based on their highest level of education. It appears that the highest number of nurses' responses, 55 (34.0%), emanated from nurses with the RN certificate as their highest level of qualification.

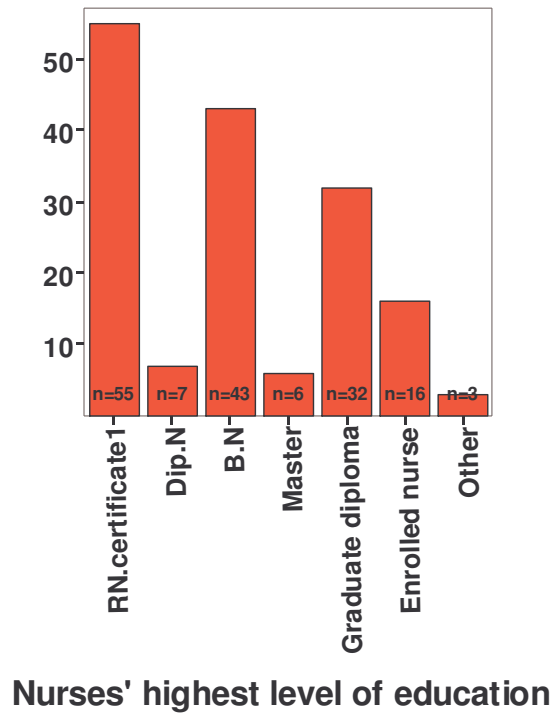


Figure 5-12: The number of nurses' responses based on nurses' highest level of education

Figure 5-13 description: The number of nurses' responses based on their rating of their own quality of life. These data show that the highest number of nurses' responses 89 (55.6%) was made by those nurses who rated their own quality of life as 'very good'.

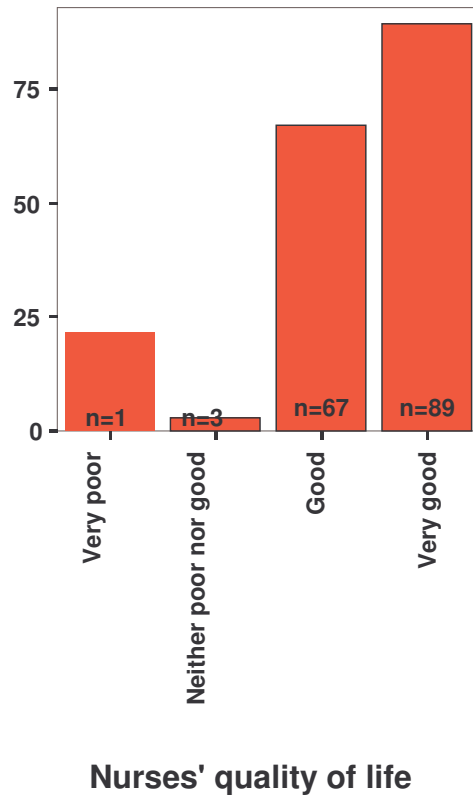


Figure 5-13: The number of nurses' responses based on their rating of their own quality of life

Table 5-5 description: Distribution of nurses’ responses based on their number, their clinical experience, and time spent with cancer patients/shift. These data also show that 95 nurses participated in this study with an average age of 37.5 (\pm 8.30 SD), ranging from 21-55. The mean time the nurse spent for providing care for the given patient (hour/shift) was 2.63 (\pm 1.86 SD) with a range of 0.08-8 hour. The mean clinical experience of nurses was 14.1 years (\pm 9.60 SD) with a range of 0.16-37 years. The nurses’ mean clinical experience with cancer patients was 8.15 years (\pm 6.78SD) with a range of 0-22 years.

Table 5-5: Distribution of nurses’ responses based on their number, their clinical experience and time they spent with cancer patients/shift

Characteristics	Nurses
Number	95
Age (Years)	
Mean	37.5
Standard Deviation (SD)	8.30
Range	21-55
Nurse’s clinical experience	
Mean	14.1
Standard Deviation (SD)	9.60
Range	0.16-37.0
Nurse’s clinical experience with cancer patients	
Mean	8.15
Standard Deviation (SD)	6.78
Range	0-22
Time nurse spends with cancer patients (Hour/Shift)	
Mean	2.63
Standard Deviation (SD)	1.86
Range	0.08-8

Outcomes of assessing the reliability of the WHOQoL-BREF questionnaire (patients and nurses)

As noted earlier, one important psychometric test characteristic of QoL tools is reliability testing. To assess the reliability of the tool, internal consistency was measured using the Cronbach alpha coefficient for patients’ and nurses’ QoL mean domain scores. The ideal acceptable level for the Cronbach alpha coefficient is 0.70 (Pallant 2004) and was used for this study.

Table 5-6 shows the reliability of the WHOQoL-BREF questionnaire based on patients' and nurses' QoL mean domain scores. More details of the reliability test can be seen in **Appendix J**.

Table 5-6 description: The reliability test of the WHOQoL-BREF questionnaire completed by patients and nurses based on QoL mean domain scores. These data show that the Cronbach's alpha value for patients' responses were 0.83, 0.80, 0.37, and 0.69, for the physical, psychological, social relationship and environmental domain, respectively. The corresponding data for nurses were 0.85, 0.78, 0.60, and 0.80, respectively.

Table 5-6: Test of reliability of the WHOQoL-BREF questionnaire completed by patients and nurses based on QoL mean domain scores

QoL domain	Cronbach alpha	
	Patients	Nurses
Physical (7 items)	0.83	0.85
Psychological (6 items)	0.80	0.78
Social Relationship (3 items)	0.37	0.60
Environmental (8 items)	0.69	0.80
Overall (26 items together)	0.89	0.92

Outcomes of measuring the level of agreement between patients and nurses about cancer patients' QoL

Patient and proxy agreement is usually assessed at an individual level to measure the similarity of scoring of each item between the two rater groups and at the group level to identify any systematic bias between two raters (i.e. proxies underestimate or overestimate patients' QoL) (von Essen 2004). The following pages indicate how different measures have been used to measure agreement at the different levels (i.e. individual and group levels).

Correlations (r and ICC)

Correlation tests are used to describe the strength and direction of a linear relationship between two variables. One of the correlation methods is the Pearson-moment coefficient (r) that has been designed to test for an association between two

continuous variables. The result of the test (r) is indicated by a value of between -1 and +1. The + or - at the front indicates whether there is a positive correlation (as one variable increases, so too does the other) or a negative correlation (as one variable increases, the other decreases). The size of the absolute value provides an indication of the strength of the relationship. A perfect correlation of -1 or +1 indicates that the value of one variable can be determined exactly by knowing the value of the other variable (Pallant 2004).

Pearson correlation was conducted in the first step of this analysis despite the belief that it might lead to inaccurate conclusions about the level of agreement between two groups (Tang & McCorkle 2002b). For example, sometimes proxies provide a rating that is completely higher or lower than the patients' rating, but still a high correlation between two raters might exist (Moinpour et al. 2000).

An Intraclass Correlation Coefficient (ICC) was therefore calculated for determining the level of agreement between patients and nurses of continuous data (Nelson et al. 1990) that best accounts for chance agreement between the groups (Lee, Koh & Ong 1989). While the correlation (r) indicates whether paired scores go up and down together (or level of covary) (Lobchuk & Degner 2002), the ICC is the appropriate way for determining the level of agreement (equality of ratings or concordance) on continuous data between the two groups (Sneeuw et al. 1998).

There are criteria for making a judgment about the results of correlation coefficient values, For example, Cohen (1988) states that the results of correlation (r), irrespective of the sign in front, should be interpreted as below:

$r=0.1$ to 0.29 indicates a small correlation

$r=0.3$ to 0.49 indicates a medium correlation

$r=0.5$ to 1.00 indicates a large correlation

Landis and Koch (1977) also proposed criteria to judge the results of kappa statistics across studies as follows: less than or equal to 0.20, poor; 0.21-0.40, fair; 0.41-0.60, moderate; 0.61-0.80, substantial; 0.81-1, almost perfect. These criteria can also be used for correlation coefficient and ICC as well (Tang & McCorkle 2002b; von Essen 2004). The latter was used to judge the results of both r and ICC in this research study. Tables 5-7 and 5-8 show the results of correlation (r) and ICC. The ICC values between patients' and nurses' scores for all 26 items on the WHOQoL-

BREF questionnaire are included in **Appendix K**.

Table 5-7 description: Pearson correlations between different mean domain scores of patients and proxies (nurses). These data show that there was moderate significant correlation in the physical domain ($r=0.50$, $p<0.01$), a poor significant correlation in the psychological domain ($r= 0.19$, $p<0.05$), and a fair significant correlation in the environmental domain ($r=0.34$, $p<0.01$) between patients and nurses. There was also a non-significant and poor correlation in the social relationship domain ($r=0.08$, $p=0.34$) between patients and nurses.

Table 5-7: Pearson correlations between different mean domain scores of patients and nurses

Domains	Patient-Nurse correlation (r)	Significance*
Physical	0.50	0.00
Psychological	0.19	0.02
Social relationship	0.08	0.34
Environmental	0.34	0.00

*Only significant differences at ($p<0.05$) are important

Table 5-8 description: Intraclass correlations between the QoL mean domains of patients and nurses. There was moderate significant correlation in the physical domain ($ICC=0.48$, $p<0.05$), a poor significant correlation in the psychological domain ($ICC= 0.19$, $p<0.05$), and a fair significant correlation in the environmental domain ($ICC=0.30$, $p<0.05$). There also was a non-significant and poor correlation in the social relationship domain ($ICC=0.06$, $p=0.22$) between patients and nurses.

Table 5-8: Intraclass correlations between QoL mean domain scores of patients and nurses

Domains	Patient-Nurse ICC*	Significance **
Physical	0.48	0.00
Psychological	0.19	0.01
Social relationship	0.06	0.22
Environmental	0.30	0.00

*Results of single measure are reported

**Only significant differences at ($p<0.05$) are important

The proportion of exact agreement between patients and nurses

Even with a moderate association between patients and nurses, both ratings might be quite similar (von Essen 2004). Therefore, the proportion of exact agreement is suggested as a complementary test for measuring the level of agreement (Lobchuk & Degner 2002; Sneeuw et al. 1998; Tang & McCorkle 2002b). This test was also conducted to measure the level of agreement between cancer patients and nurses at the individual level. Exact agreement is defined as those cases where the response category chosen by the patient and the nurse for a given item is identical (Sneeuw et al. 1997). Percentage agreement is calculated by adding up the number of cases that received the same rating by both judges and dividing that number by the total number of cases rated by the two judges (Stemler 2004). While this test allows an estimation of the magnitude of agreement based on a calculation of the proportion of exact responses (Lobchuk & Degner 2002), it also is criticised as having no attention to agreement by chance (Magaziner et al. 1988; Sneeuw et al. 1997).

Unfortunately, there is not a cut-off point above which we can say that there is a good exact agreement between patients and nurses in their responses to each QoL questionnaire item. However, previous research studies (Fisch et al. 2003; Sneeuw et al. 1997) suggest that at least 60% of agreement between patients and proxies in a QoL tool items is satisfactory. This criterion was also used in this research study.

The proportion of exact agreement between patients' and nurses' scores was calculated for all 26 items on the WHOQoL-BREF questionnaire and reported in **Appendix L**. The exact agreement for each domain was then calculated as an average of exact agreement of corresponding items related to that specific domain. The average of exact agreement for all 26 items together was also calculated. The results of the exact agreement are shown in Table 5-9.

Table 5-9 description: The proportion of exact agreement between patients and nurses for different QoL domains of the WHOQoL-BREF questionnaire. These data show that the average proportion of exact agreement between patients and nurses is 35.5%. The proportion of the exact agreement between the two groups was 34.9%, 34.5%, 33.8%, and 36.9% for the physical, psychological, social relationship, and environmental QoL domains.

Table 5-9: The proportion of exact agreement for different QoL domains between patients and nurses

QoL domain	Proportion of exact agreement
Physical	34.9%
Psychological	34.5%
Social relationship	33.8%
environmental	36.9%
Average	35.5%

Bland-Altman test

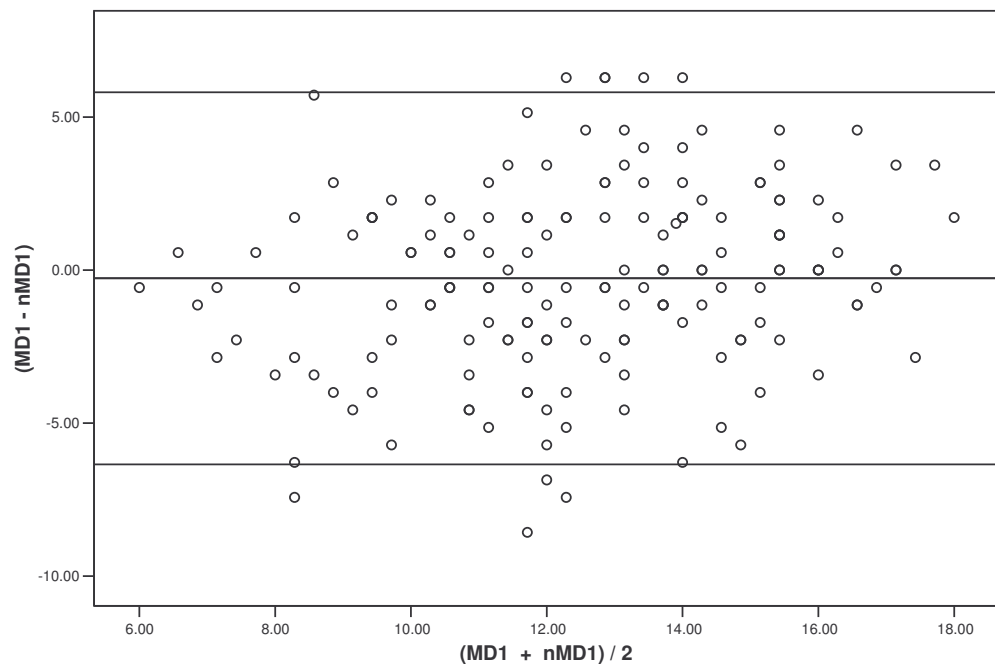
As noted earlier, the Pearson correlation (r) is not the most robust indicator for assessing the level of agreement between patients and their nurses. Bland and Altman proposed an alternative way that is named the Bland-Altman test (Bland & Altman 1986). In this test instead of using a simple correlation between two methods/raters, the difference between two raters is plotted against the average of two QoL scores (Bland & Altman 1986). In this research study, for example, the difference between the patient and nurse QoL scores was plotted against the average of two scores for each patient-nurse pair.

In this plot, two important issues need to be considered. The first point is the acceptability of the overall width of the scatter (upper and lower levels of agreement between the two groups). This is an interval measure and 95% of differences (in this case patient-nurse difference) would fall within this interval (Moinpour et al. 2000). Unfortunately, there is no cut-off point regarding the percentage difference between upper and lower levels of agreement that can be considered a significant difference. The acceptable level of difference between upper and lower levels of agreement was set at 10 %. The researcher referred to another research study (Sloan et al. 1998) in which a difference of 10 points out of 100 for the Spitzer scale was not considered an

acceptable difference between patients and proxies.

Another point of interest is whether there is a pattern in the scatter of points. In fact, this method finds out if agreement varies across a range of QoL scores by visual examination of a scatter plot (Lobchuk & Degner 2002). More details about how Bland-Altman plots were drawn for different QoL mean domain scores can be located in **Appendix M**. See Figures 5-14 to 5-17 for actual results of the Bland-Altman test.

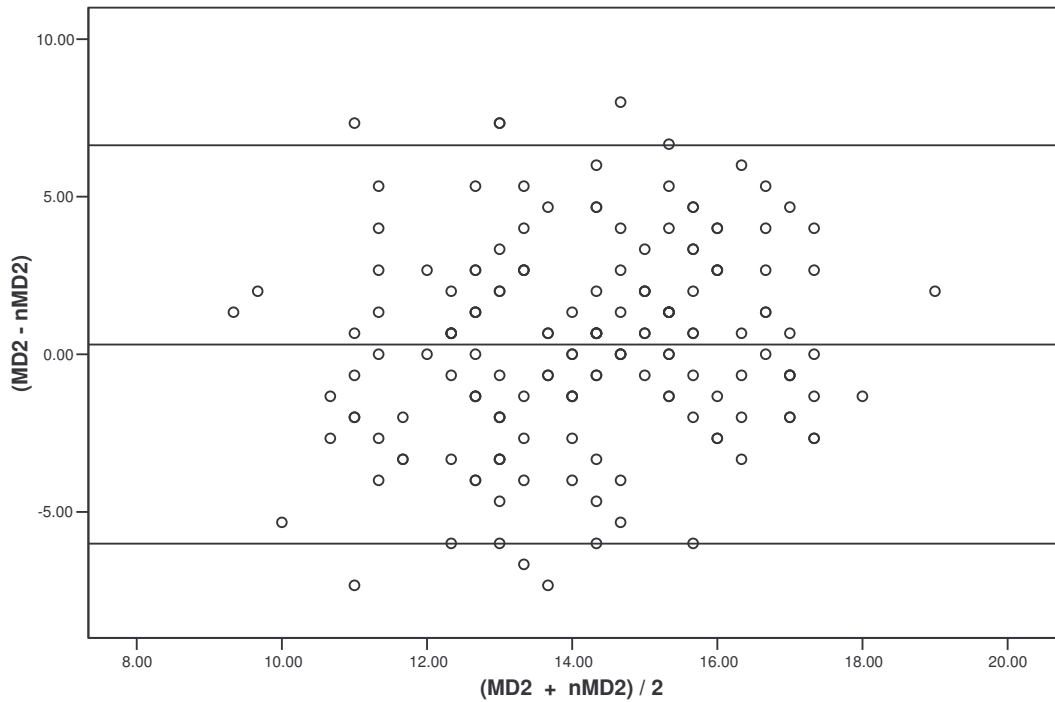
Figure 5-14 description: Bland-Altman plot* indicating average physical QoL mean domain scores of patients and nurses against differences in their mean domain scores. These data show that the location of the upper and lower limits of agreement of two raters (patients and nurses) differs by around 6 points. This figure also shows that there is not an obvious pattern between the difference of means and the average of means in the physical QoL domain.



* $(MD1+nMD2)/2$: This shows the average of mean domain scores of two groups in the horizontal (X) axis.
 $(MD1-nMD2)$: The difference between mean domain scores of two groups in the vertical (Y) axis is shown. There are three lines in the plot. The first one in the middle (near to the point 0.00) shows the mean of differences. The line above this (near to the point 5.00) and the line below (near to the point - 5.00) are upper and lower limits of agreement, respectively.

Figure 5-14: Bland-Altman plot indicating average physical QoL mean domain scores of patients and nurses against differences in their mean domain scores

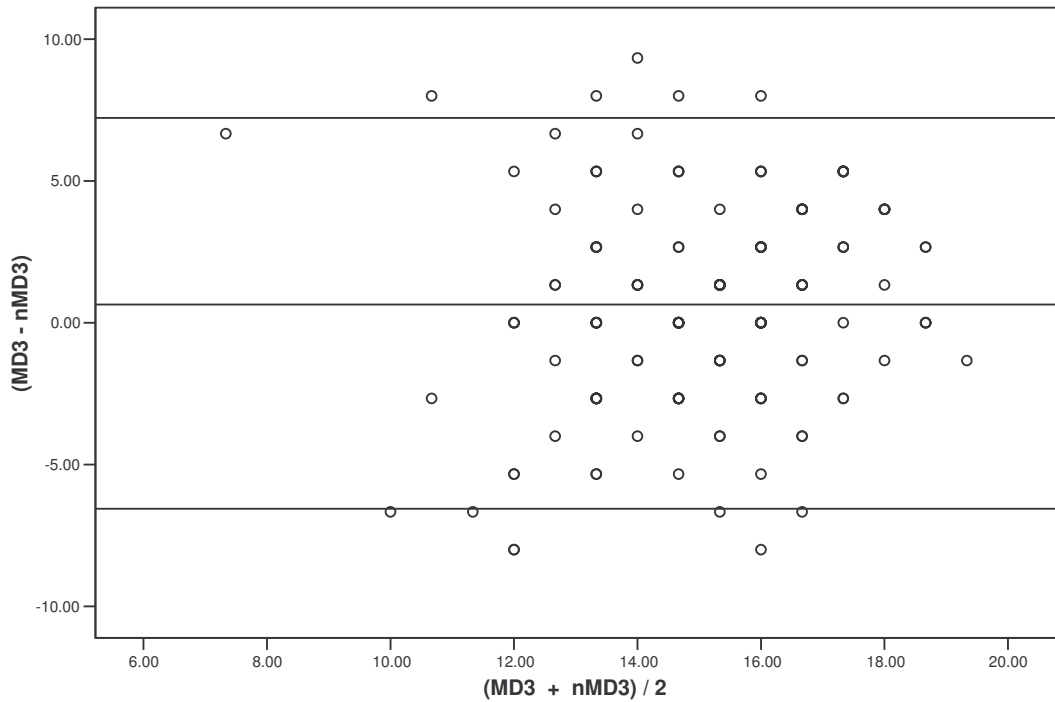
Figure 5-15 description: Bland-Altman plot* indicating average psychological QoL mean domain scores of patients and nurses against differences in their mean domain scores. These data show that the location of the upper and lower limits of agreement of two raters (patients and nurses) differs by around 6 points. This figure also shows that there is no obvious pattern between the difference of means and the average of means in the psychological QoL domain.



* $(MD1+nMD2)/2$: This shows the average of mean domain scores of two groups in the horizontal (X) axis.
 $(MD1-nMD2)$: The difference between mean domain scores of two groups in the vertical (Y) axis is shown. There are three lines in the plot. The first one in the middle (near to the point 0.00) shows the mean of differences. The line above this (near to the point 5.00) and the line below (near to the point - 5.00) are upper and lower limits of agreement, respectively.

Figure 5-15: Bland-Altman plot indicating average psychological QoL mean domain scores of patients and nurses against differences in their mean domain scores

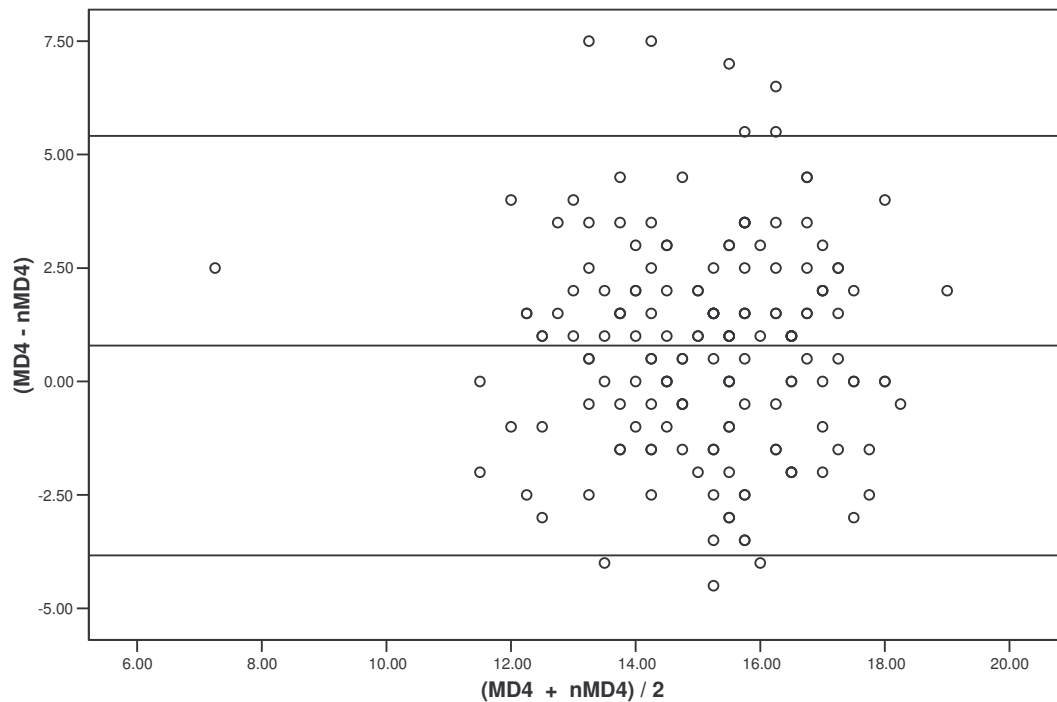
Figure 5-16 description: Bland-Altman plot* indicating average social relationship QoL mean domain scores of patients and nurses against differences in their mean domain scores. These data show that the location of the upper and lower limits of agreement of two raters (patients and nurses) differs by around 7 points. There is no obvious pattern between the difference of means and the average of means in the social relationship QoL domain.



* $(MD1+nMD2)/2$: This shows the average of mean domain scores of two groups in the horizontal (X) axis.
 $(MD1-nMD2)$: The difference between mean domain scores of two groups in the vertical (Y) axis is shown. There are three lines in the plot. The first one in the middle (near to the point 0.00) shows the mean of differences. The line above this (near to the point 5.00) and the line below (near to the point - 5.00) are upper and lower limits of agreement, respectively.

Figure 5-16: Bland-Altman plot indicating average social relationship QoL mean domain scores of patients and nurses against differences in their mean domain scores

Figure 5-17 description: Bland-Altman plot* indicating average environmental QoL mean domain scores of patients and nurses against differences in their mean domain scores. These data show that the location of the upper and lower limits of agreement of two raters (patients and nurses) differs by around 5 points. This figure also shows that there is not an obvious pattern between the difference and average of means in the environmental QoL domain.



*(MD1+nMD2)/2: This shows the average of mean domain scores of two groups in the horizontal (X) axis.
 (MD1-nMD2): The difference between mean domain scores of two groups in the vertical (Y) axis is shown. There are three lines in the plot. The first one in the middle (near to the point 0.00) shows the mean of differences. The line above this (near to the point 5.00) and the line below (near to the point - 5.00) are upper and lower limits of agreement, respectively.

Figure 5-17: Bland-Altman plot indicating average environmental QoL mean domain scores of patients and nurses against differences in their mean domain scores

Paired t-test for comparing means of two group responses

The above mentioned statistical tests (r, ICC, the proportion of the exact agreement, and the Bland-Altman test) identify the amount of association or agreement between two groups of patients and nurses but cannot show how nurses rate their patients as having a higher or lower level of QoL than did the patients themselves. In this situation, comparing the means of two groups of patients and nurses can help in identifying such differences more clearly (Lobchuk & Degner 2002; Sneeuw et al. 1998; Tang & McCorkle 2002b).

In this research study, a paired t-test was used to compare the means of two groups of patients and nurses in order to find out the statistically significant differences between different QoL mean domain scores. The significance level was set at 0.05 ($p < 0.05$). The effect size is also reported below in the description of Table 5-10. Effect sizes provide an indication of the magnitude of the differences between groups. There are different ways to obtain effect size but one of them which is calculated in this research study is the Eta squared:

$$\text{Eta squared} = \frac{t^2}{t^2 + N - 1}$$

Cohen (1988) classifies 0.01 as a small effect, 0.06 as a medium effect and 0.14 as a large effect. These criteria were used in this research study. Table 5-10 shows the results of the t-test.

Table 5-10 description: Paired samples t-test values between different QoL mean domain scores of patients and nurses. These data show that there were significant differences between social relationship QoL mean domain scores of patients and nurses [$t(161) = 2.27, p < 0.05$] and between environmental mean domain scores of patients and nurses [$t(165) = 4.39, p < 0.01$]. For the social relationship and the environmental QoL domains, the Eta squared (as an indicator of effect size) was 0.03 and 0.10, indicating small and medium effect size, respectively. There were no significant differences between patients and nurses in the physical [$t(165) = -1.14$] and the psychological [$t(165) = 1.25$] QoL mean domains.

Table 5-10: Paired samples t-test values between QoL mean domain scores of patients and nurses

QoL domain	Patients		Nurses		Patient-Nurse difference		Patient-Nurse t-test	
	Mean	SD	Mean	SD	Mean	SD	t	d.f
Physical	12.4	3.25	12.6	2.70	-0.27	3.04	-1.14	165
Psychological	14.3	2.66	14.0	2.28	0.31	3.16	1.25	165
Social relationship	15.4	2.86	14.8	2.41	0.64	3.60	2.27*	161
Environmental	15.5	1.99	14.7	2.03	0.79	2.30	4.39**	165

*Statistically significant difference between patient and nurse score ($p < 0.05$)

**Statistically significant difference between patient and nurse score ($p < 0.01$)

Outcomes of assessing the relationship/effect of demographic and clinical variables of patients and nurses on the level of agreement using Bivariate and Multivariate analysis

One major issue in using Bivariate tests such as t-test or correlation as previously reported is that they overlook the influence that might exist between variables themselves (Sneeuw et al. 1998). Using Multivariate tests such as Multiple regression was introduced to identify if this is a problem. In fact, such tests are useful for determining the relative contributions of different causes to a single event (Katz 2006).

One of the aims of this study was to conclude if any patients' and nurses' clinical and demographic variables (independent or predictor variables) can significantly

influence the level of agreement between patients and nurses (dependent variable), and whether this variable is still able to affect the level of agreement when the effects of another variable(s) are controlled for. Multiple regression is a very sophisticated statistical test that can be used to answer such questions (Tabachnick & Fidell 2001). The Standard multiple regression was used for Multivariate analysis. Unlike other studies that chose the Hierarchical multiple regression (Rothman et al. 1991), this study did not have any theory to support entering the data into the equation in a given order.

At first, a Bivariate correlation (r) was conducted between patient-nurse absolute QoL mean domain differences as the dependent variable with patients' and nurses' clinical and demographic variables as the independent variable. Bivariate correlation identified only one or two significant correlations at 0.05 between patients' and nurses' clinical and demographic variables with absolute QoL mean domain differences. Therefore, in order to conduct Standardised multiple regression analysis, those correlations with the significance level less than 0.10 simultaneously entered into the equation. It is worth stating that both Bivariate and Multivariate analysis require one continuous dependent variable and two or more continuous independent variables (or categorical variables with only two levels) (Pallant 2004). Therefore, at both Bivariate and Multivariate levels those categorical variables had more than two levels translated to dummy variables before entering into the equation. Altogether 15 dummy variables were created (see Table 5-11).

At Multivariate level, Beta coefficients with p values of 0.05 or less were considered significant. Moreover, Adjusted R-square was used to determine the proportion of variance in patient–nurse differences that could be explained by the patient and nurse variables combined. There is no cut-off point to judge if outcomes of Adjusted R-square are trivial or not. The significance of these outcomes will be discussed along with the results of the second phase.

Table 5-11 below shows Bivariate and Multivariate correlation between patients' and nurses' clinical and demographic variables and absolute difference between patients and nurses QoL mean domain scores.

Table 5-11 description: Bivariate and Multivariate correlations between patients' and nurses' clinical and demographic variables and absolute difference between patients and nurses QoL mean domain scores. At the Bivariate level only a few variables were identified to be significantly associated with the absolute difference between patients' and nurses' QoL mean domain scores (being an indicator of agreement). Larger differences between patient and nurse physical QoL domain scores were noted when the nurses had less clinical experience with cancer patients. In the psychological and social relationship QoL domains, greater differences between nurses and their patients were found to exist for inpatients. Finally, larger differences between patient and nurse environmental QoL mean domain scores were noted for inpatients and nurses with lower levels of QoL.

However, using Multivariate analysis, the Adjusted R-square indicated that these variables explained only 4%, 2%, 3%, and 6% of the variance in absolute patient-nurse differences in the physical, psychological, social relationship and environmental QoL mean domain scores, respectively. Where the patients were receiving treatment ($\beta=0.20$) was the only statistically significant predictor of differences between patient and nurse scores obtained for the social relationship and psychological QoL domain scores. In the environmental domain, the only statistically significant predictor of differences between patient and nurse was the nurse's QoL ($\beta=-0.20$).

Notes for Table 5-11

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

*** Correlation is significant at a level between 0.05 and 0.1 (2-tailed). These significant correlations also imported into the equation in order to better conduct the regression. Also, in all four equations, patient's first language, patient's treatment setting, nurse clinical experience, nurse clinical experience with cancer patients, and nurse' quality of life imported into the equation.

^o As these categorical variables had more than two categories, they were entered into equation after creating dummy coding variables. Some variables recoded before creating dummy coding variables.

•In the parenthesis in front of all variables, the reference groups are identified. For example, male vs. female indicates that male is the reference group. This is the situation for other variables.

Table 5-11: Bivariate and Multivariate correlations between patients' and nurses' clinical and demographic variables and absolute difference between patients and nurses QoL mean domain scores

Patients and nurses characteristics*	Absolute difference							
	(Physical)		(Psychological)		(Social relationship)		(Environmental)	
	r	Beta	r	Beta	r	Beta	r	Beta
Patient's gender (male vs. female)	0.03		0.12		-0.01		0.02	
Patient's age (year)	-0.01		-0.11		0.06		-0.13	
Patient's first language (English vs. other)	0.13***	0.12	0.03	0.01	0.12	0.10	-0.04	-0.07
Patient's treatment setting (outpatient vs. inpatient)	0.15***	0.08	0.20 *	0.20*	0.16*	0.20*	0.19*	0.17
Patient performance status (From fully active to completely disabled)	0.10		0.09		0.07	0.13	-0.05	
Nurse's gender (male vs. female)	-0.08		-0.04		0.09		-0.06	
Nurse's age (year)	-0.10		-0.04		0.05		-0.09	
Nurse's language (English vs. other)	-0.10		0.02		-0.04		0.01	
Time nurse spends with patients/shift (hour)	-0.02		0.11		-0.00		0.07	
Nurse' clinical experience (year)	-0.14 ***	-0.02	-0.10	0.05	0.00	0.13	-0.14***	-0.15
Nurse' clinical experience with cancer patients (year)	-0.17*	-0.14	-0.13	-0.08	-0.04	-0.06	-0.05	0.15
Nurse' quality of life (from very poor to very good)	0.10	0.13	0.06	0.10	0.10	0.13	-0.22**	-0.20*
Patient marital status (married vs. Divorced/widowed) °	0.03		0.04		0.08		0.10	
Patient marital status (married vs. other) °	-0.10		0.06		-0.00		0.11	
Patient educational level (secondary vs. Primary school) °	0.07		0.02		-0.10		-0.04	
Patient educational level (secondary vs. Tertiary school) °	0.01		0.05		-0.01		0.05	
Cancer diagnosis (Breast cancer vs. Leukaemia) °	0.08		0.01		0.05		0.00	
Cancer diagnosis (Breast cancer vs. Reproductive) °	-0.09		-0.09		-0.07		-0.09	
Cancer diagnosis (Breast cancer vs. NHL) °	0.03		0.07		0.03		0.10	
Cancer diagnosis (Breast cancer vs. GI) °	-0.00		-0.03		-0.01		-0.04	
Cancer diagnosis (Breast cancer vs. lung cancer) °	-0.03		-0.02		0.06		0.04	
Cancer diagnosis (Breast cancer vs. other kind) °	0.02		-0.04		-0.02		0.04	
Nurse marital status (Married vs. Single) °	-0.07		-0.11		-0.01		0.02	
Nurse's marital status (Married vs. other) °	0.05		0.03		0.13		0.04	
Nurse's educational level (RN vs. BN) °	0.12		0.05		0.01		0.03	
Nurse's educational level (RN vs. Graduate diploma) °	-0.08		-0.06		-0.05		-0.021	
Nurse's educational level (R.N vs. other)°	-0.02		-0.08		-0.02		-0.02	
Patient 's current cancer treatment (chemotherapy vs. other)	0.08		-0.01		0.12		-0.04	
Adjusted R-square		4%		2%		3%		6%

Outcomes of the exploratory factor analysis showing the structure of domains of the WHOQoL-BREF questionnaire completed by cancer patients

Factor analysis is a very complex statistical test that takes a large set of variables and tries to summarise them to a smaller set of factors or components (Pallant 2004). This test is helpful for researchers who want to see how items in a tool or scale can be grouped together and create smaller subscales or tools. While factor analysis needs at least 300 cases, when the sample is strong and reliable and contains only a small number of factors, a smaller sample may be chosen (Harris & Heard 2004). Tabachnick and Fidell (2001) also recommended a sample size of 300 for more comfortable results. But they also suggested that having 5 cases for each item of the tool or scale is adequate in most cases. The WHOQoL-BREF questionnaire contains 26 items. However, two items (health satisfaction and rate QoL) are not included in the scoring. Given that 5 cases are needed for each item analysis, a sample of at least 120 (24 multiply 5) is enough for this analysis. In this research study the sample size of patients is 166, which would be enough to conduct an exploratory factor analysis.

Having considered the complexities and differences in conducting and reporting the outcomes of an exploratory factor analysis, the method as suggested by Pallant (2004) was conducted using SPSS version 12 software. Following these guidelines, at the first step, items of the WHOQoL-BREF questionnaire were assessed for suitability of the data for factor analysis. For example, inspection of the correlation matrix supported conducting this analysis because there were many coefficients of 0.3 or above. The Kaiser-Meyer-Olkin measure of sampling adequacy was 0.83, exceeding the recommended value of 0.60. Bartlett's test of Sphericity reached statistical significance, supporting the factorability of the correlation matrix for patients.

At the second step, factor extraction was conducted using Principal Components Analysis (PCA). In this step, for each component or factor (in this case each item of the questionnaire) the eigenvalue was calculated (named Total in the table) which shows the amount of the total variance explained with that factor (% of Variance in the table). However, as recommended as a rule of thumb by Harris & Heard (2004), the researcher generally considered seriously factors with eigenvalues greater than 1.

Table 5-12 shows the eigenvalues more than 1 and related variances for the WHOQOL-BREF questionnaire completed by patients.

Table 5-12: The Eigenvalues over one and related variances for the WHOQoL-BREF questionnaire completed by patients

Component	Initial Eigenvalues		
	Total	% of Variance	Cumulative %
1	6.60	27.5	27.5
2	2.79	11.6	39.1
3	1.55	6.44	45.6
4	1.38	5.74	51.3
5	1.23	5.13	56.4
6	1.08	4.49	60.9
7	1.01	4.20	65.1

Extraction Method: Principal Component Analysis

Table description: Table 5-12 shows the eigenvalues more than 1 and related variances for the WHOQoL-BREF questionnaire completed by patients. Principal components analysis revealed the presence of 7 components eigenvalues exceeding 1, explaining 27.5%, 11.6%, 6.44%, 5.74%, 5.13%, 4.49%, and 4.20% of the variance, respectively.

Conclusion

In the first phase of this study, QoL scores of patients and nurses were analysed using parametric tests because the data were considered continuous and generally met prerequisites of a normal distribution. Descriptive outcomes related to demographic and clinical variables of patients and nurses were presented through a number of tables and figures. Several important findings were found as a result of different statistical tests:

1. Correlations of r and ICC ranged from 0.06 in the social relationship domain up to 0.50 in the physical domain indicating a poor to moderate association between patients' and nurses' QoL scores.
2. Bland-Altman test revealed a 6 point (out of 20) difference between each patient-nurse score (around 30 % differences).

3. Bland-Altman test also revealed that there was no obvious association between the level of agreement and the patients' level of QoL.
4. Paired sample t-test indicated that nurses' scores were significantly lower than patients' scores in the social relationship and environmental domains.
5. Bivariate correlation (Pearson correlation) identified that a number of patients' and nurses' variables were associated with the level of agreement. However, at the Multivariate level (using Standard multiple regression) only a limited number of these variables were found to be associated with the level of agreement including (a) where the patients were treated (outpatients versus inpatients) was associated by the level of agreement in psychological and social relationship domains; and (b) nurses' rating of their own QoL was associated with the level of agreement in the environmental domain.
6. The test of the reliability of the WHOQoL-BREF questionnaire using the internal consistency test showed that except the social relationship domain, Cronbach alpha values approached or were above 0.70 for both patients and nurses scores.
7. The exploratory factor analysis for patients' scores using the WHOQoL-BREF questionnaire identified 7 factors (or domains) with the eigenvalues more than 1. In other words, based on patients' responses items of the WHOQoL-BREF questionnaire can be grouped into 7 domains.

No further interpretations of empirical findings are made in this chapter. The above important empirical findings will be used in the discussion and the concluding chapters, which will also incorporate interpretive outcomes that seek to answer the research questions, make conclusions, and provide suggestions for future research studies.

CHAPTER SIX: METHODS OF THE SECOND PHASE

Introduction

In the previous chapter, results of the first phase using different statistical tests were presented. These statistical tests were those that measured the level of agreement at the individual level (between each patient-nurse score) and at the group level (patients as a group with nurses as a group).

This chapter explains and justifies the methods that were used in the second phase in order to deeply understand nurses' perceptions about cancer patients' QoL. Two important issues need to be addressed here. Firstly, while this chapter is in fact a method chapter it can also be seen as an audit trail chapter that shows what steps were undertaken in the second phase. It is important for researchers to elaborate on methods and processes they used in interpretive studies so that other researchers can also scrutinise them. In the next chapter the results of the second phase will be provided. This chapter is mainly concerned with the methods used in the second phase. However, these methods incorporated some features and outcomes of the first phase. In other words, some outcomes of the first phase were used to construct the second phase. These issues are further elaborated on throughout this chapter.

Aim of the second phase

In the second phase, the major aim of the study is to explore why nurses' perceptions about cancer patients' QoL is different from those of cancer patients' own perceptions.

Research methods

As explained in the methodology chapter, the second phase of the study was based on the principles of a classical version of grounded theory. While the processes of data collection and analysis in an interpretive study are interwoven, for the purpose of easy understanding they are discussed in two separate sections.

Data collection

In the first phase, the WHOQoL-BREF questionnaire was used in order to collect data, and a complementary interview method was used in the second phase. In the following section, a justification is given as to why the interview has been chosen as the data collection method in this phase of the study.

Why use interviews

While interviews or participant observation or a combination of them are the main way of data collection in a research study based on a grounded theory methodology (Stanley 2006), there is no limitation on the kind of data to gather because different kinds of data give the analyst different views (Leedy & Ormrod 2005). Such different views are called “slices of data” (Glaser & Strauss 1967, p.65). However, an interview was found to be more suitable for this research study because it allowed cancer patients and nurses to talk more openly about their QoL perceptions. In fact, in a QoL research study researchers might combine QoL tools (that was used in the first phase) with interviews for a variety of reasons. Interviewing is a good way for respondents to express individual information that may not be revealed in a questionnaire (Aaronson 1988; Grant & Rivera 1988). It is particularly applicable to a variety of patients such as elderly, poorly educated, and moderately or severely ill groups (Aaronson 1988, 1989; Mandelblatt & Eisenberg 1995) and therefore can mitigate the problem of missing data (Aaronson 1989).

Cox (2003) in a study that used interview and questionnaires to compare QoL of cancer patients, discussed reasons why these two ways of collecting data do not always match with each other, probably related to the fact that questionnaires usually ask patients to express their feelings over a specific time, for example one week or two. By then researchers may be able to compare participants’ responses better because they were based on experiences that occurred in a similar time frame. Conversely, interviewing aims to go beyond such limitations and allows patients to talk widely and deeply about their experiences.

Anderson et al. (1986) in a study that compared self versus interviewer modes, states that self-report in QoL assessment is a good approach in terms of saving time and

cost; however, the validity and reliability of results should also be considered. They concluded that an inquiring interview mode is more sensitive than a questionnaire to assess QoL accurately. Gill and Feinstein (1994) are of the opinion that along with standard QoL tools, some supplemental items should be provided so that clients have the opportunity to express their individual opinion and reactions further. Cella (1996) emphasised that it is reasonable to use a self-report QoL questionnaire with an exploring interview whenever possible, because the richness and completeness of interviewed data can never be compared with self-report information.

As the research study was about patients' and nurses' perceptions about cancer patients' QoL, the researcher realised that participant observation cannot add any more to his understanding than interviews. It also was not feasible to make observations throughout a variety of inpatient and outpatient oncology wards and across different hospitals. Given the fact that oncology patients are usually sick and undergoing palliative or curative cures or treatments, observation might be considered intrusive. Therefore, in the second phase of the study the interview was chosen in order to find out why nurses are different in their perceptions about cancer patients' QoL.

Ethical considerations

Like the first phase, for conducting this phase of the research study, ethics committee approval was gained from relevant ethics committees of two hospitals. These committees are linked to Flinders University and approval from them is considered as Flinders University Ethics Committee approval. Both hospitals are located in South Australia. The major difference between the two hospitals is that in one of them cancer patients receive services in a specialised oncology ward whereas in the other one such patients were distributed across different wards (non-specialist oncology wards).

Similar to the first phase, the letters of support from the Director of Oncology and Director of Nursing of two hospitals were accepted and sent to the ethics committees in order to get approval to conduct the research study. Given the fact that the aim of

the study was to include the cancer patients having palliative care, another letter of support was accepted from the palliative system.

Recruiting the participants was conducted by the researcher (see pages 124 and 125 for more details). Before starting the interviews, patients and nurses received a participant information sheet. More verbal information was given to participants if they so requested. The aim was to be sure that participants were completely aware of all aspects of the study. The major issues discussed with them were about the aim and main research questions, significance of the study as a postgraduate study, voluntary participation in the study, ability to withdraw from the study at any stages, and confidentiality of personal information. If they were satisfied, then they were asked to sign another consent form. The participant information sheets that were used in one of hospitals are shown in **Appendices C** and **D** for patients and nurses separately. The same sheet with only small modifications was used in the other hospital.

In order to prevent possible emotional distress, supportive care was negotiated so that the Clinical Nurse Consultant or a more experienced nurse was available to talk with participants. While there was no obvious report of such distress from patients and nurses, minor emotional changes might have occurred within the participants due to the nature of face-to-face interviews.

Interview questions and strategies used in the research study

During the interview semi-structured questions were used. However, one of the most important and challenging parts of the interview process was to prepare the interviewee's questions. As explained earlier, the major aim of the second phase was to explore why nurses differ in their perceptions about cancer patients' QoL with those of the patients. In other words, what is actually going on between cancer patients and nurses that make their perceptions different?

General open-ended questions were prepared that guided interviewees through the process that fitted in with the grounded theory approach on the interaction between

cancer patients and nurses. It is more common to use the ‘how’ and ‘what’ questions in interpretive studies particularly those based on the principles of a grounded theory methodology. This is because the focus is mainly on the processes (Stanley 2006; Wilson & Hutchinson 1991). ‘Why’ questions are asked cautiously in interpretive studies because “the question of why things happen the way they do can lead to inferential leaps and empirical speculations that propel qualitative analysis far from its stock-in-trade” (Gubrium & Holstein 2000, p.502). Therefore, in this research study research questions were based on more ‘what’ and ‘how’ questions which were then named as *essential questions*. These questions for patients and nurses were relatively the same with only small modifications. Some of these questions are stated below:

Nurses

- 1-When you hear the concept quality of life what do you think of? What comes to mind?
- 2- How do you usually assess cancer patients’ quality of life?
- 3-What factors do you think influence your assessment of cancer patients’ quality of life?
- 4-How do you know whether your assessment of a patient's quality of life is accurate or not?
- 5-What are the outcomes if your assessment of cancer patients’ QoL is similar or different from that of cancer patients’ own perceptions?

Patients

- 1-When you hear the term quality of life, what does it mean to you?
- 2-How do nurses usually assess your quality of life?
- 3-How can nurses have a better understanding of your quality of life?
- 4- In what ways do you think nurses’ understanding of your quality of life affected your actual quality of life?

As well as essential questions, it was also necessary to ask some *extra questions* due to the nature of the grounded theory (see the following sections about theoretical saturation and theoretical sensitivity). For example, in the first interviews it was identified that interviewees were talking about the individuality of the QoL concept. The researcher was sensitive to understanding if the next interviewees would also express their ideas on whether the QoL concept has different meanings for different

people. As Minichiello et al. (2004, p.422) point out, researchers must not “rely too heavily on the initial interview guide and ask the same questions and in the same order”.

Because the second phase of the study is based on the principles of grounded theory methodology, it also helped the researcher to incorporate and elaborate on some significant results from the first phase. For example, the researcher was interested in whether patients and nurses agree that nurses with more clinical experience with cancer patients have a better understanding of some aspects of such patients' QoL (one of the significant results of the first phase) and if yes, why such differences exist. Therefore, the *elaborating questions* were prepared. Some examples from results of the first phase were applicable to the second, particularly when talking with participants about influencing factors of agreement. For example, when the researcher asked nurses about factors influencing their assessment of cancer' patients' QoL, he also queried their ideas about the effect of nurses' experiences. The researcher asked, for example: 'how does your experience as a nurse affect your assessment of cancer patients' QoL?'

Probing questions were also developed. These questions help an interviewer to stay on track while participants are encouraged to talk widely about the topic(s) in question. Probing questions are those that ask participants for: elaboration (providing more details); clarification (resolve confusions); completion (finish a talk); communication (keep talking); evidence (providing more facts); and attention (seeking participant attention) (Liamputtong & Ezzy 2005). Given the fact that the researcher, as an interviewer, had English as a second language, the clarification probes were the most used. For example, sometimes the researcher restated or rephrased interviewees' unclear statements to ensure that his understanding was correct. Such probing questions were quite necessary as the participants sometimes used slang words or phrases that did not make sense to the researcher.

At the beginning of interviews, some *demographic questions* were also asked so that participants could provide a background about themselves, such as their age and their clinical experience. However, if participants for any reasons did not want to talk

about some of their demographics in detail, the researcher did not repeat the question.

In order to ensure that participants were completely relaxed, open and did not have any concerns during the interview, some *assuring questions* or statements were used to ease the situation and to make the interview atmosphere friendlier, for example: “If there is anything or any concern at the beginning, please feel free to let me know otherwise we can start”. Toward the end of the interview, participants were encouraged to feel relaxed and open and tell the interviewer about anything which was related to the issue under study. For example, the researcher stated, “This is now the end of the interview. If there is anything else you want to discuss, please let me know”.

In some cases the interviewees emphasised that they were not sure if their experiences were important or relevant. The researcher advised them that they were. This was an important strategy to remind the interviewee that what is important or relevant are what the participant thinks is important. The following statement can also be very helpful:

The world is a serious place where people who are directly involved in it can know completely what it is like. You are an expert and I meekly beseech your help in gaining a more complete - never complete - understanding of it. (Liamputtong & Ezzy 2005, p.62)

An attempt was also made to be silent as much as possible and try not to interrupt the interviewees when they were talking. Altogether, the research questions consisted of essential, extra, elaborating, probing, demographic, and those questions or statements that ensured that interviews were going smoothly and participants felt relaxed.

Participants

After finishing the data collection for the first phase, three cancer patients and 10 nurses were selected to take part in the second phase of the research study. It should be noted that while the number of nurse interviewees was three times more than patient interviewees, the interview period for patients was significantly more than that with nurses. Given that the main focus of the interview questions was on the

QoL assessment as performed by nurses, generally it appears to the researcher that nurses can provide more detailed information about the process of QoL assessment than what patients might do.

The main aim of the second phase was to further understand why nurses differ in their perceptions about cancer patients' QoL with patients' perceptions and to elaborate on some results emanating from the first phase. Therefore, conducting the qualitative phase in a sequential order after the quantitative phase proved more suitable than doing both phases simultaneously. Although sequential sampling takes time it is a very useful approach, particularly for purposes of elaborating on results of a preliminary phase (Teddlie & Tashakkori 2003).

Patients had been diagnosed with prostate, lung, and breast cancer with metastasis to some organs. Two were male and one was female. One of the nurses was male and nine were female with clinical experience ranging from only one year to around 30 years. The nurses worked across different inpatient and outpatient services including the palliative system. One patient experienced both oncology and palliative areas. Seven nurses also worked in both oncology and palliative areas. While some PhD theses have described participants in more detail (Long 1998; Power 1998), this research chose not to do so. While choosing a number or a pseudonym can help to maintain confidentiality, Zollo (2002) has pointed out readers may be able to make accurate guesses about the participants' identity, for example, through their demographic characteristics.

The sampling strategies

In this research study two strategies were used by the researcher to access participants. The first sampling strategy used in this research study was convenience sampling. The researcher's first contacts were with participants of the first phase because he had communicated with them for more than one year and built a good rapport and relationship with them. Glaser & Strauss (1967) noted that rapport is an important aspect of sampling in a grounded theory research study that is time-consuming. Moreover, a number of participants of the first phase were also very thoughtful, articulate and wanted to talk about their experiences in the second phase.

More experienced participants proved to be good interviewees due to their willingness to talk, knowledge and experience (Morse 1991, cited in Cutcliffe 2000).

Along with the first strategy, snowball or chain sampling was used in which the researcher asked the initial more experienced participants to nominate other interviewees who might be suitable and happy to take part in the study. As well as establishing a good rapport between the researcher and more experienced participants, they claimed that they were also aware of the importance of the research study for cancer patients. Cutcliffe (2000, p.1478) pointed out that more experienced participants can work as a “gatekeeper” to introduce subsequent interviewees.

On reflection, the researcher personally also found that more experienced and knowledgeable participants can provide more information. They are in the environment for quite a long time and have more experience in talking about the focus compared with the less experienced. They also may work better at introducing the subsequent interviewees as a gatekeeper. Introducing a participant by the previous participants may be criticised as leading to less diversity in the sample. However, the researcher personally found this technique very helpful, particularly as an international student who was very new to the sampling environment.

Theoretical sampling

While the main strategy for data collection used in this research study was convenience sampling, the framework of sampling in the second phase consisted of theoretical sampling. As the categories emerged through the first interviews, a decision was made about who was the best person to interview during the next step and where the researcher could find them. For example, in the first interviews, nurse interviewees articulated that the best way for QoL assessment is to improve the relationship and rapport with patients rather than using QoL tools even for palliative patients. This encouraged the researcher to select one patient in the next interviews from the palliative area to elaborate on that issue further. Theoretical sampling is the main feature in a study based on the principles of grounded theory and “is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyses his data and decides what data to collect next and where to find

them, in order to develop his theory as it emerges” (Glaser 1978, p.36; Glaser & Strauss 1967, p.45). Therefore, theoretical sampling does not necessarily mean sampling persons; it also means sampling “situations, events or processes which are regarded as theoretically relevant to the emerging concepts” (Llewellyn, Sullivan & Minichiello 2004, p.215). Theoretical sampling does not result in success unless researchers are theoretically sensitive.

Theoretical sensitivity

During the whole process of theoretical sampling, researchers need to be “sufficiently theoretically sensitive so that he can conceptualise and formulate a theory as it emerges from the data” (Glaser & Strauss 1967, p.46). In other words, to achieve theoretical sensitivity researchers must enter the field by putting aside any preconceived ideas and generate a theory based on the data (Glaser 1978; Jeon 2004). To achieve this sensitivity as much as possible, the following strategies were used in the second phase of the research study.

The first strategy to achieve more sensitivity during the process of data collection and analysis was to put aside any preconceived ideas and let the data speak. The researcher conducted a line by line analysis more than any other method. Glaser believes that theoretical sensitivity is a process achievable only by immersion in the data, line by line, comparison by comparison, memo by memo, and code by code and let the data speak (Walker & Myrick 2006).

The second strategy that improved theoretical sensitivity in the second phase was information arising from conducting the literature review relevant to the topic. This information was very useful in order to be familiar with current concepts and to develop other conceptual concepts during the coding process. To achieve this, a comprehensive literature review was conducted toward the end of the second phase in the coding process. The research study had a preliminary empirical phase and in order to narrow the field, find existing gaps, construct research questions, and justify using a grounded theory approach, conducting a literature review at the beginning of the research study was completely necessary. Glaser and Strauss (1967) highlighted that although a preliminary literature review may be conducted before a research

study using grounded theory methodology, a full literature review is done at the coding stage in order to allow the theory to arise completely from the actual data and not to be influenced by pre-existing knowledge or perceptions of truth.

Altogether, in the second phase theoretical sensitivity was mainly achieved by relying on the actual data, by conducting a literature review of both phases, and by entering the field and the knowledge arising from the first phase. Theoretical sensitivity helps researchers to achieve to the point of theoretical saturation.

Theoretical saturation

Theoretical saturation is another feature of a grounded theory approach whereby:

no additional data are being found whereby the sociologist can develop properties of the category...He goes out of his way to look for groups that stretch diversity of data as far as possible, just to make certain that saturation is based on the widest possible range of data on the category.

(Glaser & Strauss 1967, p.61)

In fact, when researchers are satisfied that the data are rich enough, then the sample is large enough (Llewellyn, Sullivan & Minichiello 2004). In this research study, after nine interviews, the researcher felt that for a few categories no new or additional information would arise. From this point onward only some interviews were conducted to ensure that the categories were saturated. There were time constraints that did not allow for all categories to be saturated. As explained in Chapter Three (see page 59), in this research study a core category was not sought (i.e. a theory was not being developed). Therefore, the researcher considered the saturation only for important categories that were in line with research study aims.

Strauss and Corbin (1998, p.136) argued that in reality if a person looks “long and hard” in the data there is always a possibility for the “new” to emerge but at the point of data saturation such “new” cannot “add much more to the explanation at this time” (Strauss & Corbin 1998, p.136). In other words, as researchers proceed through their theoretical sampling, they will develop different categories and not all of them have the same importance. “Core categories with the most explanatory power should be saturated as completely as possible” (Glaser & Strauss 1967, p.70). Saturating less relevant categories depends on the resources available. Therefore, researchers need

to balance the depth and breadth they are looking for in the saturation process with the resources of time and money available, and make a judgment about additional sampling (Liamputtong & Ezzy 2005). For example, researchers might limit their study in order to make a final conclusion (Llewellyn, Sullivan & Minichiello 2004) and leave the results to be developed in future research studies.

Inclusion and exclusion criteria

All adult cancer patients under different treatments and in different wards (inpatients or outpatients) who were able to articulate well in English about their experiences and had consented to be interviewed were included in the research study. Included nurses also were all registered (RNs and ENs) to work in South Australia, spoke in English and had consented to take part in the study. According to ethics guidelines, the participants were able to withdraw from the study at any time.

The interview process

Before starting the interviews with cancer patients and nurses, the researcher conducted interviews with three university lecturers at Flinders University with the aim of improving his interview abilities. This was the first experience of the researcher doing an interpretive study using the interview method, and provided him with the opportunity to receive feedback from more experienced people and to improve his interview technique. Generally speaking the feedback was positive and therefore the researcher felt that he could start his actual interviews. This is a good technique particularly for less experienced people using semi-structured interviews and is comparable with a pilot study in an empirical research study.

Data were collected from each participant through a semi-structured interview during a nine month period from June 2006 to February 2007. Patients and nurses were generally interviewed in oncology units. There were some exceptions in which cancer patients or nurses were interviewed in their offices as they requested. Generally speaking, the interviews were conducted in a quiet and private atmosphere at a time suitable for participants. Only one patient was interviewed while he was under chemotherapy with ward curtains around to make the environment more private. Also, when the researcher interviewed two nurses in the oncology wards, we

had to change the location due to interruptions. After that, the interview proceeded well and the interviewees apologised for such occurrences. The researcher did not have any issues regarding the conduct of interviews in the clinical area. Participants were generally talkative and were interested in expressing their thoughts and feelings.

The patients' interviews lasted approximately one hour. Before interviews were conducted, the general interview questions were given to some participants so that they had enough time to think about them deeply. While the researcher was taking some notes during the interviews, the interviews were audio recorded on an MP3 player which enabled the researcher to transfer the audio files into the computer and transcribe using Express Scribe software and link into the NVivo software. There was also on the MP3 player a pause button that the interviewee could press whenever they wished throughout the interview if they did not want certain comments recorded. While no participant used this button, this is a helpful strategy that allows interviewees to feel free and to talk about any things if they can stop recording (Grbich 1999).

The researcher also arranged a time before and after recording the interviews for interviewees to talk. The time before recording is in fact a settling-down period whereas post-recoding time is one that provides interviewees with the best possible opportunity to talk more about those issues that they did not want recorded. Some valuable comments that interviewees make may come before or after an interview begins (Grbich 1999). For example, a couple of nurse interviewees briefly pointed out to problems related to the health system that might cause a QoL assessment to be conducted inappropriately. This made the researcher theoretically more sensitive to trace the issue more fully in the next interviews.

Data analysis

Transcribing the interviews

The interviews were transcribed verbatim by the researcher. Transcription is a time-consuming activity and might take around 6-10 hours of typing for each hour of interview tape (DePoy & Gitlin 1998). As English was the researcher's second

language, transcriptions took around 16 hours per one hour interview. There was no record of non-verbal effects such as change in the voice of participants and possible emotional changes in transcriptions. The interviewee could make any modifications to the transcript and return it to the researcher. Six of them had positive responses and requested to see the transcribed interview. They made minor changes such as punctuations, adding or deleting some words or small sentences, and then returned it to the researcher.

Using NVivo software to facilitate the data analysis

The NVivo version 7 computer software was used to analyse the textual data. However, the researcher also found it useful to do some aspects of the data analysis such as coding and categorising concepts manually. This software is one of the products of the Qualitative Research Solutions International (QSR). The original name of the NVivo is in fact Non-numerical Unstructured Data (NUD). This programme was then improved and named as NVivo. NVivo utilises participants' own words to name categories during the coding process (Bringer, Johnston & Brackenridge 2004).

Using computer software like NVivo to analyse the interpretive data is a controversial issue (Richards 1999). Charmaz (2000) stated that using such computer software might impose limitations on the study particularly in a grounded theory study. This includes a poor understanding of grounded theory methods, using the software to "legitimate" the study rather than to conduct it, its usefulness more for objectivist modes of grounded theory rather than constructivist versions, and finally reducing rich interpretation of qualitative data to a set of procedures (Charmaz 2000, p.520). Occasionally the researcher also thought that such computer software might hinder his rich interpretations of data by constructing a distance between him and the actual data. In order to avert this, the transcribed interviews were read several times and the data coded by hand as well as with software.

On the other hand, soon after starting the data analysis, the researcher was faced with a bulk of textual data that appeared very difficult to analyse manually. It was difficult for the researcher to even imagine how he could do the coding of the textual data on

the floor by cutting and collecting the same texts with each other. Charmaz (2000, p.520) stated that such programs are useful for “data management” due to huge amount of qualitative data. Moreover, having the capacity to integrate all information together, this therefore can also maximise the “transparency” of the audit trail particularly within a grounded theory study (Bringer, Johnston & Brackenridge 2004, p.247). It seems that this software is particularly consistent with the grounded theory methodology (Lonkila 1995, cited in Bringer, Johnson & Brackenridge 2004), which generally needs a line by line coding and analysis. The memo option on this software, which is an essential part of the grounded theory method, in particular helped the researcher to write his memos during the coding process.

Comparative data analysis

The data analysis process was based on the principles of the Glaserian (classical) version of grounded theory at the same time as data collection, using comparative data analysis. Comparative data analysis is another feature of a grounded theory approach in which a researcher collects the data, makes comparisons between data through the analysis, and aims for more data collection if it is necessary in order to reach the point of theoretical saturation (Browne 2004). In other words, in grounded theory it is impossible to do theoretical sampling and reach theoretical saturation without coding and analysing at the same time (Glaser & Strauss 1967). This is in contrast to other ways of data analysis in which it can be done with already collected data or after finishing the data collection. For example, in content analysis the categories are identified prior to coding or in post-structural and in semiotic analysis the focus is more how a text is produced rather than its content (Liamputtong & Ezzy 2005).

Therefore, the following steps were conducted:

1-Providing a reflective journal: The researcher prepared a reflective journal and wrote down any ideas that came to his mind such as personal thoughts, theoretical ideas, and any concerns about the research study before data collection and analysis. It is very important to write reflective thoughts as soon as possible otherwise they may be forgotten. Grbich (1999) commented that a reflecting process at least allows

one to think about their beliefs and values and how they might affect their interactions and the interpretations in the research setting.

2-Memo writing: The notes from the reflective journal were then transferred into the NVivo software as memos and the process of memo writing was continued all through the coding process using the NVivo software. Memo writing is one of the major features of grounded theory. Glaser (1967) points out that the coding process or making categories can produce conflict in researchers' minds. He suggests in these situations that researchers "stop coding and record a memo" on their ideas (p.107). This can help researchers prevent possible breaks in their logic (Strauss & Corbin 1998), develop more "abstract thoughts into more clear thought-out ones" (Bringer, Johnston & Brackenridge 2004, p.254) and reach the point of theoretical codes (Jeon 2004). When a researcher has codes and available memos, this will help them write their analysis (Charmaz 2000). Consider, for example, the following two memos the researcher wrote during stages of the analysis process:

October 2006

I realised that the majority of participants in some parts are talking about the individuality of the QoL concept. It has also been addressed in the literature that QoL is an individual experience. I asked myself what they mean by the individuality. It was necessary to ask in later interviews what do they mean by the individuality or do they believe that QoL is an individual concept.

February 2007

During the phase of coding, I understood that participants are talking about the QoL concept in any way. At first three subcategories under the category of QoL concept emerged which were named QoL characteristics, QoL aspects, and QoL definitions. In the subcategory of QoL characteristics, I had properties of a complex issue, a broad statement, an individual concept, and an ever changing type event. I was confused if subcategories of QoL aspects and QoL definitions can be merged into another category of QoL characteristics or not. Then, I realised that in fact in the subcategory of QoL aspects, participants are talking about different things that increase the breadth of the QoL concept. Therefore, I merged the subcategory of QoL aspects into the property of a broad statement. The subcategory of QoL definitions at this moment can stand for itself.

3- Naïve reading of the transcribed interviews: The transcribed interview files were naïvely read several times. The first reading coincided with the listening to the relevant audio-recorded file. While the major aim was to become immersed in the data, this also helped the researcher to ensure that interviews were transcribed

verbatim. As pointed out by DePoy and Gitlin (1998), it is very important for transcriptions to be read several times so that during the analytical process the researcher is accurately immersed in the data.

4- Importing of the transcribed interviews into NVivo: The transcribed files were then imported into the NVivo software for further analysis.

5- The coding process: Coding is another feature of grounded theory (Kendall 1999; Walker & Myrick 2006). While in Strauss' version, the coding consists of three stages of open coding, axial coding, and selective coding (Strauss & Corbin 1998), in the Glaser version, none of the above coding systems can be identified (Glaser & Strauss 1967). Instead, they describe four stages for the constant comparative method: (1) comparing incidents applicable to each category; (2) integrating categories and their properties; (3) delimiting the theory; and (4) writing the theory. While in the first and second stages a researcher tries to code data and develop categories and their properties, in the third stage, a researcher attempts to modify and reduce categories by constant comparison method reaching to a core category. When a researcher is confident about categories, in the final stage the theory is written based on categories and related memos (Glaser & Strauss 1967).

Glaser (1978) in his later publication used two major coding systems to describe these stages: "substantive and theoretical coding". Despite the ambiguity of this coding, this is more understandable compared with the previous one. The substantive coding consists of open and selective coding which allows the analyst to "conceptualize the empirical substance of the area of research. Theoretical codes conceptualize how the substantive codes may relate to each other as hypothesis to be integrated into the theory" (Glaser 1978, p.55). What is clear is that there is no axial coding in Glaser's mode and in fact it seems that axial coding is integrated into the substantive coding (Walker & Myrick 2006).

When the researcher reflected on the coding process, it proved to be the hardest part of the second phase. This has been reported in other PhD studies. Redden (2005, p.108), for example, in her thesis reported that "deciding how best to use grounded theory to analyse the data for this work was not easy". The researcher found coding,

conceptualising, and categorising very difficult, time consuming and sometimes completely frustrating. The words of participants sometimes seemed to have different meanings. It was only near to the end of the coding and categorising that the researcher got a comprehensive and meaningful understanding of the data. Anxiety about nothing emerging at the beginning of coding is a source of concern for many students that will change later (Glaser 1978). Auerbach and Silverstein (2003, p.32) point out that sometimes beginners feel they are “immobilised” because they assume that there is no right way to interpret data. They might feel that nothing really is directly related to one’s research concerns. This stage is named finding yourself “a drift in a sea of data”.

The process of coding in this study consists of the first step (substantive) of the Glaserian (classical) version. In other coding, the following steps were conducted:

5-A) *Open coding*: This process consists of three stages: reading the first transcription and identifying the relevant text, conceptualisation, and using comparative data analysis and memo writing for subsequent transcriptions.

During the first stage, after reading the first transcription, the researcher tried to delete unrelated textual materials and identify the relevant text. The relevant text also named the relevant incidents/ideas/events that in fact were related to research questions. This process in NVivo was named creating ‘free nodes’.

In the second stage, the researcher tried to conceptualise the incidents in the first interview and this meant giving them a name. In order to name concepts, the researcher usually used ‘in vivo codes’, which in essence means taking the concepts’ names from the participants’ words (Strauss & Corbin 1998). However, there were some cases where the researcher chose concepts’ names from his own words or from the literature. For example, one interviewee said to me that ‘quality of life would be to enjoy life’. The researcher coded it as ‘having enjoyment’ which is in fact driven from the interviewee’s own words.

Finally, open coding of the subsequent interview transcriptions was then conducted based on comparative data analysis and related memos. Similar names were given to

the emerging codes if it was applicable when the researcher compared them with the previously coded data, otherwise the researcher used new names. It was also necessary sometimes to rename previous concepts. Generally speaking, the outcome of open coding was having numerous concepts and reducing the textual data. The process of open coding can be seen in Figure 6-1.

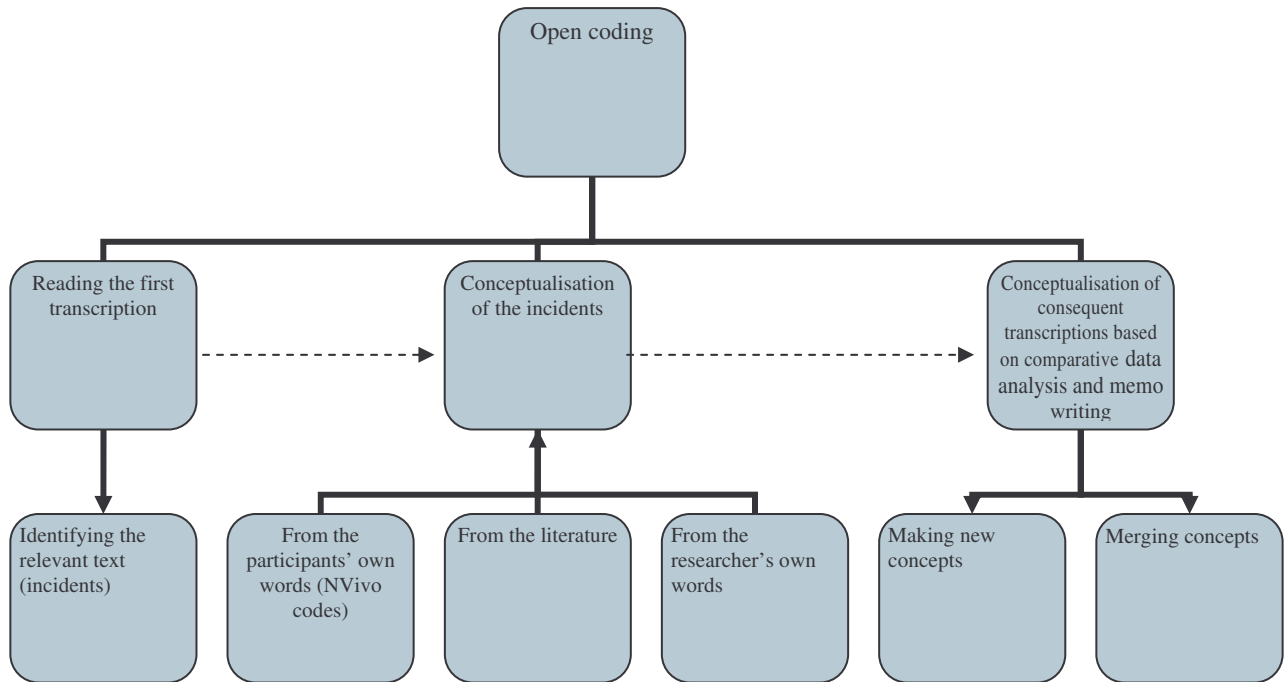


Figure 6-1: Open coding process

5-B) Selective coding: This step was in fact similar to the previous one but instead of finding the relevant text (incident) and comparing it with other incidents, an attempt was made to compare the concepts with concepts and try to reduce their number by collapsing them based on similar characteristics. This finally led to a list of categories and subcategories. This was called selective coding because it is when the researcher focused on the list of major or core categories and tried to reach saturation point. This in turn, becomes a guide to further data collection and theoretical sampling (Glaser 1978). This step of coding is more in line with creating ‘tree nodes’ in the NVivo. In fact, the researcher tried to link smaller concepts in order to create a broader category.

For example, ‘nurses are fantastic in assessing quality of life’ and ‘nurses are exemplary in assessing quality of life’ are collapsed into one category named ‘nurses are the best people to assess QoL’. Or in a later stage of theoretical coding,

categories like ‘having freedom’, ‘having enjoyment’, and ‘having choice’ were classified under a broader category ‘quality of life meanings’. The process of open coding can be seen in Figure 6-2.

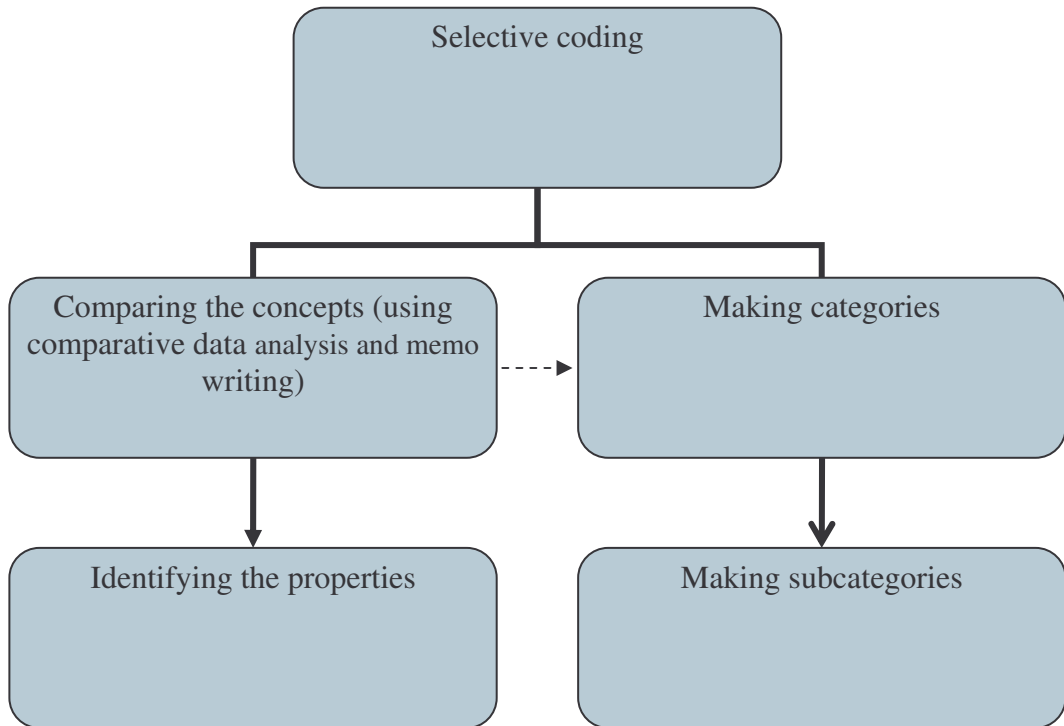


Figure 6-2: Selective coding process

6-Improving the credibility (rigour) of findings:

The issue of rigour in interpretive studies is a controversial one in that rigour is more about covering all aspects of the phenomenon being investigated with less disturbance to the setting and a clear interpretation and presentation of the results (Grbich 1999). Auerbach and Silverstein (2003, p.78) proposed using the concept of “justifiability” to show the rigour in an interpretive study instead of reliability and validity, which are used in empirical studies. By justifiability, they mean that data need to be transparent, communicable, and coherent.

For “transparency”, a researcher needs to show how the results are created so that other researchers can also follow how they did it. It does not mean that others agree with your interpretation but presents how you arrived at your interpretations. Data have “communicability” if categories you create make sense not only to other

researchers but also to participants. Finally, if your theoretical constructs fit together so that you can tell a story about them, then your data are “coherent” (Auerbach & Silverstein 2003, pp. 84-85). In order to address the issue of transparency in this research study, the detailed process of the second phase, coding and conceptualisation have been addressed in this chapter. Moreover, the categories explored in this study (presented in the next chapter) were discussed and made sense to other PhD researchers as a linked and sound review.

In summary, the issue of rigour in the second phase of the research study has been addressed in relation to general criteria (transparency, communicability, and coherency).

Conclusion

In this chapter the methods used in the second phase of the research study in order to collect and analyse data were discussed. It was argued that semi-structured interviews provided the researcher with this opportunity to get an in-depth understanding of why nurses’ perceptions about patients’ QoL are different from patients’ own perceptions. Moreover, conducting interviews allowed the researcher to elaborate on some significant results of the first phase. An attempt was made to clarify the steps undertaken for data collection and analysis. These steps incorporated the process of comparative data analysis undertaken by the researcher. These steps show how the researcher arrived at the results and address the issue of rigour in this research study. In the next section the results of the second phase, i.e. the conceptual categories, are addressed.

CHAPTER SEVEN: RESULTS OF THE SECOND PHASE

Introduction

The purpose of this chapter is to describe the categories derived from the qualitative data using an interpretive approach based on the principles of a grounded theory study. In the next chapter, these categories will be discussed in conjunction with the quantitative findings, and with reference to the literature, where this is possible

In this study, exemplars are provided to elaborate on the categories. This allows the features of the experience to be portrayed (Benner 1985). It helps to provide an understanding of how conceptualisations have been made from the qualitative data. A number was allocated as an identifier for each participant, rather than a pseudonym, and these numbers are stated when exemplars of interviews are presented. 'Patient' was used to refer to patient interviewees and similarly 'Nurse' for nurse interviewees. The exemplars numbers do not relate to the chronological order in which interviews were performed. For example, 'Patient 1' does not mean it was conducted before 'Patient 2'.

Selected exemplars naturally cannot reflect all of the nuances of a category or sub-category. Moreover, these conceptualisations have not been made solely on the basis of interview data. Other inferences emerging, for example, from the quantitative data of the first phase, from memoing and reflecting on the texts as a whole and from the literature also helped the researcher in the process of coding and conceptualisation. The exemplars presented in this chapter have been chosen because they exemplify or reflect a particular feature of that category.

Results

After data collection and analysis, the following main interpretive categories were identified:

1-QoL aspects;

- 2-QoL meanings;
- 3-Cues-based QoL assessment;
- 4-Purpose-based QoL assessment;
- 5-Facilitators of QoL assessment; and
- 6-Barriers to QoL assessment.

The following sections present each category and sub-category. Each sub-category section ends with a summary followed by a conclusion at the end of the particular category.

QoL aspects

In response to questions put to the interviewees, participants expressed that individuals' QoL influenced by a whole range of aspects in life including physical, psychological, social relationships, family interactions, financial, environmental and spirituality issues. Consider, for example, the following extracts:

They [nurses] didn't ask me about my quality of life, they did not ask me where I lived or anything about my quality of life. In fact there was a lot happening in my life at the time which it would help me if they had asked me about. Who was my primary contact person, where I am living or how is it going for me? What is happening in my life? Who do I want information shared with? What's been happening in my life?...There is a whole range of things around quality of life. (Patient 3)¹

Immediately I think it [quality of life] is a very big and too generalised concept. When you look at quality of life a little more deeply, I have to say that it would have to be based on how or what you getting out of life from the experience that you are having at a particular point of time, whether it would be something that is influenced by your physical health, whether it is something influenced by emotional things going on in your life, whether it is a combination of things influencing the quality of life for you. (Nurse 3)

Both nurses' and patients' interviews articulated that individuals' QoL can be influenced by a range of factors. Some nurses in the first phase commented that they did not agree with several items in the WHOQoL-BREF questionnaire or they did want to see some other themes noted in the tool. This encouraged the researcher to write a memo about items in the questionnaire and to further search for QoL aspects in the second phase. Consider, for instance, this memo that the researcher wrote:

¹ Words in the [] added by the researcher for clarification of the textual segment.

It is apparent from the literature that QoL is a multi-dimensional concept. It is also clear that participants share this view about the complexity of the QoL concept. For example, participants described the term QoL with characteristics like very big and very broad. QoL has different aspects but do participants of the study agree with them or suggest other aspects? Do participants value a specific aspect more than others? It is therefore important to focus on QoL aspects and ask participants further questions to elaborate on the broadness of the QoL concept. (29/02/07)

The category 'QoL aspects' was created to reflect on how different aspects may impinge on an individuals' QoL. These aspects are explained in the following sections.

Physical aspects

An important aspect of the QoL concept highlighted by participants was physical abilities:

Eating, normal eating, going to the toilet, mobility, survival basically...I can function. (Patient 1)

I can still get out and about and live almost at the same level as I had in the past. There are some restrictions as far as what my capabilities in some situations although I still do quite a lot of work. (Patient 2)

Physical functioning at the level acceptable to individual patient participants is an important aspect of QoL. This can range from basic activities such as eating, mobilising and elimination, to more complex activities identified by patients.

Nurses also saw physical functioning as an important part of QoL:

[Quality of life] for the patients would be ultimate wellness, feeling well, and being physically able to do, being financially stable, and having support from your family, being able to eat and drink comfortably, being able to have usual bowel and bladder comfortably, not restriction in your life, just being able to function normally like every one else. (Nurse 3)

Get out of the bed, pop on the car, go to work, do the work, return home... This is the physical part of quality of life. (Nurse 7)

Therefore, an important aspect of QoL for both patients and nurses is physical functioning. In every day life individuals are doing a number of basic activities like

eating, mobilising, and elimination that contribute to their QoL. It is very important for participants to work and have function as normally as possible.

Psychological aspects

Even though the physical aspect is a very basic and important aspect of QoL for participants, it was evident from the interviews that other aspects of QoL were also important. Some participants pointed out the psychological aspects as an essential part of their QoL. In the subsequent exemplars, nurses expressed that:

I think that quality of life has facts of well being, mentally or psychologically feeling well, physically feeling well, financially feeling well, and support from your family (Nurse 1).

Persons' quality of life, their perception is going to change daily; sometimes several times maybe in a day according to how they are feeling about their physical and psychological health (Nurse 2).

Similarly, patient interviewees also think that psychological aspect is an important part of their lives but they used a slightly different language to express it. One patient, for example, in response to the research's question about the psychological aspect, said:

To be honest I have no idea about this [psychological aspect]. What I can say is that I am feeling good, I am extremely fortunate with my situation. Yes I know other people that they had cancer and they had all sort of complications and concerns (Patient 2).

Another patient remarked:

My feelings keep changing, good, bad, good, bad but I am feeling good now. It is all stayed stable and now I know what is going on exactly. I am amazed how well I can cope on my own and now I let people in (patient 1).

Patients might use plain language to articulate their psychological status by referring to their concerns, feelings and emotions during the cancer journey. This might be different with the professional language that nurses might use or expect to hear from patients, such as mentally or psychologically feeling well. It is interesting that patients expressed that they are generally happy with their current situation even though their feelings to some extent were variable during the cancer journey.

Spiritual aspects

Nurses expressed the view that spiritual aspects of life are also important contributors to individuals' QoL. For example, participants stated:

There is also the spiritual part of quality of life and the psychosocial part of the quality of life with a lot of layers. (Nurse 3)

Quality of life gets right down to the basic of comfort, and I guess at the next level we need to be spiritually nourished and respected and valued. All of the aspects that make us and help us to feel there is a sense of quality, have to be met on a day to day basis. (Nurse 7)

The spiritual needs to come into it [quality of life]. So they [patients] will talk a lot about existential stuff, things like death and dying and how patients actually want that to happen, whether they actually believe in certain things that might happen after they die. (Nurse 9)

The bigger picture of spiritual life or meaning does not come into it until I got a relationship with the patient. (Nurse 10)

Similar to psychological aspects, patients did not use an explicit language to talk about their spirituality; however, nurses explained that their patients talked a lot about spirituality. They realised that spirituality is both multifaceted with a lot of layers and pervasive aspects of patients' lives. From participants' statements it appears that spirituality is more about the meaning of life and what will happen after people die. In other words, how they have lived and what will happen for them as a result of this kind of living after they die. Spiritual issues can be defined as a belief system which creates meaning of life and being for a person and can include religious as well as non-religious beliefs (MacDonald 2001, p.383).

Nurse interviewees also mentioned that there are meanings in lives that often people take-for-granted and do not think about them in a great depth:

I think there are many aspects to quality of life in everyday life that you take them for granted. (Nurse 7)

Most of us live our lives without deep consideration of what deeply satisfies us. When people come into crisis in hospital sometimes it is a new consideration for them. (Nurse 10)

It is very interesting to see that participants pointed out taken-for-granted aspects of life. As addressed in some studies (Kwok & Sullivan 2007; Nelson 2007), participants highlighted that taken-for-granted aspects of life are those that people

rarely attend to, like their health, their immediate environment and their social relationships. Often people pay attention to taken-for-granted aspects of their lives when their lives are challenged, for example, being in an emergency situation. The term ‘shattered assumptions’ has been used in some studies (Berzoff 2006; Davies 1997; Matthews & Marwit 2006) to show how taken-for-granted aspects or accepted meanings of life shatter when people are in unusual and challenging circumstances. Many people, for example, assume that the world is a safe place to live in and they can look after themselves. Many people suppose that they are invulnerable and cancer or other threatening diseases will not happen to them. However, suddenly a problem or trauma emerges such as being mugged in the street or diagnosed with a threatening disease like cancer. This causes individuals to reconsider the taken-for-granted assumptions that hitherto they had and rebuild their value systems.

Environmental aspects

Environmental issues are also an important aspect of QoL. This can be seen, for instance, in the following extracts:

Just being in a different environment, what is usual, when a person comes to the hospital their quality of life is changed and you have to be mindful of that. (Nurse 2)

If you are left in the hospital room all the time for reasons beyond your care that it can have a negative impact on quality of life because it is a little room, regardless if four to five people are in it or not. You lose your privacy. You lose your ability to have your own things. That has to impact on your quality of life. (Nurse 3)

Nurse interviewees valued the relationship between environmental issues and patients’ QoL. Here patients did not talk explicitly about environmental issues but nurses became a voice for them. Nurse interviewees stated that when a person lives in an environment that is different from their usual place of residence, for instance, it can influence individuals’ QoL. This is particularly important when a person is hospitalised and especially for a long period of time. Putting aside problems related to the disease and the treatment, just being in the hospital might have a negative impact on individuals’ QoL. The privacy and usual habits of individuals are hindered in the hospital and health care professionals, particularly nurses, need to be aware of that all the time. For example, leisure opportunities and choices of patients

(MacDonald 2006) and their dietary regimen (McMillan et al. 2005) might be altered when they are in an another environment other than their home place.

Social aspects

Relationship with family and significant others are important contributors to individuals' QoL as it can be identified, for example, in following extracts:

My small research [as a nurse] showed me that dying is a very lonely experience. There are lots of sub-themes that come with that [research]. One is when a person has gone through a long trajectory of illness and the family has already buried him. They've decided that he's outlived his prognosis. Sometimes the family has already separated and, as a health care professional, it is very traumatic. I see them [patients] realising they are a burden on their own remaining family members because they didn't die in the time frame that the doctors had told them. (Nurse 8)

What is happening at the home, have the family dealing with them, are they living on their own, are they not getting out at the proper time when they leave us. (Nurse 4)

If that person has a very supportive family come in [to the hospital] and is with that person and I can see there is an interaction going there then my estimation [of patients' quality of life] goes up slightly. If on the other hand the same person in the same situation has no family, no visitor, I assess his quality of life lower than the person who does. (Nurse 2)

Here again nurse interviewees highlighted that family issues and other interactions are quite important contributors to patients' QoL. People do not live in isolation and interactions with other people, particularly those who love them are a critical issue. Interactions might also indicate how much support patients receive in the hospital or in the home particularly when they are dying. A chronic disease like cancer might bring patients and their family together through a long journey. Patients' families might exhaust their own psychological resources in order to support patients. The patient-family interactions and supports that patients receive from their family will affect how nurses think about patients and their QoL.

Conclusion for the category: QoL aspects

As highlighted by other researchers (Cella et al. 2002; Kaasa & Loge 2003), it was discussed that many aspects contribute to an individual's QoL. These include: physical, psychological; spiritual; environmental; and family aspects and other social interactions. Both patients and nurses stated that physical and psychological aspects

are important parts of individuals' QoL. For other aspects nurses generally became a voice for patients. More importantly, participants stated that the spirituality in itself is multifaceted and there might be aspects in the life that can be taken-for-granted. This can imply that there might be more than above identified aspects that contribute to individuals' QoL although they did not become evident in this research.

These findings also show that nurses generally are aware of importance of a number of aspects in the construction of individual's QoL when they consider patients' QoL. However, this does not mean that they have enough understanding of the current state of these aspects when they consider individual patient participants.

QoL meanings

Participants also explained that QoL is an individual concept with many different meanings. Consider, for instance, the following extracts:

Quality of life would be different for everyone. Every one would determine quality of life differently. (Nurse 1)

It [quality of life] is an individual thing at a particular time. It is probably the thing that you may be thought when you are 20, you may thought some quality of life things were as a most quality factor in your life, but when you are 34, and it is a different situation, you completely reconsider what are you doing, and even when you are 34 and 6 months down the track, it might change again, because something else is influencing it (Nurse 3).

My view could be different. It [quality of life] is personal belief or thought...Everyone's would be different. (Patient 3)

Both patients and nurses expressed their views that the QoL concept has different meanings. At this stage, the researcher wrote a memo about QoL meanings. This can be seen as follows:

I realised that the majority of participants in some parts are talking about the individuality of the QoL concept. It has also been addressed in the literature that QoL is an individual experience. But is there any shared or common definition of this concept amongst participants? It was necessary to ask in later interviews what do they mean by the QoL concept. (23/10/06)

The category 'QoL meanings' was created to explain different meanings participants

allocated to the QoL concept. These QoL meanings are explained in the following sections.

Happiness and enjoyment

It became clearer during the research process that one important meaning of QoL is related to being happy in life:

Quality of life for me is just to be happy and calm like we are here [in the shade in the courtyard in the ward]. When I come here and sit down here is like heaven. I get the same relaxation being here in courtyard as I get from my normal recreation. (Patient 1)

Quality of life for me means how happy some one is to live, how enjoyable I found life. (Nurse 6)

I ask different questions to assess patients' quality of life. Are you happy? Are you happy within yourself? Are you happy to come in to us? Are you happy to go home again? (Nurse 4)

Both patient and nurse interviewees expressed their opinions that the QoL concept means having happiness and enjoyment in life. Activities that create enjoyment might lead to happiness but there might still be other sources for happiness (Joly et al. 2002; Ventegodt, Merrick & Andersen 2003). In the first phase of the research study it was also identified that cancer patients have a better QoL than nurses might think about their QoL (nurses' underestimation of patients' QoL). There were different reasons or sources that make patients happy, for example according to some patients:

Do not really care [about the enjoyment], does not matter, just happy and being relaxed, like we are here, beautiful...I always have a frame on my mind, that is, do not worry, just work, just do it, do not worry about cancer. (Patient 1)

The quality of life of the patient was not what I thought. They seemed quite happy, no issues. Even though they lived alone, on the pension, did not have any friends, be in pain, cannot work, but they did not seem bothered by that. They thought that their lives are meaningful. (Nurse 5)

'Patient 1' has cancer at an advanced level with different metastasis to the lung and kidney. However, he said that he is happy because he is relaxed at this moment (in the shade in the courtyard in the ward when he was smoking) even though it might appear that he does not have any specific enjoyment. It can also imply that sometimes even simple things can make patients feel happy. Another reason for happiness of

this patient seems to be the acceptance of the current situation because the patient, at least to some extent, tried to put aside his worries particularly about cancer and attempted to become relaxed. In the interview with 'Nurse 5', this matter was again emphasised, that cancer patients she experienced were happy although she did not think in this way. More importantly, 'Nurse 5' pointed out another reason for happiness when she expressed that patients still think that they have a meaningful life even though it appears that they do not have positive emotions or specific enjoyments. This implies that for individuals to feel happy it is important to have positive emotions and enjoyment in their lives (e.g. through their relationships with others). In addition, meanings of such emotions and how individuals reflect on them are also critical issues. Altogether, a comparison between patients' and the nurses' perceptions implies that maybe the reason for such perceptual differences is that nurses are not completely aware of different sources that make patients happy.

Satisfaction

Satisfaction in life is another meaning that nurse participants referred to as a QoL concept. The following excerpts, for instance, are from two nurse interviewees:

First of all I think almost in the academic sense what does that mean as a definition and this is all those things which provide satisfaction...an individual feels has deep value and satisfies them. (Nurse 10)

So quality of life to me I guess means ability to fulfil all aspects which is important for me is in term of all aspects of quality of life. (Nurse 7)

In the above extracts, QoL was defined by nurse participants as having satisfaction and fulfilment in aspects that are important for them. Patient participants did not talk that much about the issue of satisfaction. Later, Nurse 10 explains that such a thing that can satisfy the person might have a deep value. Some people might think, for example, that money is something that has deep value and satisfies them whereas many people might look at the issue differently. This is, for instance, what can be seen in the following extract:

I guess in Western society there is often some doubt that money can buy a lot of things but it cannot buy good health and if you have a diagnosis that has a poor prognostic outcome and you are dying. (Nurse 7)

This nurse participant emphasised that people might doubt that money is what life is

all about and can solve all manner of problems. This situation might be identified by individuals when a crisis happens. When individuals are faced, for example, with a dying person or they experience a threatening disease, they might deeply recognise that money is not as important as they thought. How can a dying person buy a new life? Where is that life-saving drug that advanced cancer patients can buy to get rid of their long months or years of suffering? Who is that doctor who can alleviate their pains?

Having choice

Nurse participants also defined QoL as having choice. Consider, for instance, the following extract:

It [quality of life] would be to enjoy life, to be able to do the things you choose to do, to have the choice. (Nurse 1)

Having choice is important when the person is having an unpleasant experience:

Quality of life is what gives us a framework for what we are going to do and if it's going to be very unpleasant, we might make another decision, another choice. (Nurse 8)

It is therefore quite important that the health care professionals can explore and support patients' choices:

We had a patient who came in with a Fungating Vulval Carcinoma who had terrible pain, terrible odour from the cancer. Her chief complaint when she came in, was that her cat needed to be relocated and not that her odour needed to be contained or her pain managed but her cat that she adored needed to find a new home because she was going to die. So the first thing we did was to get the social worker in to see her, not the doctor and when you put a structure in place for the patient you are actually supporting their quality of life choices. (Nurse 8)

Sometimes a minor issue becomes a major concern for the patient. Health care professionals need to consider the broad range of patients' choices and try to meet them as much as they can. Keeping pets like cats and dogs, for example, is a relatively common custom in Australian culture. This can become a major concern for some people when they cannot do it. In some other cultures, however, this is not an issue.

Conclusion for the category: QoL meanings

In the previous category (QoL aspects), it was explained that QoL is a broad concept that incorporates a variety of categories. In the first stance it appears that QoL is a complicated concept and is difficult to understand. However, participants in this research study teased this concept out and gave some common definitions to this individual concept that facilitates an understanding of this broad concept. Patient interviewees used a simple language and defined the QoL concept mainly as being happy in life whereas nurse interviewees considered QoL to be more complicated. They allocated a broad range of meanings to it including happiness, enjoyment, satisfaction and having choices.

Participants stated that cancer patients might be quite happy, cheerful and satisfied with their lives even though no specific enjoyment can be identified by caring people. In fact, depending on the situation even little things like being relaxed might make the patient feel satisfied and happy. It appears from participants' statements that cancer patients' acceptance of the real situation, particularly at more advanced levels, facilitates the process of satisfaction and happiness. As well as these meanings, participants expressed that the QoL concept means having choice especially in unpleasant circumstances. Patients' QoL choices need to be supported by health care professionals, particularly nurses. Nurse participants also stated that they need to be mindful that when considering patients' QoL, patients might talk about QoL in a simple language, such as being happy in their lives.

Cues-based QoL assessment

In response to the research questions, it was found that nurses pick up on simple cues during their relationships with patients as a way for QoL assessment. This is what one nurse participant highlighted below:

I think a lot of time when nurses do assess quality of life they do not do it in a structured official capacity. This is more something that they are picking up during their encounter with patients. They pick up on cues of cancer patients rather than usually doing a formal assessment of the patient's quality of life. (Nurse 9)

In the first phase of the research study it was also identified that nurses differ in their

perceptions about cancer patients' QoL with patients' own perceptions using the WHOQoL-BREF questionnaire in oncology wards. The category 'cues-based QoL assessment' was created to show how participants think about the kind of QoL assessment that nurses actually perform in oncology wards and the reasons and consequences of this kind of assessment.

The category 'cues-based QoL assessment' consists of the following sub-categories: 1) Just simple cues; and 2) Assessment with uncertainty. These sub-categories are discussed in the following sections.

1) Just simple cues

This sub-category was created to demonstrate how nurses actually are doing a cues-based QoL assessment and how it varies in oncology wards. Nurses expressed that in oncology wards they pick up on cues of cancer patients when they communicate with them:

So you pick up on cues of people, like I mentioned before, up or down or stressful a pain or whatever but they might tell you, they might actually tell I've had enough, yes, constantly looking at people and try to assess where they are. (Nurse 2)

You can over the years, pick up on little ways and little things that patients do especially when you look after them for a while and you think, oh, that does not seem quite right. There are some things a little off colour. They are coming and they are quite introverted when they normally would be out spoken, happy to see you full of hope for their treatment, no I feel much better off the last time, and they come suddenly right down at the bottom...just simple little things. (Nurse 4)

So just a clue is the first thing [for quality of life assessment] and then later in the day, I will often ask how things are going. (Nurse 10)

Similarly, patients in response to research questions as how nurses assess your QoL stated that:

[Nurses] generally ask me how are you feeling, generally they are concerned...The only time that I can think of it [a formal quality of life assessment], was not here but my local doctor, whose one of his nurses came to my home and did a survey of my situation. (Patient 2)

There might be some odd questions here and there [that nurses ask for quality of life assessment] but not in a structured way. (Patient 3)

It is clear from both patient and nurse interviewees that QoL assessment in oncology wards is something that each nurse will do individually. One nurse, for example, might only consider pain as an important cue to QoL whereas another nurse may focus on patients' general feeling of happiness. Moreover, such assessments are being conducted informally because nurses do it during their communications with cancer patients and not based on any agreed process or structure.

Even though nurses might assess cancer patients in different ways, they focus mainly on physical issues. Nurse participants stated:

I think when you [nurses] assess the patient you do not broaden or do more global assessment. You only assess what you require to assess. If you ask about nutritional status or if you ask about bowel management or something like that this is the only thing you assess. (Nurse 3)

From the very beginning when you train to become a nurse, it is a physical thing to address all the way through, physical, physical, all the time. We deal with a bit, with psychological. (Nurse 4)

And similarly a patient participant stated that:

They [nurses] use a medical model. The medical model is a medical approach where they see you [patient] as somebody who has had a left lumpectomy and 12 nodes removed. You have a drain in situ, therefore you need these kinds of observations; to watch out for infection you'll need these antibiotics for 3 days and then we'll take the drain out and then we'll send you home. That's medical model. The doctor will come in and check your site, your wound; the drain will be removed. If you don't spike a temperature you'll be sent home. That's a medical model. It's not a social health. (Patient 3)

Both patient and nurse participants stated that a QoL assessment could focus on aspects that nurses think they are required to do, i.e. physical aspects of the job. It is interesting that a more educated patient, Patient 3, introduced the 'medical model' term and believes that physical aspects are often a focus of nurse assessments.

Another important character of a cues-based QoL assessment highlighted by participants is that more experienced nurses often better pick up on QoL cues. Nurses' clinical experience was also a significant finding in the first phase affecting the level of agreement between cancer patients and nurses about cancer patients'

QoL, which was further elaborated in the second phase under another category (see nurses' experiences as a facilitator to QoL assessment in page 172).

Summary

One way for QoL assessment in specialist and non-specialist oncology wards is that nurses pick on cues. There are some important characteristics to this assessment. In this assessment nurses informally pick up little things that they individually think are important indicators for patients' QoL. The focus is more on physical issues even though more experienced nurses might assess a broader spectrum of QoL cues such as social and emotional status.

2) Assessment with uncertainty

This sub-category was created to explain the uncertainty that nurses feel about a cues-based QoL assessment, and what could be the possible reasons and consequences of this uncertainty. Participants stated:

You probably do not assess it too much. You probably subconsciously assess quality of life for patients but [you are] not sure if it is quality of life assessment or not. (Nurse 5)

It [quality of life assessment] is like a gut feeling. It is what you get with most nurses. (Nurse 4)

I'm not sure they [nurses] know how to assess and unpack it [quality of life]. What quality of life means and how it is influenced by different things? It is being taught but even the people teaching it don't understand it, therefore, the outcome is less than optimal. (Patient 3)

Here both patient and nurse participants demonstrated they are not certain if nurses are doing a QoL assessment or not. Throughout the interviews nurses frequently expressed that they are not sure if what they have done is a QoL assessment or not.

The reason for this uncertainty might be that health care professionals including nurses often do not have enough information about patients' situations. For instance, participants said:

Whether really as a health professional we have actually any idea about what quality of life means to our patients at all is questionable. (Nurse 9)

You [as a nurse] just make some assumptions which sometimes may not be right...You can never be totally sure that you are going to be spot on and really know how this person is feeling. (Nurse 2)

Here, 'Nurse 9' explicitly questioned interpretations that health care professionals are making about patients' QoL. This implies that she is not sure if she, as a health care professional, has the correct idea of patients' QoL or not. 'Nurse 2' highlighted more specifically that nurses' interpretations of patients' QoL might not be correct.

Another reason for this uncertainty could be that nurses generally do not use the professional language of QoL. This is identified below:

Regardless of thinking what it [quality of life] is, I do it but I do not think about it too much, just as a part of my work. You do not think of it in terms of quality of life. That is a term you don't really use. You tossed it around but it is not something that you focus on. This term is a bit confusing. Nursing staff do not really know what quality of life [concept] means. (Nurse 3)

It [quality of life assessment] is really hard because it is just a sort of do it but I don't really think about it too much as how I assess every one that comes in. I don't know really [if my assessment of patients' quality of life is correct or not]. I guess from the feedback I get from patients. (Nurse 5)

It appears that QoL is not a concept that nurses normally use in their professional conversations. They do not know what QoL assessment means exactly so that they can only evaluate it if they have done a QoL assessment previously.

QoL assessment with uncertainty has problematic consequences for patients. For example, nurses often anticipate more problems for patients:

We probably think their [patients] illness is dominating their life but it may not be. We anticipate problems. We anticipate that the human is full of problems. Therefore we probably underestimate their quality of life. (Nurse 10)

The frame of reference for nurses is to predict more problems for patients. This will

affect nurses' perceptions of cancer patients' QoL. They may not imagine that a patient with cancer still can live happily as other people do. This was also identified in the first phase of the research study in which it was identified that patients' QoL scores were higher than nurses' scores (as patients' proxies) indicating that nurses underestimated cancer patients' QoL. The sub-category 'QoL has different meanings' shows that cancer patients are generally happy with their lives.

Summary

Participants in the second phase stated that a cues-based QoL assessment, as seen in specialist and non-specialist oncology wards, is an experience shrouded in uncertainty. This scenario has reasons and consequences. The possible reasons for this uncertainty would be that health care professionals including nurses often do not have enough information about patients' situations and therefore they are not sure how accurately they understand patients' QoL. Moreover, nurses generally do not use the professional language of the QoL concept and QoL assessment. Therefore, they are not sure what they need to assess as a means for QoL assessment and specific criteria they need to evaluate if their assessment of patients' QoL is correct or not. Outcomes of such an assessment might be only assumptions about patients' QoL, which is more like anticipating problems for patients and underestimating patients' QoL.

Conclusion for the category: Cues-based QoL assessment

Participants emphasised that QoL assessment in specialist and non-specialist oncology wards is conducted informally, and based on nurses' relationships with patients, during which nurses pick up on patients' cues. QoL assessment in oncology wards does not appear to be conducted using any agreed process or structure, but by individual nurses picking up on cues of cancer patients. The main focus of such an assessment is the physical aspect, but the experience seems to play a role in the choice of indicators utilised. Another important feature of a cues-based QoL assessment is that nurses feel uncertain if what they are doing is really a QoL assessment or not. The reason for this uncertainty appears to be that nurses know that they do not have comprehensive knowledge about the patients' situation and must make some assumptions about patients' QoL. Moreover, it is not clear to nurses what the QoL concept means for the patient and what they need to consider in undertaking

their QoL assessment. Outcomes of a cues-based QoL assessment may be to underestimate the QoL of those patients coping with cancer.

Purpose-based QoL assessment

There were participants who had experiences specifically with palliative care or had a shared experience in both oncology and palliative care areas. They expressed the view that generally QoL assessment in the oncology wards differs from that in the palliative situation:

I believe that down the track in palliative care the situation changes. From the little bit I've seen and heard of palliative care because I have looked into it... and I actually did have an interview with somebody in the palliative care area and I had to say the interview was totally different, all about quality of life. (Patient 3)

In palliative care quality of life is important because the aim is to have the patient live more comfortably and that frames how we think and how we structure things, whereas in acute care services the aim is to cure even if the patient endures a bit of discomfort. (Nurse 8)

From both patient and nurse interviewees it appears that QoL assessment in the palliative care area differs from that conducted in oncology wards. The researcher wrote the following memo:

QoL assessment in the palliative area seems to be performed differently from that in the oncology wards. In the palliative area the final aim is for patients to live more comfortably whereas in the oncology area the aim of QoL assessment is to respond to patients' expectations for cure and recovery. There might be some overlaps in a way that QoL assessment is conducted between oncology wards and the palliative area. However, it appears that some characteristics of QoL assessment in the palliative is unique and needs to be searched further. (30/02/07)

The category 'purpose-based QoL assessment' was created to reflect on the usefulness of this approach to QoL assessment in the palliative care area.

One important character of QoL assessment in the palliative care area, as explained by nurses, is that it is being conducted using a specific guideline. One nurse, for example, in the palliative care area brought for the interviewer the assessment and the care plan sheet specifically used in the palliative area. She explained how nurses

assess patients' QoL in the palliative care area:

We actually write down how they feel, we assess all their problems, discuss the background of their family, how much help they have in the home, that sort of thing and we also ask them to make a comment about their quality of life. They actually scale it from one to ten. We also do background assessment on other areas that might impinge on that. (Nurse 6)

The Likert score gives you a line in the sand. There are a whole lot of things we do. We do a thorough symptom list and find out the impact that symptom has on the patient's quality of life...you've got a fairly comprehensive symptom assessment which addresses a lot of that emotional, spiritual and psychological suffering as well as physical suffering. (Nurse 8)

From the above extracts, it can be seen that in the palliative care area, nurses fill out a QoL tool and a symptom checklist directly with the patients and these are universal across the palliative care area. Moreover, information is gathered from different aspects of patients' lives such as physical, psychological, and spiritual issues. These portray a fuller picture of patients' QoL.

Further to this, in the palliative care area QoL information is gathered from a range of health care professionals:

A team meeting will put everybody's assessment together. So we'll start putting the jigsaw puzzle together and that the social worker will have elements of this patient's story to contribute and the doctors and the pastoral care person and when you put the picture together, you might say this is not a good existence for this person. It might make you refocus your attention to go back and find out what is it that they actually want? Are we doing the right thing? (Nurse 8)

In the palliative care area there is an opportunity for QoL information to be discussed by the professionals involved in the patients' care. This is very helpful in order to do a more comprehensive analysis and to improve the impact of strategies designed to support patients' QoL. Such discussions between health care professionals might also happen in the specialist and non-specialist oncology wards but it appears that they are not regular occurrences. The following example can elaborate further about how the situation is managed in the palliative area:

When there is a family issue which is beyond our power to manage, we have palliative care social workers who will become involved especially

about things like legal arrangement, emotional support, financial issues, and so on. We have also the pastoral care team who come and support people in a spiritual way. They are actually non-denominational group of people, all the patients and denomination of pastoral and priest can come. So, all these ways will address the quality of life. (Nurse 6)

As well as using a QoL tool and a symptom checklist to assess patients' QoL, nurses also pick up on cues for QoL assessment particularly for patients who cannot communicate, for example those who are dying. Participants stated:

If they [patients] are unconscious then you can assess quality of life by picking up on cues like facial expression and general relaxation. Even the day before they die, a lot of patients are able to make some kinds of facial expression, or just squeezing the hand. (Nurse 6)

[For those patients who cannot communicate] I think nurses assess quality of life in terms of their [patients] comfort. For example, if they [patients] are frowning their brow or fidgeting or grimacing, there needs to be an intervention put in place. We don't have the verbal cue but we do have the strong assessment skills. (Nurse 8)

Here it can be seen that as well as using a guideline for QoL assessment in the palliative care area, nurses also assess patients' QoL by picking up on cues particularly in relationship to those patients who cannot communicate appropriately.

Conclusion for the category: Purpose-based QoL assessment

Both patient and nurse participants stated generally that QoL assessment in the palliative care area is conducted differently from the oncology wards. Nurse participants explained that in the palliative care area, a guideline exists to assess QoL because the goal of treatment is for patients to live more comfortably and to improve their QoL. In the palliative care area nurses assess patients' QoL across several areas including the physical, the emotional, and the spiritual dimensions. Moreover, information is gathered from different health care professionals and patients' families. In the palliative care area nurses also pick up on cues of patients as one important way for QoL assessment, particularly for those patients who have communication deficits. Thus, a purpose-based QoL assessment is much more holistic than a cues-based QoL assessment because the former assesses QoL using specific guidelines as well as by picking up on QoL cues through interactions and communications with patients. Palliative care nurses are well aware of the process they are undertaking rather than using an informal and intuitive assessment as can be

seen from the data gathered from the nurses working in oncology wards.

Facilitators of QoL assessment

As well as explaining the current state of QoL assessment in oncology wards and the palliative care area, during the course of interviews participants (mainly nurses) suggested a number of issues that can facilitate nurses' understanding of cancer patients' QoL. The category 'facilitators of QoL assessment' was created to incorporate the following sub-categories: 1) Relationship and rapport; 2) Doing a QoL assessment; 3) Nurses' experiences; 4) Nurses' education and training; and 5) Using alternative criteria. These sub-categories are discussed in the following sections.

1) Relationship and rapport

During the process of comparative data analysis it was found that participants address a number of concepts like openness, enthusiasm, rapport and communication to facilitate nurses' understanding of patients' QoL. Participants stated:

There is a certain amount of openness and rapport or interest or enthusiasm that I am not sure how I can describe that I think could be the key factor [for nurses' understanding of patients' quality of life]. (Nurse 6)

The only way is if you build a rapport with a person and you talk to them and you find some insights about what they are telling you, give you a little bit more idea how you see that person's situation. (Nurse 2)

These concepts were then connected under the sub-category 'relationship and rapport'. Establishing a good relationship and rapport can lead to effective communication (Corner 2002). The most important characteristics of this sub-category are considered in the following sections.

Enthusiasm

Enthusiasm directly or indirectly influences their relationships with patients (Sadovich 2005). Participants explained that enthusiasm or interest in health care professionals facilitates the process of establishing a good rapport with patients to assess their QoL. Consider, for example, the following remark:

If you've got a genuine interest in the person you're looking after [that might allow you to have a better understanding of the patient's quality of life]. Willingness to engage and spend time voluntarily...It's the emotional and psychic energy to be involved with another person and possibly with a person who is going through something painful. (Nurse 10)

Interest in health care professionals developing a good relationship with patients is very important because they need to engage with patients who are suffering from pain or other physical and psychological issues. Such experiences are not pleasant, so nurses need to be highly motivated and psychologically strong for such an engagement (Finfgeld-Connett 2008). In the following quote, the nurse described an unpleasant experience:

If you have a young mother with two young children admitted who is going to die with us, that in itself can be quite traumatic. The staff can identify with this. They may have two young children, what if that was me? And that can actually get in the way of a good therapeutic relationship. (Nurse 8)

In these situations, more interested nurses make a therapeutic relationship with patients to help them.

More enthusiastic nurses might search for a common interest in order to communicate with patients:

Just chatting with patients about what you learn, what are you do, are you knitting or sewing or have a dog. Once you have a common interest, you can talk about. (Nurse 4)

It is also possible that a more interested nurse even spends time voluntarily with the patient in and outside of the hospital in order to communicate with patients better:

As most nurses do I have been guilty of after hours, I go around and walk the dogs or clean for them. (Nurse 4)

When they [doctors] told me that I had full bone cancer after all other cancer, there was a student nurse...she is standing next to me, after doctor told me what has gone on, and I grabbed her hand, I was in tears, she is starting on tears, that sort of things you just cannot replace, and she was just student nurse, and she rang later on that night to see how I was. That sort of thing is fantastic, communication. When I go home I miss nurse, miss the care. (Patient 1)

In contrast, less interested nurses might only respond to the surface issues to make their work and duties easier:

Sometimes there are days when I just want to do the work and [I am not interested] to be bothered by the complexities of quality of life...If this person [patient] looks bright and fairly happy, then I think that is OK, that is good. This is a little bonus. This person does not seem to have problems. I won't go looking for trouble here. I'll just accept this as one of the easy patients. (Nurse 10)

More interested nurses try to establish patients' problems and to solve them, whereas less interested ones only try to do their job and earn money. This will mitigate against a holistic QoL assessment. One patient alluded to this issue as follows:

Nurses can be judgmental without fully understanding [patients] because nurses see themselves as the expert. That's very hard for them to put themselves in the patient's shoes. If they try and find out what the patient's view is, the patient will say possibly something quite different from the nurse...Some nurses just need to get a job. They might say: Right! No money therefore they're no hoppers...I could be judgmental there too because not all nurses would do that...The nurses are doing an allocation of duties because management are trying to save money. There's a lot of that going on too. (Patient 3)

To facilitate nurses' relationships with patients, nurses need to explore in what areas they would actually like to work:

The beauty of being a nurse is that you can find your special niche for your personality type. The theatre if you're more of a production line type. If you have a great ability and interest to relate to people then you are drawn to places like palliative care, medical units where you have the opportunity to develop relationships with people. It's about your natural sense of which you are. (Nurse 8)

In oncology and palliative care wards, patients are often hospitalised for a longer time and the situation is not critical. Here, nurses need to be more therapeutic in their relationships so that they can relate to patients, understand their situation and improve their level of comfort and QoL. Conversely, in acute areas such as surgical and emergency wards, there is not much time for a detailed relationship with patients but rather nurses need to have an ability to make quick decisions to manage sudden problems.

Openness

Openness is also very important during the relationship and rapport with patients. It is the quality of being able to think, accept or listen to different ideas or people. Participants remarked:

You need to be aware of what information [patients] got and discuss with them openly. (Nurse 4)

That's why I keep coming back to communication through this entire interview. It's the key. Not being restricted but being ready for whatever might come up. (Nurse 8)

I think having an inquisitive mind and seeking new knowledge and being open to new ideas and new thoughts [is a factor to better understand patients' quality of life]. (Nurse 9)

Here participants expressed the idea that nurses need to be prepared to enquire, listen and discuss issues with their patients if they are to have a better picture of patient QoL. An open-minded nurse is ready to hear and/or discuss about everything that might happen during the course of a relationship and communication with patients. Nurses cannot restrict themselves to hear specific things they want to; instead they need to be prepared to listen to a variety of thoughts and opinions. Moreover, nurses need to encourage patients to talk about all issues even if they think these ideas would be unpleasant and/or contrasting with them and their ideas.

Be fit and well

The first phase of the research study explored nurses' QoL, which influences their understanding of patients' QoL. This issue was further elaborated in the second phase. One nurse, for example, said:

You have to make sure you are fit and well and ready to listen. (Nurse 6)

It is important that nurses who are looking after patients are at a high level of wellness otherwise this will affect their ability to communicate with patients:

Things like stress and so on would decrease the amount of listening power they [nurses] have. (Nurse 6)

The happier they [nurses] are, the happier they are with the people. If they are happy with themselves, they more switched on. (Patient 1)

If I [nurse] have poor quality of life, that is going to colour my perception against the people that I am looking after...I suppose you can look at the issue in this way. If I come to work and I have got headache that is impacting on my quality of life. Is not it? on that point of time, and yes I would be more grouchy than usual, I might not feel like opening up to the people, and encouraging me to talk and build up a rapport, therefore I think in that way so every one knows it is a bad day. (Nurse 2)

Both patient and nurse interviewees expressed that nurses who are not happy or with lower levels of QoL might be too engaged with themselves and cannot focus on the patients and listen to them appropriately. Nurses' feelings may colour their perceptions of what other people are feeling.

Patients who took part in this study also expressed their ideas about how happy nurses are when they interact with them in their clinical practice:

Nurses here are fantastic. Very few not good, and they always have a reason, they can say they have stress or they have too many shifts, or they are grumpy, but generally I have happy people around all the time, happy people, I like that...They do not show anxiety and depression. (Patient 1)

It appears that patients are observing nurses generally as happy people. This can confirm results of the first phase indicating that nurses generally rated their QoL as good or very good. It is interesting to see that patients appear to have a reasonable understanding of nurses' QoL.

Consider patients' characteristics

Participants pointed out that some patients' characteristics are very important when nurses want to develop rapport with them. Gender is one such characteristic:

My opinion is that females have been more open about the issue and they also want to know about their condition whereas I sometimes found that males are just, do it I do not want to know about it, but it is not for every one because there are some people that want to know. But I do find in general females are more open in the discussion. (Nurse 5)

Sometimes female patients are more comfortable with female nurses and sometimes male patients with male nurses. (Nurse 2)

Female patients are seen to be more interested about detailed discussions with nurses compared with male patients. Patients also may feel prefer to talk with a nurse from

their same gender. If these issues can be taken into account by nurses, they may better communicate with patients.

Another issue is the age of patients when nurses communicate with patients:

Younger people seem more frightened and older patients may be more accepting. (Nurse 5)

Maybe an older person who has come to the realisation that accept the process that I have this disease, I am 80, 90, and I am tired, and I am ready to go, such acknowledgement makes it easy compared to a 22 year old who has leukaemia and is dying, that is more challenging, confronting and emotional for nurses compared to an older person who is ready to go to the heaven. (Nurse 7)

Here it can be seen that dealing with older cancer patients might be generally easier compared with younger ones because older people might have accepted and acknowledged their diagnosis. Nurses need to be aware that communication with a younger cancer patient might be more challenging.

Nurses also need to be aware of patients' language and culture:

Patients having English as a first language are more communicating... There is a lady there and she suffers from dementia or something, she is a foreigner and she speaks in a language and she gets angry and she wants to wander around, she is a bloody nuisance and that is hard for the nurses to function properly. (Patient 1)

I suppose it is not only the better language skills to communicate with but you might have more cultural background for example when the person comes from the similar culture you have a few more cues as to what person thinking but when the person comes from different culture or background you can find yourself thinking maybe I should not have said that. You have to be sort of mindful of the culture. (Nurse 2)

Nurses need to be mindful that Australian English is considered difficult to understand for those who have a different first language or are more conversant with British or American accents:

Specifically, Australians have a lot of funny words. We have an awful lot of funny words for different things, for example, down in the dumps means feeling low, and a lot of people, we have now a Chinese girl, she just looked at me a couple of times. It has a big impact; this is the way that Australian people say things. (Nurse 4)

Accordingly, nurses must be very careful in their communication with second language patients and arrange an interpreter if or when necessary:

Non-English language patients, they are a bit harder, but most people when they are having treatment, they have still the same reactions to the treatment, and you can pick up, and if I cannot understand, I get some one who can, so involving a family member if I can because they can discuss openly. Sometimes they prefer to have an outsider to come in and do some translations and someone who gives them better understanding. (Nurse 4)

Also, according to type of patients' treatment, the communication might differ:

They [patients] react in different ways depend on what treatment they are given. Like chemotherapy they walk on egg shells. (Patient 1)

Chemotherapy is the major type of cancer treatment but has many side effects that can hinder patient-nurse communication, something that nurses need to be mindful of.

Nurses also need to be aware of the stage of cancer if they want to be more in tune in their communication style:

Understanding the cycle of cancer, understanding the type of cancer they have, understanding the impact these cancers have on their quality of life, knowing the full cycle, what really gets to you because you know the cycle of the cancer and you know, all right at the best you have three years, you can be much more in tune or aware of the stages they are at, because you are aware of the stages of the cancer and how it works and its impact on the patients. (Nurse 4)

When communicating with patients, nurses need to consider the demographic and clinical characteristics of patients such as age, gender, language, culture, treatment and stage of cancer. It is interesting to note that a couple of these characteristics were found (in phase one) to be associated with the level of agreement between patients and nurses about cancer patients' QoL using Bivariate analysis (such as Pearson correlation).

Be non-judgmental

When nurses communicate with patients, they need to be aware of differences that

exist between their perceptions about a patient' QoL with those of the patient. Nurses need to approach patients in a non-judgmental way. Participants stated:

I think it is very important that in a non-judgmental way the person ask me, are you happy for someone to assess your quality of life because it has been shown people who are being given some support going through this journey do better, have better outcomes. (Patient 3)

That is part of nursing try not to put your own. Remember that is your patients' view that you are considering and to understand that they do have different views to you...aware of differences between patients and yourself. (Nurse 1)

You might have your own assumptions about what that person may be feeling, just looking at from your own point of view, but at the same time you need to be mindful of trying to see how that person would see things from their perspective. (nurse 2)

Here it can be concluded that in order to better understand patients' QoL, nurses need to put aside their own assumptions and not be judgmental about patients' QoL. Nurses with a non-judgmental approach toward patients are often more supportive in their roles:

I have to be just there and provide supportive capacity to try to listen, at least he found some one to communicate his feeling with in non judgmental way, somebody not to turn around and push his feeling aside, just got to go with it. (Nurse 2)

Quite often more experienced nurses who observed different patients and situations might be less judgmental in their approaches:

I suppose you see enormous range of people of all walks of life, a lot of diversity and it probably teaches you to be very accepting and non judgmental and tolerant and not to be biased but we still measure quality of life to a degree from our own experiences and so going through the process of caring for people. (Nurse 7)

Altogether, for an effective communication and rapport nurses need to approach patients in a non-judgmental way. This is an approach allowing nurses to be more supportive in their roles.

Involve the family and other health care professionals

Participants in this research study also commented that relationship and rapport with

patients need to go beyond the patient and include the family:

If you establish a very close rapport with the person you are caring for and their family in a very accelerated manner and I think that you have an opportunity to be witness to very private and deep and important relationship issues that maybe give you a sense of what is important for that person. So, there are opportunities that they are made available to facilitate, opportunities to explore quality of life. (Nurse 7)

This is a good example of how the family is important and health care professionals need to recognise, through their communication, if patients have a supportive family or not. This is particularly important when patients are in advanced levels of a chronic disease or when they are dying because at these stages patients are more dependent on their families.

Participants in this research study also recognised the family as an important source of information when patients cannot communicate or are in the palliative care area:

I guess a lot of time they are in the palliative situation and are not able to comprehend the questions or if they are they are not able to verbalise their feeling. I guess quality of life can be determined by speaking to their family. (Nurse 1)

We had an interesting situation only a few days ago...We actually spoke to the family about using a drug that we hadn't used before...They said, "We know our mother would want to receive that."...That woman stopped twitching the minute that infusion started. And that family was delighted because she looked a whole lot more comfortable and peaceful. They became the voice for their mother. They kept saying, "I know this is what my mother would want." We'd had these conversations so we do use the family in that way. (Nurse 8)

The patient's family can be used as a good source of QoL information (proxy) particularly when patients cannot communicate well. This also supports findings of the first phase indicating that nurses generally are not good proxies for patients and families are more suitable for such purposes. Nurse 8 explained how the family can be useful to provide QoL information instead of patients.

In order to better understand patients' situation, communication with other health care professionals is also important:

When something comes up that you [nurse] don't have the skills to

manage and that's where having a multi disciplinary team is so vital. You might have to say to your patient, this is an issue that I can't help you with, but I have a colleague who can, a social worker. Would you like me to get them to speak with you? It all adds to a greater understanding and why they behave the way they do, why they react as they do, why they put the coping mechanisms in place that they do. (Nurse 8)

I think discussing the patient in a multidisciplinary group would be useful as well to bring out issues and I think it would be useful overall to bring out issues that need to be discussed about the patient care. (Nurse 9)

The relationship and rapport need to be established not only with patients but also by patients' family and other health care professionals. Developing a relationship with the family is especially very important because they have a supportive role for patients and they can work as a proxy in some situations.

A holistic approach

An effective rapport is also one that attempts to understand all aspects of individuals' QoL such as physical, psychological, and social relationships. This is referred to in some studies as the holistic approach (Bishop & Griffin 2006; Saylor 2004). Participants, however, identified what a holistic approach meant to them:

I think holistic is very over rated and I think it locks people in. We all strive for the ideal, that Utopian way of life. If we say that it's holistic care, therefore we are doing the right thing. Unless you get in and really understand your patient on a deep level of communication, holistic care is just a concept. (Nurse 8)

A holistic approach in fact is a relationship and rapport with the patient that is deep enough to understand all aspects that may impinge on patients' QoL:

Make sure that you care for all parts of patients...Make sure you listen to what is happening, you look after the spiritual, emotional needs as well...I think it needs more intensive evaluation than evaluating physical capacity. (Nurse 6)

Unless you've interviewed them [patients] at length and done a thorough psycho-social assessment, I don't think any nurse would advocate for them. (Nurse 8)

So often it is physical care and emotional support that it is the first response of what the patient needs. The bigger picture of spiritual life or meaning does not come into it until I got a relationship with the patient. (Nurse 10)

In a comprehensive approach all aspects of patients' needs to be taken into consideration. Although the physical issues are an important aspect of individuals' QoL, the psychological and spiritual aspects of QoL cannot be overlooked.

In a comprehensive approach, personal issues such as sexual aspects need to be taken into consideration:

It wouldn't be common that patients talk about those personal aspects. But yes, it could be beneficial. Even just expression of these issues with somebody else is useful... The only ways that those discussions come about with a patient are when a relationship has been well established involving trust. (Nurse 10)

We do not really do any sexual assessment, urology patients, we do not tend to. Even though they have a need for sexual assessment, and it is an area that nursing staff find particularly difficult to deal with because they do not know how to talk about it with patients. But because we are working in haematology/oncology there is a need to address that because the patients are under chemotherapy. (Nurse 3)

Without considering all aspects of QoL including private ones such as sex life or financial issues, it is very difficult to achieve a holistic and comprehensive picture of individuals' QoL. These areas are difficult for nurses to deal with unless a close relationship and rapport is established between patients and nurses.

Summary

The issue of relationship and rapport is important in facilitating QoL assessment. As pointed out earlier, one of the main characteristics of a cues-based QoL assessment used in both oncology wards and the palliative care area is that it is very dependent on relationships. There are very important figures in such a relationship. Participants stated that nurses needed to be genuinely interested in developing an open relationship with patients in a non-judgmental way. This rapport needs to go beyond the patient and include other health care professionals as well as the patient's family. This is particularly important when patients are at advanced levels of the disease or when they are dying. Finally, these relationships need to go beyond the physical issues and take into consideration other aspects such as sexual and financial issues.

2) *Doing a QoL assessment*

In response to some probing questions, participants pointed out ways that a QoL assessment can be conducted. The sub-category ‘doing a QoL assessment’ was one in which participants (mainly nurses) commented about using QoL tools and interviews.

QoL tools or guidelines

In the first phase of the research study, a QoL tool was used to assess patients’ QoL. The researcher wrote a memo indicating that the use of QoL tools appears to be a challenge for nurses and needed to be investigated further in the second phase. Some nurses in response to the researcher’s questions about using QoL tools in the clinical area, explained their ideas:

We need to have a tool. We need to have a guideline. (Nurse 3)

However, the interest for using tools or guidelines varied across experienced and junior nurses:

We do not use them [quality of life tools] in the clinics routinely...It [tool] just might provide some reminders for more experienced nurses that already are becoming more professional and aware of what kind of questions to discuss but there is not a thing wrong with a reminder and for the more junior nurse it could provide some guidance as the type of things that might be useful to ask the patient or useful to consider when you are looking after a cancer patient. (Nurse 9)

I think with younger nurses, they like to have a guideline to work with. (Nurse 4)

The above nurse interviewees had been in the profession for more than ten years. They generally recommended using QoL tools for more junior or novice nurses.

Participants also highlighted their ideas about questions that needed to be included in a QoL tool or guideline and how such questions need to be asked and interpreted:

I think it is hard to get agreement on what right questions to ask...Obviously screening type tools would not incorporate everything you want to ask; it would be good to have some good trigger questions there that would highlight areas that might be problematic and then you can look at them deeply if you needed to; I think once those are sorted out, there have to be some things that ask patients about how important that actual item was to them, and how much it actually impacted on their functioning, so not just about something that existed but whether it

actually impacted on them or not and whether there are some things that they want to deal with or not. I think the other thing is interpreting the results; who actually is going to interpret the results and if the person who is interpreting is in the position that they could do something about those results or working on strategies how we can then deal with the results. (Nurse 9)

In the above extract, it has been identified that the first issue is to formulate the kinds of questions to ask in a QoL tool or guideline. Moreover, the importance of each question for patients also needs to be questioned and the interpretations should be conducted in a way that is useful.

These tools or guidelines needs to have several characteristics as suggested by participants:

With a lot of older people, there is no point using the fancy statements and to use a tool as a guideline because those people do not really understand what is that. (Nurse 4)

I think if we are looking to use these quality of life tools for patients on a routine basis this has to be something that is easy for patients to complete but it must also be relevant to the clinic needs at the time as well. (Nurse 9)

Questions in a QoL tool need to be easy for patients to understand and particularly for elderly people. These tools need to be comprehensive enough to reflect on some important aspects of patients but in the meantime they need to be brief. Lengthy guidelines or tools might be very difficult for patients to complete:

Our patients get incredibly tired with a lengthy document or a couple of tools. They might say: My quality of life would be greatly improved if you just walked away and stopped asking me questions. (Nurse 8)

The frequency of QoL assessment using QoL tools is also an important matter:

I think doing a once-off quality of life assessment is useless and it would be better to do a longitudinal tool so that we can see changes to quality of life over the time. (Nurse 9)

The above participants remarked that the QoL data of patients need to be assessed longitudinally, and measured repeatedly during the admission, if nurses want to better understand patients' QoL.

A longitudinal QoL assessment might be particularly very useful in obtaining some ideas when patients cannot communicate:

When they're unconscious, it's too late and you have fighting relatives over the will. It needs to happen much earlier and even maybe in the general practice area with a GP nurse so that a quality of life tool has been completed from a very early stage of life and then is developed. I think we leave things too late. (Patient 3)

Thus, frequent QoL assessment may provide some background information about patients' QoL. This can provide health care professionals with a comparative basis to understand patients' QoL better and if patients' QoL has changed recently, how this has occurred and what interventions or care strategies may have influenced this change. This is highly important when patients are in situations in which they cannot communicate and report on their QoL.

Interviewing patients

Even though a few participants explained that QoL tools might be useful in the clinical area, participants also commented about interviewing with patients as an important way for QoL assessment:

It would be hard to quantify quality of life without talking to the patients themselves. (Nurse 8)

From such extracts it can be seen that an interview is an essential way for QoL assessment.

Even though QoL interviews can be used formally by allocating a specific time to take a seat and talk with people, it is very common for nurses to use these questions informally when they are doing their duties:

I think you can do those assessments in more informal settings, when you're washing a patient you can be talking to them about things that matter to them, not keeping the conversation neutral or selective, like, "It's a lovely day outside," but, "How did you sleep last night? Do you have anything on your mind?" Give them the opportunity to offload. (Nurse 8)

Because nurses are doing this kind of assessment during their relationship and work

with patients, this implies that this kind of assessment is very dependent on establishing a good rapport with patients (see the category 'relationship and rapport').

Moreover, more experienced nurses are more interested in using interviews for a QoL assessment:

I am not definitely a specific tool person. I can probably have a look at some and utilise some of those questions. (Nurse 4)

The above excerpt is from an interview with a nurse with around 30 years' clinical experience. It appears that she wants to use some of the questions in QoL tools but in an informal way. This raises an interesting problem in introducing tools to the care setting because some less experienced practitioners may rely on the tool as it stands while more experienced practitioners may have a more sophisticated understanding and seek the required information in other ways.

Summary

Participants who took part in this research study noted that QoL assessments need to be conducted in the clinical area using QoL tools or interviews. Both novice and expert nurses generally prefer to use interviews. However, novice nurses think that a formal QoL assessment using a complete QoL tool might also help them to understand patients' QoL. Expert nurses generally prefer to use some QoL tool items to initiate an informal conversation with patients when they are doing their work. Participants stated that QoL tools for the clinical area need to be brief and include items that are easily understood by patients.

3) Nurses' experiences

In response to questions put to participants about what nurses' characteristics might affect nurses' understanding of patients' QoL, both patient and nurse participants talked about a number of nurses' characteristics. Nurses' experiences were one of those variables that facilitated their understanding of cancer patients' QoL. This can comprise life and clinical experience:

Life experience can be a great deal when we deal with ill people, so

probably with our patient population, older nurses have better insights into what is going on in patients' life and from more personal point of view because a lot of them are dealing with elderly parents. (Nurse 2)

More specifically, however, it could be clinical experience:

I think the more patients you see and the more patients that you interact with, the better understanding you have of general factors that might affect quality of life, but also you get a better understanding of how different quality of life is for each patient because you have more experience with more patients to notice the differences. (Nurse 9)

I think years of service, years of work, how many years they have been here... I think the more broad spectrum of life as a nurse, the better help they are to the patients...I think if anything nurses should get experience in more than nursing. (Patient 1)

Several reasons were suggested why nurses with more clinical experience have a better understanding of patients' QoL:

They would have done some further education and in- depth reading and writing. They would have done case studies on their clients therefore they would have a better understanding of how quality of life might impact on client outcomes, absolutely. (Patient 3)

As you become more experienced, your assessment skills will improve and you learn to read faces better and learn to assess all the problems plus listen better and so on. (Nurse 6)

You need to have high degrees of clinical experience and proficiency to have a high degree of comfort in the workplace. Then you can have a better understanding of the person's experience. If something goes wrong in the middle of chemo-therapy, you will have the clinical know how to troubleshoot. If you're a junior nurse and something goes wrong your heart stops. What have I done? Your stress comes up and you're not actually able to get to the patient's zone because you're too busy being in your own. (Nurse 8)

I still think that probably someone with more experience may pick up on more things but it is just my personal opinion. (Nurse 5)

Patient 3 expressed her view that nurses with more clinical experience have a better understanding of patients' QoL because they have superior education and training. Nurse 6 stated that more experienced nurses have better assessment skills. As pointed out by Nurse 8, nurses with more clinical experience are more comfortable doing their work and can better understand patients' QoL. Finally, clinical experience can help nurses to better pick up on cues of patients. This is quite important because

picking up on cues is a common technique for QoL assessment particularly in oncology wards. This was addressed previously under the category “Cues-based QoL assessment”.

Clinical experience might be one reason why nurses in outpatient chemotherapy units were found in the first phase to have a better understanding of patients’ QoL:

There is another factor that might explain the differences between inpatient and outpatient units, especially in chemotherapy day unit nurses have got usually a reasonable amount of experience behind them, they are working in a specialised unit and have special training and I think that nurses in a day unit would have more clinical oncology experience compared with inpatient nurses. (Nurse 9)

The above statement elaborates on one significant result of the first phase, about why nurses in outpatients’ chemotherapy units have a better understanding of patients’ QoL compared with nurses working in inpatients’ oncology wards. It may be contended that nurses in outpatient chemotherapy units might have a better clinical experience compared with inpatient nurses. One reason may be that managers sometimes allocate more senior nurses to outpatient wards so that they can better manage sudden problems occurring in this area. Other reasons why nurses in outpatient chemotherapy units have a better understanding of patients’ QoL can be seen in pages 178 and 180.

Summary

Participants stated that nurses’ experience with cancer patients can work to facilitate better understanding of patients’ QoL. They highlighted that these nurses have developed better communication and assessment skills and can better notice the differences that might exist between patients. They are more professional and can pick up on cues better. Participants also explained that nurses in outpatient chemotherapy units have had more clinical experience. This can explain the significant findings of the first phase concerning why nurses in outpatient chemotherapy units have a better understanding of patients’ QoL compared with inpatient nurses.

4) Nurses' education and training

Participants also highlighted that nurses do need education and training in order to better understand cancer patients' QoL:

We need education on quality of life. It is probably something to work to probably nursing training when they are training, that it is an aspect that they need to start looking at. (Nurse 3)

We all need reminders of all kinds of care, physical care, emotional care...I think it is a very relevant. (Nurse 6)

I am sure. I think continuing education and training in any way can be beneficial to the patients. (Nurse 1)

Here it can be concluded that nurses need to be educated about the QoL concept.

This education needs to teach nurses how to assess patients' QoL:

I am not sure about the formal training but may be a good idea to tune to assess quality of life... Yes I think could be a good idea but I do not know how we can go about it, if we can run a course. (Nurse 5)

Thus, QoL assessment is another focus of continuing education. Participants also indicated that such education needs to include other health care professionals as well as nurses:

There needs to be some reorientation, education of the surgeons, the oncologists and the radiologists. It's not just the nurses and they are often being directed by these medical people. (Patient 3)

Summary

Education and training are useful strategies to improve nurses' understanding of patients' QoL. The most important areas for education are clarification about the QoL concept and how to conduct QoL assessment and analyse the findings. Even though such education and training focuses on nurses, it also needs to include other health care professionals.

5) Using alternative criteria

Participants also suggested using alternative criteria when it is appropriate for QoL assessment:

When I was at the Psycho Conference in Venice in October last year they decided to replace the term with Patient Reported Outcomes which means they are no longer meaning quality of life but Patient Reported Outcome because that is more tangible. They can tell you if they have a benefit they can put into their management plan if they can get up and walk to the toilet this morning whereas yesterday they couldn't or they couldn't walk more than three feet. But for them that's an achievement, a realistic goal for them and they can say, "I've had some improvement today," and that, in itself, informs us of their own assessment of their quality of life. (Nurse 8)

Obviously there are other things that can be measured, not just something that a patient has to say, so it could be looking at things like independence in activities of daily living because quite often it can indicate the overall person's health status, ..., some other things that we could be thinking as a part of life, face-grimacing in pain, bringing knees on to the chest because it can bring relief from the abdominal pain, and I think it could be fair to assume that that pain would decrease quality of life". (Nurse 9)

Nurse 8 stated the Patient Reported Outcomes, implying that she may be encouraged to use this criterion to measure QoL. Nurse 9 clearly suggested measuring other criteria like pain or the activity of daily living for QoL assessment when it is appropriate.

Summary

Participants commented on some other measures that can be used to obtain some ideas about patients' QoL particularly for non-communicating patients. This consisted of the Patient Reported Outcomes, pain assessment, and the activity of daily living.

Conclusion for the category: Facilitators of QoL assessment

Participants in this study commented about some facilitators that might be useful to improve nurses' understanding of cancer patients' QoL. Firstly, relationship and rapport with patients is highly important. This relationship and rapport starts with a real enthusiasm and proceeds in an open and non-judgmental way in which patients' characteristics are considered. Moreover, this relationship is comprehensive and focuses on all aspects. This communication goes beyond the patients and includes family and other health care professionals. Nurses need to actually assess patients' QoL using the relevant QoL tools or interviews. Educating nurses and other health

care professionals can facilitate the process of assessing patients' QoL. In some circumstances other measures may help nurses to understand patients QoL better such as measuring the pain or Patient Reported Outcomes.

Barriers to QoL assessment

As well as facilitators of QoL assessment, participants also expressed their opinions about those issues that might work as barriers to QoL assessment. The category 'barriers to QoL assessment' consists of the following sub-categories: 1) Focus on tasks; 2) Time limitation; and 3) Fragmentation.

1) Focus on tasks

One underlying barrier influencing nurses' assessment of patients' QoL and particularly in oncology wards is that nurses focus on other tasks:

Quality of life is ultimate for everybody. I think it is very important. If we do not do it it's because we concentrate on what we have to do. (Nurse 3)

I think the nurses were very task oriented. CNC going up the hierarchy would sometimes get more involved in quality of life issues but not in a great depth. (Patient 3)

There's a whole culture in nursing that still hasn't been addressed fully and it hangs over from the old days when everything was regimented and people had time frames in which to do things. So, often it's my needs as a nurse overrides your needs as a patient, so that I look good to my colleagues and the patient is thinking "I might be clean but I'm miserable". (Nurse 8)

Although nurses are too task-oriented the situation is different in the palliative area:

We [in the palliative area] have an orientation manual that says the patient is not to be woken for breakfast and mealtimes but things are done in the patient's time frame so that is quite different from the philosophy of an acute care ward. My nurses are able to say at the end of the day, 'I haven't done this patient's wash because they didn't want it. I've done everything else, teeth, incontinence pad etc.' and that is the level of patient care we strive for and I think, on the whole, we're pretty successful at it. (Nurse 8)

In the palliative setting, nurses' priorities should be on patients' needs and not just

completing their duties. Nurses are able to say that we did not do this task because the patient did not want it.

Summary

Here it can be seen that nurses have different tasks and they focus more on doing them rather than assessing patients' QoL thoroughly. Maybe the CNC has more time to explore QoL issues further. However, in the palliative area the situation is different where nurses are less task-oriented and priorities are devoted to patients' needs.

2) Time limitation

During the interviews many participants emphasised that nurses do not have enough time to thoroughly assess patients' QoL. This is evident in the following extracts:

Never, never enough time to build as good a rapport as we would like...we have time limited, we have very limited time to sit and talk with patients. (Nurse 2)

They are very busy people, this morning is very quiet but sometime they are extremely busy. They do not have time to sit or stand here and ask me how are you keeping...I think they do extremely good job under these circumstances. (Patient 2)

Nurse 2 explicitly expressed how time limitations influenced nurses' communication in the oncology wards. This matter can also be seen during the interview with Patient 2 in which he expressed the view that nurses are generally very busy.

The degree of time limitation varies across inpatient oncology wards and outpatient chemotherapy units:

In outpatients because you focused on that patient for that period of time, that is why you give them your all, because you are allocated for that patient that you look after them, this is what is happening whereas in inpatients you have 5-6 patients, to try to do everything done for them, there is not enough time. (Nurse 4)

In the above comment, Nurse 4 said that nurses in outpatient chemotherapy units have more time to spend with one patient compared with inpatient nurses. This can elaborate further on the significant results of the first phase as to why outpatient

chemotherapy nurses have a better understanding of patients' QoL compared with those nurses working in inpatient wards. Other reasons why nurses in outpatients' chemotherapy units have a better understanding of patients' QoL can be seen on pages 174 and 180.

Even though time constraints are a problem, how nurses use their allocated time needs to be considered. This can be seen, for example, in the following extract from a nurse's comment in the palliative care area:

As a manager, yes, I have enough time the way the staff is allocated. In an ideal world, no. The psychosocial assessment is very important and it takes time...The danger we get into health care with and bureaucracy is there is a group who, even if they had extra time, would not spend it with a patient but at the desk. By spending more time with patients they can only benefit. (Nurse 8)

From such comments it can be stated that health care professionals may be using their allocated time ineffectively. One reason for this might be the bureaucracy and demand to follow procedures in the health care system.

Summary

Time limitation is another important barrier that influences nurses' assessment of patients' QoL. However, in outpatient chemotherapy units the situation is rather different because nurses there may spend more time with patients. Moreover, how nurses use their hours more effectively is also a matter that needs to be taken into consideration.

3) Fragmentation

Fragmentation or discontinuity works as a barrier against health care professionals wanting to assess patients' QoL:

The way that our health system is at this moment...inpatient care, hospice care, community care. They are fragmented. There is not a lot of crossing of the boundaries, and even say for palliative care, they used to have palliative care teams and they would cross these boundaries, they look at the patient in the community, when the patient comes to the hospital the same nurse will come and see them in the hospital, but it does not happen any more; either there is a community care nurse and hospital nurses. I think we can get a better idea about patients' quality of

life if there is some crossing of boundaries but it has to be made in the professional capacity. (Nurse 9)

It [the health system] was very fragmented. I think care should be seamless. Information should be passed on. This is about seamless care, integrated care but I went from the surgeon, another hospital where I saw the oncologist and then the radiologist. It felt like they didn't talk to each other...The outcome is disenfranchisement. You feel alone and I know that my family were increasingly worried about me but because there was no one really to contact I was out on a limb. I wasn't supported. (Patient 3)

Here participants expressed that there is a fragmentation in the whole health care system. This mainly refers to the number of disciplines, each of which has its own boundary and ways of doing things. This might prevent health care professionals from providing a seamless or integrated care system.

This fragmentation can also be seen more specifically in the nursing system:

I was in a breast cancer ward. The assessment they did on clients when they came in was...very brief, basically medical, a little bit of quality of life stuff, then it was seeing the social worker, the physiotherapist or the psychologist's job to deal with inherent issues that may come up during the treatment. At discharge there was a discharge plan but it was again handed over to a discharge planning nurse. (Patient 3)

The patient cited above expressed her idea about fragmentation by pointing out that her assessment was conducted by different people. It implies that she expected her assessment by nurses to be better integrated rather than being shared around by many health care professionals. The fragmentation also varies across inpatient and outpatient wards:

[In outpatient chemotherapy units] you have more time to spend with them [patients] and you see them in a more regular basis, whereas in the wards you might see them once and then you move around different patients, even if they are for a month you can only look after them once. It is very small contact, continuity of care definitely. (Nurse 5)

In inpatient wards the care received might be more fragmented compared with outpatient chemotherapy units. This again elaborates the significant result of the first phase regarding why nurses in outpatient chemotherapy units may have a better understanding of patients' QoL compared with inpatient nurses. Other reasons for such a difference can be seen in pages 174 and 178.

Summary

Fragmentation in the health care system might prevent patients from receiving a seamless or an integrated care, such as in the nursing system. Discontinuity of care might be seen more in inpatient wards compared with outpatient chemotherapy units.

Conclusion for the category: Barriers to QoL assessment

As well as facilitators to QoL assessment, there are some issues that make QoL assessment difficult to impossible. Nurses have different tasks and may not have enough time to thoroughly assess patients' QoL. Fragmentation exists in the health care system generally and in the nursing system in particular, and these can work against nurses who want to assess their patients' QoL more thoroughly.

Conclusion

Interpretive aspects of this research study found six major categories that can better portray why cancer patients and nurses differ in their perceptions about QoL. These categories consist of: QoL aspects; QoL meanings; Cues-based QoL assessment; Purpose-based QoL assessment; Facilitators of QoL assessment, and Barriers to QoL assessment.

Each of these categories consists of sub-categories. Some examples from the data have been added to help readers to understand the sub-categories and their characteristics. This might also shed light for readers to understand how the conceptualisations have been made. These categories are briefly reviewed below.

QoL was found in this research study to be connected to a whole range of life aspects such as physical, psychological, spiritual, social interactions, and environmental factors. Participants interpreted this concept in their own way to broadly include happiness, enjoyment, satisfaction, and having choice in life. In order to understand the QoL experiences of cancer patients in oncology wards, nurses currently are doing a cues-based QoL assessment in which they pick up on cues that they individually think are salient to patients' QoL. These assessments are mainly focused on the physical aspects and more experienced nurses can assess these cues better. This kind

of assessment is tainted by uncertainty and it cannot provide nurses with a fully holistic picture of the patient's condition.

However, the situation to some extent varies in the palliative area in which nurses are doing a purpose-based QoL assessment in which nurses use QoL tools and guidelines as well as picking up on cues. In outpatient chemotherapy units nurses also do a cues-based QoL assessment but this will be done in a broader way compared with the inpatient oncology wards. QoL assessment is also hindered by nurses' focus on tasks, time constraints, and fragmentation in the health care system generally and in the nursing system in particular.

Participants also suggested some points that will be useful for nurses to develop their understanding of patients' QoL. Relationship and rapport are very important variables. Such a rapport starts with a real interest and enthusiasm and proceeds in an open and non-judgmental way. Moreover, this relationship needs to take into consideration patients' characteristics and be conducted in a comprehensive way and include patients' families and other health care professionals. Formal QoL assessment by novice nurses using tools or guidelines is recommended. In the meantime, interviewing patients in a less formal way can also be used with a focus on all aspects when nurses communicate with patients. Nurses might use some other measures such as pain measurement alone or a complementary approach involving other measures to obtain a better idea of an individual patient's QoL. Training nurses and other health care professionals can facilitate nurses' understanding of patients' QoL.

In the next chapter, which discusses the findings, an attempt is made to connect all the relevant data arising from the two phases of this study and answer the research questions.

CHAPTER EIGHT: DISCUSSION OF THE RESULTS

Introduction

In Chapter Five, results of the first phase were presented. The outcomes of the first phase were empirical in which patients' and nurses' perceptions about cancer patients' QoL were compared with each other using different statistical tests. In Chapter Seven, outcomes of the second phase were explored using an interpretive approach. Outcomes of this phase were presented in six major categories and supported by using quotes from the actual data.

In this chapter information arising from the two research phases will be compared and discussed in order to answer the research questions with regard to nurses' perceptions of cancer patients' QoL. However, the discussion of the results needs to be seen in the framework of the limitations of the research study which are provided at the end of the chapter.

Presenting the results of a mixed research study is challenging (Cox 2003). One way that was chosen here is to present the basic results of each phase of the study in a separate chapter and then combine the overall discussion into a singular chapter organised under the headings of the research questions (Thomas 2000). The use of one discussion chapter will help the reader to identify the answers from the results when both quantitative and qualitative results are examined together. Each question is introduced and discussions appear in the subsections regarding 'key findings' by referring to the research phase outcomes and by drawing support from the relevant literature.

'The level of agreement between patients and nurses about cancer patients' QoL' and 'nurses' understanding of cancer patients' QoL' are two terms which are used to present empirical and interpretive findings with regard to similarities and differences of QoL perception between cancer patients and nurses in the following sections.

Question One: What differences and/or similarities are there between cancer patients' and nurses' perceptions of cancer patients' QoL?

This question is answered by considering findings of the first phase. However, empirical findings of the first phase are also supported by categories found in the second phase. Three trends were found as a result of this inquiry: (a) at the individual level (comparing each patient-nurse score) the level of agreement ranges from poor in the social relationship domains up to moderate in the physical domain; (b) at the group level (comparing nurses' scores as a group with patients' scores as a group) nurses' mean domain scores are similar with those of patients in physical and psychological domains; and (c) at the group level (comparing nurses' scores as a group with patients' scores as a group) patients' scores were significantly higher than those of nurses in the social relationship and environmental domains. In other words, nurses underestimated cancer patients' QoL in the social relationship and environmental domains. These findings will be considered in turn in following sections.

(a) At the individual level, the level of agreement ranges from poor in the social relationship domain up to moderate in the physical domain

Despite a variety of statistical tests that can assess the level of agreement at the individual level (Altman & Bland 1983; Lobchuk & Degner 2002; Sneeuw et al. 1998), there is little consensus about what statistical methods are most suitable to analyse rater agreement (Uebersax 2003). In these situations using more than two statistical tests is usually recommended for research studies (Lampic & Sjoden 2000). Therefore, Pearson correlation (r) and Intraclass Correlation Coefficient correlation (ICC), the proportion of exact agreement, and the Bland-Altman test were used to assess the level of agreement between patients and their nurses.

Results of r and ICC identified moderate, poor, poor, and fair agreement between patients and their nurses in the physical, psychological, social relationship, and environmental QoL domains, respectively. In other words, the results showed no substantial agreement between each patient and nurse ratings about a cancer patient's QoL. These findings are similar to general trends found in many other research studies where the level of agreement between patients and proxies (nurses or others)

were assessed using QoL tools other than the WHOQoL questionnaires (Larsson, von Essen & Sjoden 1998; Molzahn, Northcott & Dossetor 1997; Wilson et al. 2000). The outcomes are also very similar to two other studies (Becchi et al. 2004; Herrman, Hawthorne & Thomas 2002) where WHOQoL questionnaires (WHOQoL-BREF or WHOQoL-100) were used but with non-cancer patient populations.

Herrman, Hawthorne and Thomas (2002) in their Australian study compared psychosis patients and their case managers as patients' proxies using a set of questionnaires including the WHOQoL-BREF questionnaire. Results identified that case managers' and patients' scores correlated moderately; correlations ranged from 0.31 in the social domain up to 0.47 in the physical domain. They concluded that a significant difference exists between patients and proxies. These outcomes are generally supported by another study conducted by Becchi et al. (2004) in which QoL of patients with schizophrenia was compared by proxies using the WHOQoL-100 questionnaire. Of the proxies, 52.7% were relatives whereas 47.3% were non-relatives (e.g. friends, social workers, and nurses). The outcomes of ICC ranged between 0.26 for the psychological area to 0.42 for the physical area, indicating a poor agreement between patients and proxies.

A comparison between the results of the above studies and the research project indicates that nurses had a better understanding of cancer patients' QoL in the physical domain. This was greater than agreement in the psychological, social relationship, and environmental domains. In order to better understand why nurses' perceptions about cancer patients' QoL vary across the QoL domains, a discussion of each domain based on QoL items that constitute each domain will follow in the next sections.

Physical domain

Items in the physical QoL domain consist of: pain; medical treatment; energy for everyday life; ability to get around; sleep; capacity for work; and daily living activities. Compared with other QoL items, these circumstances generally appeared to be more concrete, objective and related directly to the patients' clinical care or recovery program. Therefore, nurses can better understand what is going on in relation to these situations when they encounter patients in the clinical area.

'Energy for everyday life' (ICC=0.42%), for example, is one of those items that nurses had a better understanding of compared with other QoL items. Having energy for conducting daily living activities is generally an objective situation. Patients' having energy to conduct daily living activities can be assessed by nurses when they are working with patients, for example, giving their medication or serving their food. Such trends can generally be applied to other physical QoL items mentioned above.

Psychological domain

The psychological domain consists of items including enjoyment in life, having a meaningful life, ability to concentrate, accepting bodily appearance, satisfaction with one's self, and having negative feelings. The common thread amongst these items is their subjectivity. Without a deep level of communication, this is not an easy task for nurses, for example, to understand if life is really meaningful for patients (ICC=0.05) or if they have negative feelings (ICC=0.05).

Social relationship domain

Social relationship domain encompasses three items: having a sex life, having friends, and having personal relationships. The general trend dominating these items is their private nature. It is not surprising that nurses had a very low or poor understanding of how patients have received support from their friends (ICC=0.05). Nurses may not know how to ask patients about their sex life and unless a major issue exists in this area, it is not acceptable for nurses to query patients about it.

In the empirical phase of the research study, social relationship items also had the most missing data of all 26 items. This was the case not only for patients but particularly for nurses. This again suggests difficulty for nurses to estimate the patients' actual situation in these private aspects. As the social relationship domain heading suggests, these activities mainly refer to patients' situations when they are interacting with society. Without a good relationship and a thorough baseline assessment, it is less likely that nurses accurately understand patients' social situations.

Environmental domain

The environmental domain includes being safe in one's daily life; having a healthy

physical environment; having money to meet needs; information at hand; having the opportunity for leisure activities; one's own living place; having access to health services; and transport. These items also tend to be relatively subjective and private but less so than psychological and social relationship items. This is why empirical evidence generally rated nurses' understanding of the environmental QoL items better than psychological and social relationship items. For example, safety in daily living activities (ICC=0.14) and a healthy physical environment (ICC=0.19), at least partly, can be addressed by nurses. Nevertheless, there are still items like patients' conditions of living (ICC=0.05) that are very problematic for nurses to understand.

Altogether, empirical findings emphasised that nurses generally have a better understanding of the physical QoL items compared with other aspects. This was further supported by findings of the interpretive phase which found that nurses in oncology wards focus more on physical aspects. Consider the following extract obtained from a nurse interviewee on an oncology ward:

From the very beginning when you train to become a nurse, it is a physical thing to address all the way through, physical, physical, all the time. We deal a bit, with psychological. (Nurse 4)

The next measurement of the level of agreement between patients and nurses at the individual level, evaluated the proportion of the exact agreement between ratings of two parties. This test identified that in 35.5% of cases a similar response category had been chosen by both patients and nurses in the questionnaire. It means that, for example, in answering item one in the questionnaire, 35.5% of both patients and nurses chose the category 'satisfied' or 'very satisfied' for that item. This was not considered to represent a substantial agreement because it was below the acceptable level (60%) which was set for this study. Moreover, the decision was also made on the basis of other complementary tests conducted (r, ICC, and Bland-Altman test) and these confirmed each other. Other researchers may have their own interpretations of the results of the proportion of the exact agreement.

In a research study conducted by Sneeuw et al. (1999), the QoL of cancer patients was assessed and compared to the perspectives of significant others, physicians, and nurses using a QoL tool. Part of the outcomes identified that 41% of all comparisons

were in exact agreement. While the level of agreement was far from 60%, the authors concluded that “judgments made by significant others and professional caregivers about general aspects of cancer patients’ QoL are reasonably accurate” (Sneeuw et al. p.93). The authors explained that these interpretations were based on calculations of the proportion of approximate (global) agreement as well as the proportion of exact agreement. In calculating the proportion of approximate (global) agreement, when both patients’ and nurses’ responses differ from each other on the response scale by one category in either direction, differences can be interpreted as small. Only differences of more than one category are considered large. The proportion of approximate (global) agreement in Sneeuw’s study (1999) was 43% and in regard to outcomes of the exact agreement (41%), it was concluded that a reasonable level of agreement exists between patients and nurses.

Finally, in order to confirm the findings of correlations and the proportion of exact agreement, the Bland-Altman scatter plots were checked. This method is one of the most accurate ways of measuring the level of agreement in which difference between scores of two raters can be seen visually (Bland & Altman 1986). The scatter plots also confirmed around 6 out of 20 points (or around 30%) of difference between a patient’s QoL score and a nurse’s score in different domains. This difference also indicates that no substantial agreement exists between each patient and nurse about each cancer patient’s QoL.

Checking the Bland-Altman plots can also be helpful to identify whether the level of agreement is related to the patients’ level of QoL or not. This is an important point because those patients for whom outcomes of the proxy research studies may be vital, usually cannot take part due to their poor health status (non-respondent participants). For example, those patients at an advanced level or those who are dying from cancer cannot participate. Research studies cannot confirm if an agreement at the moderate level between patients and nurses, for instance, can be generalised exactly to this non-respondent group of patients.

Having checked the plots in this study, no obvious pattern was identified that can imply that the level of agreement between patients and nurses about cancer patients’ QoL was better for cancer patients with a specific level of QoL. It was therefore

concluded that the results of this study that no substantial agreement exists between cancer patients and nurses about cancer patients' QoL may not be generalised to non-respondent patients. These results differ from a study by Sneeuw et al. (1998) who reported more scatter (poorer agreement) at moderate levels of patient' QoL, with less scatter at either extreme. In other words, in Sneeuw et al.'s study, proxies had a better understanding of QoL of those patients with either higher or lower rating of their QoL compared with those in the middle range.

The empirical outcomes of this study indicate that at the individual level each nurse differs in their perceptions of each patient's QoL. This is a new finding in Australia indicating that cancer patients and their nurses differ in their perceptions. Such findings are also found in the interpretive phase of this study. Generally, nurses had difficulty defining their patients' QoL and were uncertain about the QoL assessment they conducted. Consider, for example, the following statement:

You probably do not assess it [quality of life] so much, you probably subconsciously assess quality of life for patients ... your assessment of quality of life might be a general statement of your perception for that person that would be completely wrong. (Nurse 3)

When a nurse differs in his/her perceptions of each patient's QoL, it is most likely that their decisions do not meet a patient's needs. Conversely, when a nurse has a reasonable understanding of a cancer patient's QoL, their decision-making is relevant to a patient's needs. In turn, the nursing care they will provide may improve patients' QoL and care can be more individualised (King 2006).

Even though each nurse differs in their perceptions of each patient's QoL at the individual level, a comparison was also made between the QoL mean domain scores of patients and nurses using t-test. The aim was to understand how patients differ from nurses at the group level. This comparison revealed two important points. Firstly, nurses' mean domain scores are similar to those of patients in the physical and psychological aspects of patients' QoL. Secondly, nurses underestimated patients' QoL in the social relationship and environmental domains. These important issues are discussed below.

(b) At the group level, nurses' mean domain scores are similar to those of patients in physical and psychological domains

One important point arising from comparing the means of the two groups is that in the physical and psychological domains, the QoL mean domain scores of nurses were very close to those of their patients. In clinical research trials, the similarity of QoL mean domain scores of patients with those of proxies is more important than individual scores and may be useful in substitution of missing data arising from non-respondent patients (Sneeuw et al. 1997b; Sneeuw et al. 1999; Tripoliti et al. 2007).

The reason for this is that in such research studies groups of patients are compared with each other rather than as individuals. If comparison between patients' and nurses' scores only is made on the basis of mean scores, empirical findings of the research study indicates that QoL mean domain scores of patients are close to those of patients in physical and psychological domains. So researchers could substitute QoL mean scores of nurses with those of patients, of course with the necessary caution, in order to manage missing data in their research studies. For example, a researcher may want to assess the effect of a new chemotherapy regimen on survival rate and the QoL of a group of cancer patients. Because some patients are in an advanced stage of cancer, they cannot fill out the QoL questionnaire. Due to similarity between nurses' scores and patients' scores in physical and psychological domains, researchers may ask nurses who know the patients well to act as patients' proxies in this situation. However, the substitution of patients' scores with nurses' scores might be even more accurate in the physical domain because not only the means of the two groups are the same but also the correlations (r and ICC) are stronger in the physical domain compared with the psychological domain (0.48 versus 0.19).

Although QoL mean domain scores of patients were similar with those of nurses as patients' proxies in the physical and psychological domains, the comparison between QoL mean domain scores of patients with those of nurses in the social relationship and environmental domains had different outcomes. This finding is discussed next.

(c) At the group level, nurses underestimated patients' QoL in the social relationship and environmental domains

Another important point emerging from comparing means of two groups (patients and nurses) is that patients' QoL domain scores were significantly higher than that of nurses in the social relationship and environmental domains. In other words, nurses significantly underestimated patients' QoL in the social relationship and environmental domains. This has been reported in many other studies in which proxies reported lower levels of QoL than patients themselves (Pierre et al. 1998; Sprangers & Aaronson 1992; Wilson et al. 2000). Because nurses did not have a clear idea about the social relationship and environmental domains, they underestimated patients' QoL. There are several underlying reasons why nurses may have underestimated cancer patients' QoL.

The first reason refers to differences between patients' and nurses' expectations, standards, and goals. There is more evidence now that cancer patients go through a process named 'response shift' during which they change their internal standards and expectations (Breetvelt & Van Dam 1991; Schwartz & Sprangers 2002). Through this process they adapt themselves to a stressful situation (King et al. 1995). This does not mean that they have no issues at all but they can cope and manage issues to the level that satisfies them. This can lead to re-evaluation and what they deem as a reasonable level of QoL.

In contrast, staff may not understand clearly such internal changes (King et al. 1995; Molzahn, Northcott & Dossetor 1997; Tamim, McCusker & Dendukuri 2002). They may judge patients' QoL based on their own expectations, standards, and goals. Nurses may also compare a patient's circumstances with other patients and make a judgment as to which ones would have more problems. Even though comparing individuals' QoL with each other as a way to assess one's QoL might work occasionally, this approach is generally problematic because each person is different in terms of their expectations and goals.

The second reason for nurses' underestimations of cancer patients' QoL relates to differences between patients' and nurses' knowledge and experiences. Staff generally have more information about the cancer and its process than the patients. During their

relationship with cancer patients, nurses might develop a perception that cancer is a devastating problem that dominates all aspects of patients' lives. They might see more people dying from cancer rather than surviving (Lampic et al. 1996). This may lead to more negative and pessimistic thoughts in the staff, which are also labelled as a 'clinician's illusion' (Breetvelt & Van Dam 1991; Larsson, von Essen & Sjoden 1998). On the other hand, cancer patients may not be given as much detailed information about their prognosis by health care professionals. This might lead to the outcome that patients generally have more positive views about their lives and their QoL after being diagnosed with cancer compared with health care professionals.

The third reason for such underestimations is for nurses to "reassure themselves that their value systems are still meaningful: a phenomenon called the requirement of mourning" (Jennings & Muhlenkamp 1981, p.485). Consider, for example, the following extract that describes the requirement of mourning:

When a person has a need to safeguard his values, he will either (1) insist that the person he considers unfortunate is suffering (even when he seems not to be suffering) or (2) devalue the unfortunate person because he ought to suffer and does not. This implies that the devaluer wants the unfortunate person to suffer. He wants him to suffer as a sign that the values denied the unfortunate person are still worthy and important and good. Especially if this security depends upon maintaining these values will he insist that the unfortunate person admit his suffering. (Wright 1960, cited in Jennings & Muhlenkamp 1981, p. 1981)

In this study, for example, nurses underestimated patients' QoL in the social relationship and environmental domains. Nurses implied that they are actually aware of how these domains are still important for patients even though they do not have enough information about these domains.

Finally, patients might rate their own QoL better than the actual situation in order to have a better sense of well-being. This is named 'self-deception' during which patients try to retain a belief in order to feel more comfortable and satisfied even though they may know that it is not true (de Sousa 1998, cited in Larsson, von Essen & Sjoden 1998). This might work as a coping mechanism for patients, particularly at difficult stages. For example, when the patients' QoL has significantly deteriorated following hearing the cancer diagnosis, this strategy might be used by patients.

Patients may also overrate their own QoL in order to please health care professionals (Schipper & Levitt 1985). Health care professionals may feel better when they assume that their clients generally are satisfied with the kind of treatment or care they are receiving. Then patients might receive more attention from the health care professionals (Westbrook & Nordholm 1986, cited in Lampic et al. 1996). Patients might also overrate their QoL because they do not want to be considered a burden (Rubenstein et al. 1984). They may want to be perceived as someone who is happy and coping.

Therefore, different reasons are involved in nurses' underestimation of patients' QoL. Whatever the reason, these underestimations by nurses have negative consequences for patients. Nurses are usually with the patients from the beginning of their diagnosis to the end of their lives. Patients may try to adapt themselves to the cancer, and underestimations in QoL by nurses might postpone this process. So this impacts on nurses' therapeutic relationships with patients and their role may not be as supportive as it may otherwise be (King 2006a).

It can be concluded from the outcomes of this part that often individual nurses will differ in their perceptions about each cancer patients' QoL. However, nurses as a group have a reasonable understanding of the physical and psychological aspects of cancer patients' QoL, but they tend to downgrade patients' QoL in the social relationship and environmental domains. This is also portrayed by nurses in the interpretive phase:

The quality of life of the patient was not what I thought. They seemed quite happy, no issues. Even though they lived alone, on the pension, did not have any friends, be in pain, cannot work, but they did not seem bothered by that. They thought that their lives are meaningful. (Nurse 5)

Although the above general trends were identified about the level of agreement, different conditions or variables can influence variations in patients' and nurses' perceptions of cancer patients' QoL. These situations are explained in the following section to answer the second question.

Question Two: Why do differences and/or similarities exist between cancer patients' and nurses' perceptions about cancer patients' QoL?

Why patients and nurses differ in their perceptions of cancer patients' QoL, is mainly answered by considering categories that were found in the second phase of this study. However, interpretive outcomes are also supported by some findings in the first phase. The reasons for the difference in perceptions are discussed in the following sections in relationship to: (a) Emergence of spirituality, (b) How nurses assess cancer patients' QoL, (c) Barriers to QoL assessment, and (d) Patients' and nurses' clinical and demographic characteristics.

(a) Emergence of spirituality

Even though most of the QoL domains found in this research study are the same as those introduced by the WHO and applied in the construction of the WHOQoL-BREF questionnaire (such as physical, psychological, social relationship, and environmental factors), participants in the interpretive phase emphasised that spirituality is an important issue. In the WHOQoL-100 questionnaire, spirituality is a separate domain. Spirituality was modified in the construction of the WHOQoL BREF questionnaire (Department of Psychiatry of the University of Melbourne 2000) and is measured mainly by the item 'having a meaningful life' under the psychological domain. It is interesting that participants highlighted spirituality as an important aspect of QoL. Other researchers (Hinds & King 2003; Taylor 2003) also proposed that spirituality is a significant element of QoL and that it is important to measure it in great depth.

Spirituality may focus on a belief in, or a relationship with, a higher power which gives purpose, meaning, and direction to life and may include religion (Baker 2003). Even though people might conflate spirituality with religiosity, spirituality is a broader concept that deals with both religious and non-religious thoughts and behaviours (Holley 2007). Due to the importance of spirituality in this thesis, it will be discussed in the following sections in more detail along with outcomes of the second phase of the research study.

Religious aspects of spirituality

Religiosity is an important aspect of spirituality. Taylor (2003) explains that religiosity is a narrower concept than spirituality and shapes the individuals' worldview to answer questions related to the meaning of life. Participants in this research study also highlighted that issues related to the meaning of life and what will happen after death are quite important. Consider, for instance, the following remark that was put forward by a nurse who took part in the second phase:

The spiritual needs to come into it [quality of life]. So they [patients] will talk a lot about existential stuff, things like death and dying and how patients actually want that to happen, whether they actually believe in certain things that might happen after they die. (Nurse 9)

This study did not aim to explore how religiosity might be beneficial for cancer patients. However, an ample amount of literature exists indicating how religious thoughts and beliefs might help people in their lives and make them happier. For example, from the literature it can be seen that a relationship and connection with God is an important source of strength for many people (Burkhardt 1994) particularly in more stressful situations (Maton 1989) such as when individuals experience cancer (Jenkins & Pargament 1988). Gall (2004) conducted an empirical research study involving thirty-four men with prostate cancer to explore the relationship with God and its influence on QoL issues. It was identified that relationship with God is a significant predictor of role, emotional, and social functioning for these participants. For example, those patients who considered that prostate cancer was in any way related to God perceived that they have a greater control over the illness and its management. They also viewed God with a variety of positive characteristics which would support them particularly in stressful situations. In another study involving a group of breast cancer patients, religion was identified as a very important factor in coping with breast cancer (Johnson & Spilka 1991).

Religious texts argue that the connection with God is very important and highly related to individuals' fulfilment. For example, in Islamic literature a number of Islamic Persian philosophers like Ibn Seena (commonly known in English by his Latinised name Avicenna) (cited in Morewedge 1973) argue that all means and states of happiness and satisfaction are helping human beings reach God and individuals

find a true sense of happiness in connection with God (Avicenna 2005). This idea can further be seen in the following extracts from the Holy Quran:

[O, People]Be sure that real tranquillity for the hearts rests in Allah's Remembrance [both in thought and action] (Quran, 13:28)

Those who avoided worshipping false deities and turned to Allah, seeking his forgiveness, for them will be glad-tidings [happiness], so [O, Messenger] give the good news to my obedient worshippers! (Quran 39:17)

[And the Devoted Friends of Allah are] those who believe in the oneness of Allah and constantly act piously. For them is glad-tidings [happiness] in the life of this world and in the Hereafter. No change can be there in the words and promises of Allah; this is indeed a great achievement. (Quran 10:63-64) (Saffarzadeh 2001)

These verses from the Holy Quran, show that God (Allah) guarantees happiness, now and forever, for God's believers. We learn from the Holy Quran that happiness is a quality of the soul. A person who attains all materialistic desires such as money, power, and reputation may end up being an unhappy person. Other religions and Western philosophers also discussed similar issues. For example, Western philosophers like Aristotle (cited in McKeon 1947) long ago explained that:

...the question is asked, whether happiness is to acquired by learning or by habituation or some sort of training, or comes in virtue of some divine providence or again by chance. Now if there is any gift of the gods to men, it is reasonable that happiness should be god-given and most surely god-given of all human things inasmuch as it is the best. But this question would perhaps be more appropriate to another inquiry; happiness seems, however, even if it is not god-sent but comes as a result of virtue and some process of learning or training, to be among the most god-like things; for that which is the prize and end of virtue seems to be the best thing in the world, and something godlike and blessed. (Aristotle cited in McKeon 1947, p. 322)

Similar issues also pointed out by participants who took part in this research study:

I guess in Western society there is often some doubt that money can buy a lot of things but it cannot buy good health and if you have a diagnosis that has a poor prognostic outcome and you are dying. (Nurse 7)

Participants in the second phase of the research study emphasise that people value health and relationships and the spiritual life and doubt that material riches are important to happiness or able to solve all problems. Accordingly, one important aspect of spirituality for many people is that religiosity needs to be considered in a

QoL assessment. But non-religious aspects of spirituality are also important and worthy of discussion as explained below.

Non-religious aspects of spirituality

Spirituality is not limited only to religious beliefs and thoughts (Mahlungulu & Uys 2004). Mahoney and Graci (1999) conducted a research study to explore the possible differences existing between religiosity and spirituality. Two groups of experts in the fields of death studies and spiritual studies responded to 54 statements in a questionnaire. One main finding of the research study was that both groups identified themselves to be spiritual but not religious. The main categories related to spirituality explored in this research study by both groups were charity, community or connectedness, compassion, forgiveness, hope, meaning and mortality.

The above findings relating to the broader aspects of spirituality were also put forward by Taylor (2003), specifically for cancer patients. She proposed several positive explanations for individuals who experience cancer. Cancer patients might perceive changes in themselves (e.g. development of new skills and confidence), changes in relationships with other people (e.g. more receptivity, sensitivity, and compassion for others) and changes in their philosophy of life (e.g. more spiritual awareness). Such changes might allow cancer patients to conclude “cancer was the best thing that happened to me” or “cancer made me a better person” (p.107). Such comments are consistent with the outcomes of other studies arguing that cancer helps people to have a greater understanding of their lives, develop a greater appreciation of daily activities, or understand the importance of their supportive family and reliable friends (Hinds & King 2003; McGrath 2004).

Similar issues related to spirituality were also remarked on by some participants in the second phase but in a slightly different language:

I think there are many aspects to quality of life in everyday life that you take them for granted. (Nurse 7)

Participants used the language regarding the ‘taken-for-granted aspects’ of QoL to show that they had stopped to reflect on the meaning of life. In other words, participants highlighted that many of them live without a deep consideration as to

what really satisfies them. On occasions when individuals' QoL is challenged, for example, when they have a life-threatening disease like cancer, they might then think deeply about issues that contribute to their QoL. Generally, individuals may think about their health when they are ill or their valuable lives when death is approaching.

One main reason for differences existing between patients' and nurses' perceptions about cancer patients' QoL may be linked to different aspects that influence individuals' QoL. For example, spirituality is an important issue for cancer patients that may not be assessed in great depth using a QoL tool or even an interview. How nurses actually assess cancer patients' QoL is discussed further in the following section.

(b) How do nurses assess cancer patients' QoL?

Another underlying reason for differences between cancer patients' and nurses' perceptions about cancer patients' QoL can be seen in how nurses actually assess the QoL. The level of agreement between cancer patients' and nurses' perceptions about cancer patients' QoL in the first phase of the research study was assessed using the WHOQoL-BREF questionnaire. Such tools have been structured to measure QoL more rigorously across specific domains or dimensions. However, categories identified in the second phase indicated that nurses' assessments of patients' QoL in specialist and non-specialist oncology wards (the major sampling environment) were mainly conducted informally when nurses communicated with patients. Findings of the interpretive phase also indicated that such assessments focused on the physical aspects.

Findings of the study are similar to a research study conducted by King et al. (2002) that explored QoL of cancer patients from the perspective of oncology nurses. In this research study a focus group was used involving 24 oncology nurses in the United States of America. When the interviews were transcribed and after coding, five main categories and a conceptual model were identified. The major outcome of the study was that nurses' assessments of patients' QoL depended on the strength of their relationships and nurses with a better relationship with patients could better assess cancer patients' QoL.

This does not indicate that a QoL assessment achieved by nurses picking up on cues is not an appropriate method of assessment. In fact, even though nurses do not use formal QoL assessment language they do focus on and assess QoL (King 2006b). In research conducted by Fitch (1998), 25 oncology nurses were interviewed in order to explore their perceptions, values and behaviours in relation to understanding QoL. The major categories explored in this study were: defining QoL; assessment of QoL; the role of nurses in quality of life; conflicts surrounding QoL; and factors that help or hinder that understanding. The study concluded that while nurses may not use the language of QoL, they are dealing with QoL issues. Another point highlighted in this research was that the ability of nurses to achieve QoL assessment goals and thereby build a close relationship with patients.

The research concludes that nurses generally appear to assess the QoL of patients more informally during interactions with them rather than through the application of QoL tools. As an outcome of the second phase, it was noted that the state of QoL might change over time and that is relatively dependent on individual priorities and feelings. QoL tools may not be able to identify these changes unless they are performed longitudinally and frequently, and often this is not practical. Therefore, the best way for nurses to assess patient QoL is to improve their rapport and ability to develop a relationship. However, the research identified a notable exception in that less experienced junior nurses might have some interest in using QoL tools for more formal assessment of patient QoL as guidelines while they develop better skills and gain additional experience of assessing patients in their care. Nurses can use some QoL tools as trigger questions to initiate conversation about patients' QoL. Several publications (Caton & Klemm 2006; Sherman & Dyess 2007) addressed the importance of guidelines in dealing with issues that novice nurses face in clinical practice.

In Benner's seminal work, *From Novice to Expert* (1984, pp.13-34), nursing proficiency was defined using five levels. These levels consist of novice, advanced beginner, competent, proficient, and expert. Novice nurses generally rely on rules, guidelines, and standards rather than experience based knowledge. Even though discussions have occurred regarding Benner's idea over the years, it is still generally accepted that experience is an important issue in the clinical area in order to provide

better care. An interpretive research study by Taylor (2002) observed how novice and expert nurses access different sources of information before meeting a patient. One main finding of this research study was that expert nurses were more likely to access multiple sources of information than novices. Novice nurses in this research study also commented that they base their care on previous contacts with a patient. Taylor remarked that novice nurses who rely heavily on previous contacts must do the next step, and this is consistent with the classification of novice-expert nurses (Benner 1984).

This thesis found that differences existing between cancer patients' and nurses' perceptions about cancer patients' QoL are strongly related to poor relationship and rapport between patients and nurses. However, there are some barriers that may hinder nurses establishing a good relationship with patients and thoroughly assessing patients' QoL.

(c) Barriers to QoL assessment

Interpretive findings of this study found that there are some important barriers that prevent nurses from doing a thorough QoL assessment. One of these barriers is time limitation or constraint. The interpretive phase of the research study found that nurses generally have limited time to do a thorough QoL assessment. Interpretive findings were further supported by empirical findings of the first phase, indicating that nurses generally spent around 2.5 hours per shift with patients. A thorough QoL assessment is time-consuming and such time limitations can prevent nurses from becoming familiar with all aspects of patients' QoL (Frost, Brueggen & Mangan 1997).

Mohan et al. (2005) conducted a research study in two hospitals in the western suburbs of Sydney. The aim was to describe the experience of nurses caring for cancer patients in non-specialist wards using an interpretive approach. Six major categories were explored and one main category was lack of time. The researchers explained how time limitation compromised the quality of care delivered to cancer patients and their families. Nurses in this study generally wished to spend more time with patients and due to time limitations they felt frustrated and helpless. Even though time limitation is a problem for QoL assessment, this study also highlighted another

issue about the appropriate use of time. For example, like many other research studies (Nasrabadi, Emami & Yekta 2003; van der Walt & Swartz 2002) this thesis suggests that nurses working in a time limited environment may concentrate on the specific tasks they need to do. If nurses have extra time left after completing essential patient care tasks, they may spend time on activities such as talking with patients and developing rapport.

As found in the second phase, fragmentation or discontinuity exists in the health system in general and specifically in the nursing system, and this can also work against nurses who want to establish a better relationship with patients and thoroughly assess their QoL. Relational discontinuity might emerge from infrequent contacts between patients and health care professionals or when quality of communication is poor (Dumont, Dumont & Turgeon 2005) and may lead to feelings of isolation and dissatisfaction in patients and their families (Hearn & Higginson 1998). This emerged during the second phase. Consider, for example, the following remark by one patient interviewee:

It [the health system] was very fragmented...The outcome is disenfranchisement. You feel alone and I know that my family were increasingly worried about me but because there was no one really to contact, I was out on a limb. I wasn't supported. (Patient 3)

Therefore, establishing a good relationship and rapport with patients and conducting better QoL assessment is also linked to managing problems nurses face such as time limitation and relational discontinuity. There are also some clinical and demographic variables concerning patients and nurses that can influence nurses' understanding of cancer patients' QoL.

(d) Patients' and nurses' clinical and demographic characteristics

Another aim of the study was to identify if any clinical and demographic characteristics (such as patients' and nurses' age, gender, marital status, level of education, patient's current treatment, treatment setting, nurse's QoL, educational level) may influence the level of agreement between patients and nurses about cancer patients' QoL. In the first phase clinical and demographic variables were collected using patients' and nurses' characteristics forms and analysed using Bivariate and

Multivariate analysis.

A number of variables were identified associated with the level of agreement between patients and nurses at the Bivariate level. Bivariate analysis does not take into account the interrelations existing amongst the variables themselves. So it might lead to misleading judgments. For example, at the Bivariate level it was identified that in the environmental domain, the level of agreement between patients and nurses decreased when nurses have lower levels of QoL or when patients are treated in inpatient departments. Using Multivariate analysis, only nurses' QoL was identified as a significant predictor of the level of agreement in the environmental QoL domain. During a similar process, Multivariate analysis showed that in the psychological and social relationship domains, the level of agreement is better when patients are treated in outpatient departments. In the physical domain, none of the variables was found to be a significant predictor of the level of agreement using Multivariate analysis. However, at the Bivariate level both the variables nurse clinical experience and nurse clinical experience with cancer patients were significant.

The Multivariate analysis also showed that in each domain patients' and nurses' clinical and demographic variables together explained around 5% of variance in differences between patient-nurse scores. In other words, clinical and demographic variables may not be considered significant predictors of the level of agreement at the Multivariate level. In a study by Sneeuw (1998) several demographic and clinical variables of the patients and their significant others were associated with the level of agreement using Multivariate analysis. However, they explained less than 15% of the variance in patient-proxy differences which was considered as a trivial proportion. Given the fact that only 5% of variance in differences between patient-nurse scores was explained by clinical and demographic variables at the Multivariate level, it was necessary to investigate other clinical and demographic variables influencing the level of agreement in the interpretive phase. Moreover, the interpretive phase provided an opportunity to elaborate on some significant findings of the first phase.

In the interpretive phase, patients' and nurses' clinical and demographic variables of the first phase again were discussed with participants. In the meantime participants were also asked to discuss any other variables which might influence nurses'

understanding of cancer patients' QoL. In general, in the interpretive phase three variables (nurses' clinical experience with cancer patients, treatment setting, and nurses' QoL) were found to be salient to nurses' understanding of patients' QoL (the level of agreement).

Factors influencing nurses' understanding of cancer patients' QoL (the level of agreement) in both phases of the research study can be seen in **Table 8-1**.

Table 8-1: Three factors influencing the level of agreement between patients and nurses about cancer patients' QoL

Factors	Questionnaire survey findings		Interpretive findings
	Bivariate	Multivariate	
Nurses' clinical experience with cancer patients	√	-	√
Treatment setting (Inpatients vs. Outpatients)	√	√	√
Nurses' QoL	√	√	√

√: Significant factors

The above prominent factors salient to nurses' understanding of patients' QoL are discussed further in following sections.

Nurses' clinical experience with cancer patients

One important new finding in the first phase of the research study at the Bivariate level was that nurses with more clinical experience, particularly with cancer patients, had a better understanding of patients' physical and environmental QoL domain. Participants in the second phase also highlighted that nurses with some sort of experience may have a better understanding of cancer patients' QoL. Participants in the interpretive phase elaborated on possible reasons why more experienced nurses might better understand patients' QoL.

Participants reasoned that more experienced nurses possibly have developed better assessment and communication skills because they have communicated with a wider range of patients and can understand differences existing among patients in terms of their QoL. They might also have developed greater proficiency in their workplace and can manage a wide variety of tasks. Taylor (2002) stated that a highly developed level

of skill is recognised as essential in all expert practice. Even though education is an important factor to improve nurses' knowledge and skills, such nurses' qualities are often related to years of experience (Caton & Klemm 2006).

Participants who took part in the second phase of the study also commented that more experienced nurses can pick up more on 'little things' or cues as a way to assess patients' QoL. More experienced nurses themselves highlighted that they might assess patients' QoL by their 'gut feeling'. Literature is supportive of this notion that experienced nurses often use intuition or gut feelings to guide them in the clinical area even though sometimes they may not realise how their knowledge and practice have been influenced by such intuition (Hams 2000; Poh 1997). For example, Benner (1984, pp.13-34) explained that expert nurses do not rely only on rules and guidelines to connect their understanding of the situation to an appropriate action. They have an intuitive grasp of the situation and can concentrate on the problem without having to consider a large range of unproductive alternative diagnoses and solutions. When such nurses are asked, for example, why they acted in such a way, they may reply, "because it looked good". Ruth-Sahd (1993) commented that emphasising intuition does not indicate that expert nurses' knowledge and action are not supported by rationales. Rather, they use rationales but do not forget the importance of intuition.

MacLeod (1994b, p.363; 1994a) in two Scottish teaching hospitals analysed nursing care delivered to surgical patients by ten experienced nurses via participant observations and interviews. Nurses take note of simple signs of patients such as a change of focus of attention, interest in an outside event, interest in appearance or even being ready to wear false teeth. They also mentioned that sometimes there is no specific sign and they feel overall that patients "just look better". They also stated that sometimes their work consists of just doing "little things" such as making a handle for a chest drainage bottle or placing a bath mat differently. However, MacLeod argued that such simple assessments and practices are based on nurses' complex knowledge and skills they have gained through their experiences.

These results are very similar to another grounded theory research study conducted by Atkins (1998) in Australia. The main aim of the study was to discover and conceptualise nurses' views about QoL of patients with severe multiple impairments.

One of the main findings of this study was that nurses discovered that QoL of this group of patients for them meant “just little things” (p.134). However, this research study argued that even though nurses use the language of “just little things”, the complex nature of nurses’ knowledge and skills explains this. To address the complexity of these little things, Atkins explained that nurses become more intimate with people who have multiple impairments. Only after that do nurses realise that these patients are human beings and that their everyday lives need to be supported (Atkins 1998).

It can be concluded that more experienced nurses might better understand cancer patients’ QoL because they not only have more skills but also may pick up more effectively on cues using their intuition.

Patients’ treatment setting

Another important issue identified in the first phase of the research study was that nurses in outpatients’ oncology units have a better understanding of patients’ QoL, particularly in the psychological and social relationship domains. Participants of the second phase commented that the main reason why nurses in outpatient oncology wards have a better understanding of patients’ QoL is that they are generally more experienced. Moreover, outpatient wards included in this research study were mainly outpatient chemotherapy units. The style of communication in these wards is that nurses sit and talk with patients while delivering chemotherapy drugs. This encourages nurses to develop a closer relationship with patients and better unpack or understand private and personal issues. Finally, participants mentioned that patients come to the outpatient wards on a regular basis, for example, five days per week for 3-4 weeks continuously. Each day patients might stay for a couple of hours. So, this might provide nurses with more relational continuity and better understanding of patients’ QoL.

There are some issues arising from reviewing the literature that also shed light on why working in inpatient wards might hinder nurses’ understanding of cancer patients’ QoL. Although prolonged contact with the patient in inpatient departments might potentially increase the level of agreement (Magaziner et al. 1988), it can also lead to disagreement when a nurse is under pressure to do different tasks (von Essen 2004). It

might be the case that patients in inpatient oncology wards usually are sicker than patients in oncology chemotherapy units. Therefore, nurses might need to spend more time and do more tasks for such patients and it may be more difficult to communicate and to assess their QoL. Outpatients may have a better QoL than inpatients (Isikhan et al. 2001) and the level of agreement between patients and nurses about cancer patients' QoL could be better either when patients are very sick or when they are very healthy (Sneeuw et al. 1998; Sneeuw et al. 1999).

The findings of this research study demonstrate some important characteristics that exist in chemotherapy oncology units and may facilitate nurses' understanding of cancer patients' QoL. If these characteristics can be implemented in inpatient wards, it may improve nurses' understanding of cancer patients' QoL.

Nurses' QoL

Empirical findings identified that the majority of nurses rated their QoL as being good. It was also found that nurses with better QoL could better assess patients' QoL in the environmental domain. It might be argued that when nurses have lower levels of QoL and personally experienced tougher lives, they might better understand patients' QoL because they might have more empathy with patients who are assumed to be in a parlous situation. Even though such an empathic understanding can work in some instances, this may not be enough for a deeper level of understanding. Nurse interviewees who took part in the second phase explained that when they are happier with their lives they often make more open relationships with patients and will be more therapeutic as a result. They stated that they might be more 'switched on' and listen to patients better. This is interesting to note that the literature review could not identify any material that specifically focused on nurses' QoL and how it can influence their understanding of cancer patients' QoL. However, the literature shows that while nurses try to improve patients' QoL, their own QoL may be impacted. Consider, for example the following comment by Baycroft (2002, p.3):

As nurses, we are deeply concerned with maintaining and improving the quality of life of those we care for. It is ironic that in pursuing this career, my own quality of life has taken a severe nosedive...a shift can leave me so drained that my own health and well being is neglected and the emphasis on getting the tasks done, leaves little or no time for the rewarding and satisfying aspects of the job.

When nurses' QoL falls, this in turn can influence their understanding of patients' QoL. A literature review by Neumann, Araki and Gutterman (2000) revealed that proxies who reported more caregiver responsibilities and subjective stress from caregiver duties provided more negative assessments of subjects' health and well-being. In another study, family proxies' QoL responses were compared with those of patients. One part of the results indicated that agreement was better when caregivers reported lower levels of care-giving burden (Williams et al. 2006). These findings are similar to another proxy research study suggesting that when caregivers have more pressures, it is most likely that they will overestimate the older person's disability (Long, Sudha & Mutran 1998).

Thus it appears that how nurses feel about their own QoL can influence their understanding of cancer patients' QoL.

Limitations

The findings of this research study must be interpreted within its limitations.

Limitations of the first phase

The first phase was conducted in three major hospitals across several wards including two specialist oncology wards, five non-specialist oncology wards, three outpatient chemotherapy units, one radiotherapy centre and one palliative care area. The sample size drawn from this population of patients and nurses was calculated based on the minimum number required to identify the level of agreement between patients and nurses. This can be considered as a representative sample size and results having external validity to the wider Australian community. However, as is the case with many other research studies, those patients and nurses who were selected from oncology wards will share a common work environment and might be influenced by each other (intra-group effect). Naturally, a sample of patients and nurses from a greater number of oncology wards may decrease intra-group effects and provide more rigorous findings.

Secondly, before conducting the first phase, nurses were well informed about the

importance of the research and the need to complete the questionnaires as accurately as possible. However, the study was conducted in busy wards and on some occasions this may have affected nurses' concentration while completing the questionnaires. This is a problem that has also been reported in other studies (Sneeuw et al. 1997b; Sneeuw et al. 1998).

Thirdly, in this research study an attempt was made to include as many nurses as possible so that each nurse assessed only one patient. However, the population of cancer patients varied from time to time whereas the nurses' population did not alter much. Taking into account that the response rate of patients was more than that of nurses, the research study was faced with a higher sample of patients who had not had a nurse pairing. Therefore, proceeding with only one nurse assessing one patient, significantly decreased both cohorts of patients and nurses. Despite the best efforts undertaken during this longitudinal research study, the number of nurses was only slightly more than half of the patients (57.3%). In other words, each nurse took part in the study nearly twice. So this might lead to the bias of assessing many patients with a few proxies (Broberger, Tishelman & von Essen 2005; Lampic & Sjoden 2000). This problem has been reported elsewhere with proxies not always equal to number of patients (Blazeby et al. 1995; Molzahn, Northcott & Dossetor 1997; Slevin et al. 1988; Sneeuw et al. 1998). In most of these studies there is no statement as to how many times proxies assessed patients as proxies. However, a comparison between patients and proxies who took part in these studies shows that such assessments were done more than twice by proxies. Fortunately, this is an advantage in this thesis compared to other studies because each nurse on average assessed two patients.

Fourthly, in the first phase of the research study patients' scores were considered as the best possible information available and nurses' scores were compared with them. In this study it was found that nurses generally tend to underestimate patients' QoL. However, it can be argued that patients' scores themselves are prone to some bias as stated previously. For example, patients may rate their QoL better to please health care professionals. If this is the case, patients in this study have rated their QoL higher than what they really felt. Therefore, nurses might be closer in their rating of patients' QoL with that of patients' own rating in a real situation. However, QoL perceptual differences refer to a number of factors as discussed in this chapter.

Finally, nurses completed the QoL questionnaire for patients usually on the same day as patients did, but did not do so immediately after them due to work issues. However, participants in the second phase commented that their state of QoL might change over time. The pattern of changes and how frequently such changes might occur for patients has not been addressed yet in the literature. It is possible, however, that differences between patients' and nurses' scores were linked to changes occurring in the patients' level of QoL later when nurses assessed patients' QoL. Nurses might be closer in their rating of patients' QoL with that of patients' own rating if it was possible for them to assess patients' QoL immediately after patients did.

Limitations of the second phase

Firstly, the qualitative data was mined as extensively as possible and saturation reached to the researcher's satisfaction within the time available. There are other characteristics of categories that were not explored in this research study. This is a common feature in qualitative research studies including one based on the principles of grounded theory. No matter how often the data is investigated, new characteristics may constantly emerge. However, future research studies may be needed to more fully explore other characteristics.

Secondly, even though conceptual sampling was used in the interpretive phase of the research study, this sampling was implemented into a convenience sample of patients and nurses from two major public hospitals who were willing to take part. There was quite a good variation within the sample chosen. However, for transferability to be achieved more effectively, a random sample from patients and nurses from a wider population and more hospitals is necessary.

Finally, the researcher previously explained issues related to his background, culture and language as an international student. He also described what was conducted to manage these issues. However, the researcher's ability to deeply explore patients' and nurses' perceptions of cancer patients' QoL might still have been influenced by these factors. Psychological and spiritual aspects of QoL are particularly prone to be coloured more by the researcher's culture, background, and language issues.

Conclusion

In this chapter the findings of the research study were discussed. Question number one was answered using empirical findings to indicate that nurses generally differ in their perceptions to patients about cancer patients' QoL. Moreover, nurses tend to underestimate patients' QoL in the social relationship and environmental domains. The reasons for such differences were further investigated in order to answer the second question by referring to the outcomes of both phases, particularly those in the second phase. In general, participants commented that differences existing between patients' and nurses' perceptions about cancer patients' QoL were due to a poor relationship and rapport between cancer patients and their nurses. However, when nurses are more experienced and have better levels of QoL or when patients are treated in outpatient oncology wards, it is most likely that nurses can better understand cancer patients' QoL.

The next chapter concludes this thesis and summarises the key findings of the research. It also outlines implications for future research, education and clinical practice.

CHAPTER NINE: CONCLUSION

Introduction

In the previous chapter, the findings of the phases of the research study with regard to nurses' perceptions about cancer patients' QoL were discussed in the light of literature in order to answer the research questions.

This chapter presents the main implications of the research and concludes the thesis. These implications are provided under the themes of key issues discussed below.

Nurses' assessment of cancer patients' QoL in the clinical area

Empirical findings of the research study generally identified a fair (less than moderate) agreement between cancer patients' and nurses' scores on the WHOQoL-BREF questionnaire. This was further supported by interpretive outcomes in which participants stated that nurses mainly pick up on patients' cues as a way for QoL assessment when they communicate with patients in the clinical area rather than using QoL tools. Furthermore, nurses are, at times, uncertain if they are doing a QoL assessment and if their assessment of patients' QoL is correct or not. Participants also believed that the main reason for differences that exist between patients' and nurses' perceptions about cancer patients' QoL is a poor relationship and rapport between them and their nurses.

Therefore, this supports a need for nurses to develop a more holistic relationship and stronger rapport with patients to underpin the assessment of cancer patients' QoL through various cues. In the interpretive phase of this thesis the participants commented on how nurses can develop such a relationship and rapport with patients. Participants stated that what makes nurses have a stronger relationship and rapport with patients is a genuine interest in and their desire to nurture people. They believed that this genuine interest might encourage nurses to spend more time with patients and communicate with patients in an open, receiving and non-judgmental way.

Empirical findings supported by interpretive outcomes also highlighted that nurses' understanding of cancer patients' QoL, particularly is lower in the psychological, social relationship and environmental aspects. So in order to document these aspects, nurses need to develop a deeper level of communication and rapport with patients. Participants mentioned that as a result of such a well-developed relationship and rapport, nurses might empathise with a number of issues, some of which are quite personal.

Moreover, this research study found that spirituality is a prominent aspect in cancer patients' QoL. QoL tools like the WHOQoL-BREF questionnaire might marginalise spirituality because it does not measure it as a separate domain. Given the importance that participants placed on spirituality, higher levels of understanding of spirituality can be achievable only through a more in-depth relationship and rapport with patients.

Despite the importance of a holistic relationship and rapport to assess cancer patients' QoL, participants in the second phase commented that more junior nurses are interested in using QoL tools as guidelines for QoL assessment. QoL tools like the WHOQoL-BREF might be used as guidelines for such nurses to assess cancer patients' QoL rather than relying heavily on their perceptions and intuitions. However, this study found that there are some problems in using QoL tools in the clinical area. For example, one reason for not using QoL tools in the clinical area is that they are lengthy and may cause undue pressure not only for nurses but also for patients. Secondly, nurses generally face severe time limitations or constraints. However, this study has found a basis for a modified version of such tools being used in nursing practice. This is what can be seen in some palliative care areas in which nurses are using both formal (one item QoL tool plus a symptom check list) and an informal QoL assessment.

Therefore, for the purpose of QoL assessment in oncology wards as a first step, a modified version of QoL assessment as seen in the palliative area is useful. In other words, nurses might use some items of the WHOQoL-BREF questionnaire to initiate a conversation about QoL. These items would be those found in this research study in which nurses had less understanding of cancer patients' QoL (sex life, personal

relationships, living a meaningful life, accepting bodily appearance, and having negative feelings). In the meantime, however, nurses need to improve the breadth and depth of their relationships with patients to ensure that the holistic nature of QoL assessment remains intact.

Nurses as proxies in QoL research studies

Empirical findings of the research study arising from a comparison of patients' and nurses' scores on the WHOQoL-BREF questionnaire have important implications for researchers who are interested in knowing whether nurses may play a proxy role for non-respondent patients in their QoL research studies or not. This research study in general suggests that individual nurses cannot perform this role successfully. However, nurses as a group might be used as proxies for patients but mainly in the physical domain. This is due to the similarity of QoL mean domain scores of patients and nurses and stronger correlations in this area.

The next question is whether there are nurses with specific demographic and clinical characteristics who can better fill the proxy job. This may help in selecting a suitable proxy from those available (Tang & McCorkle 2002b). This research study suggests that nurses with more clinical experience with cancer patients and those who have a better level of QoL may provide a closer rating of cancer patients' QoL. Moreover, the findings of this study indicated that often nurses think that patients' families are a better source of QoL information for non-respondent patients and therefore might rely on them. This implies that proxy information provided by the patient's family in some instances can be used as complementary data, particularly for more private and personal aspects of QoL such as psychological, social relationship and environmental domains. Cancer has an effect on the whole family and they are generally engaged with the patient more than health care professionals and are familiar with the patients' situation much better than nurses (Sigurdardottir, Brandberg & Sullivan 1996).

Another important finding identified in this study is that assessment of QoL in others and even for ourselves is complex and at times difficult. It also appears from the

literature that an adequate replacement for measuring QoL has not been found. However, some participants in this research study suggested that nurses can use other measures to help them to obtain a more accurate or useful idea about cancer patients' QoL and to provide more therapeutic nursing care. Such measures are particularly useful when patients cannot communicate adequately and report on their QoL. For example, the Patient Reported Outcome (PRO) was recommended as a complementary measure by several participants in this study. PRO is a measure of 'progress' or 'recovery' rather than a QoL assessment but can provide general information about the patients' situation and abilities that may be useful for health care professionals to evaluate if they have achieved their nursing goals or not, for example, when nurses help a patient up who has been lying in bed for a prolonged period and send them to the hydrotherapy pool. At the end of two weeks of doing this the patient may actually walk by themselves to their therapy session. This patient-reported outcome demonstrates an improvement in the patient. Altogether, it appears that the idea of 'replacement' for QoL measurement needs to be considered seriously by researchers. Such measures, while reflecting the complexities of the QoL concept, need to be as simple as possible to be understood and performed.

Nurses' education support

One main finding in this research study is that nurses are often unskilled and uncertain about the QoL assessment they are conducting. They expressed that they need education specifically about how to do a QoL assessment. The main way for QoL assessment in oncology wards is picking up on cues when nurses communicate with patients. Education may therefore focus on issues like how nurses may build better relationships and improve communication with patients (Sivesind et al. 2003). The focus of this 'relationship program' may be applicable to issues discussed in this thesis, such as how nurses can have an open relationship with patients, what cues they need to look for and how to interpret such cues.

This education also needs to focus on the QoL concept. "Clinical oncology nurses must understand the term quality of life" (King 2006, p.5) as it applies to their patients. Participants also expressed the idea that they need education about the QoL

concept. QoL was a complex concept for participants and nurses generally had difficulty defining QoL for their patients. So introducing the QoL concept more specifically might help nurses to think more and better understand complexities of the QoL concept such as its broadness and individuality. They might be able to conceptualise QoL for specific groups of cancer patients or those who are under specific treatments and define it in a practical way when assessing QoL. Such operationalisations are quite necessary to bring perceptions of two parties (patients and nurses) much closer to each other.

Moreover, education for improving nurses' assessment of patients' QoL needs to include not only nurses but also other health care professionals. In the interpretive phase of the research study it was found that nurses are in a close relationship with other health care professionals when caring for and treating patients. They need to have a common understanding of QoL and are able to communicate effectively with patients. It is quite important that more than theoretical issues in relation to the QoL concept should be incorporated into education programmes. The more experienced nurses have a better understanding of cancer patients' QoL and their insights should be included in an education program, as reflected in the two phases of this study. Qualitative data suggested that more experienced nurses might have better communication and assessment skills. They are also better able to pick up on cues and can explain what QoL cues they look for and how they interpret them.

One direction for education is to have focus groups that include both experienced and junior nurses so that they can interact with each other. This will encourage more experienced nurses to talk about their experiences as how they have actually assessed patients' QoL. Such sessions might initiate junior nurses to develop communication skills. Another way might be that more experienced nurses conduct their communication with patients in front of more junior nurses in the clinical area. Junior nurses might then play those roles with actual cases with the more experienced nurses supervising them and make comments as to how they may improve their communication skills.

Future research studies

Some important implications emerged from conducting this research study and are useful for future research studies. Firstly, the WHOQoL-BREF questionnaire is a reliable and valid tool as recommended by the WHO. The reliability of the tool was tested again and supported by this research study. Cronbach alpha for both patients and nurses QoL domain scores (except of the social domain) approached or was above the acceptable level of 0.70. In general, a high internal consistency may not be necessary for a multi-domain tool (Cella & Tulsky 1990) like the WHOQoL-BREF questionnaire.

The low internal consistency of the social relationship domain might be related to the low number of items (only three) and their content (sex life, personal relationships, and friends) that had been reported in another research study (Hanestad et al. 2004). Generally speaking with only three items in the social QoL domain, the outcomes of Cronbach alpha may not be reliable (The WHO Group 1998a). Moreover, interpretive outcomes of the research study revealed that participants gave more weight to some domains such as spirituality. For those researchers specifically interested in the social relationship or spiritual domains of QoL, the WHOQoL-100 may be more suitable. O'Carroll et al. (2000) also argued that for more sensitive areas of QoL like social relationship domain, the WHOQoL-100 is more sensitive than the WHOQoL-BREF.

An exploratory factor analysis was also conducted to explore the structure of domains of the WHOQoL-BREF questionnaire completed by patients. Outcomes indicated that items of the WHOQoL-BREF questionnaire can be grouped into seven domains. This would be in line with the interpretive findings where participants agreed that spirituality is an important domain and there might be other taken-for-granted aspects. It appears that the WHOQoL-BREF questionnaire does not enquire about spirituality issues in as great a depth as required. Such findings imply that maybe the WHOQoL-BREF can not comprehensively assess cancer patients' QoL. However, exploratory factor analysis in this research study was conducted by a sample that might be considered small by some researchers (Tabachnick & Fidell 2001). Therefore, it is suggested that the construct validity of the WHOQoL-BREF

be explored further for cancer patients in the clinical area, using factor analysis with a larger sample size (eg. 300 or more). This would indicate if this tool in its complete form can really assess those QoL issues which are important for cancer patients.

Secondly, empirical findings of the research study identified that QoL of nurses has an influence on their assessment of patients' QoL. However, QoL of nurses was assessed against one global question because practically it was very difficult for nurses to fill out a QoL tool for themselves as well another form and a QoL tool for patients. As recommended by Haberman and Bush (2003) a single-item that measures global perceptions of QoL can be useful in some contexts. For example, in this research study, assessing nurses' QoL with a global item can be considered an initial step in searching for the possible relationships between nurses' rating of their own QoL and their understanding of patients' QoL. However, it is recommended that nurses' QoL be measured in a separate research study using a comprehensive QoL tool. The influence of nurses' QoL on the nurses' understanding of patients' QoL can then be explored further using an interpretive approach.

Thirdly, compared with other proxy research studies, this research study used a reasonably large sample size of patients and proxies (nurses) in the first phase. However, as stated previously, the number of nurses included in the first phase of the study was slightly more than half the number of patients (57.3%). This limitation in part was compensated for by conducting an interpretive study that generally supported findings of the questionnaire survey phase. However, it is still recommended that the results of nurses' understanding about cancer patients' QoL be examined in larger samples particularly with a more representative sample of nurses in Australian populations.

Fourthly, empirical findings of the research study identified that more experienced nurses have a better understanding of patients' QoL. Some nurse interviewees also stated that they assess patients' QoL using gut feeling or intuition. How the more experienced nurses use their intuition in the clinical area to assess patients' QoL deserves more investigation in another interpretive research study.

Fifthly, in the interpretive aspects of the research study it was found that nurses in

the palliative area are doing both formal and informal QoL assessment because the purpose of the ward is for patients to live more comfortably and therefore the focus is on QoL issues. It may therefore be logical that palliative nurses form more accurate ideas about patients' QoL compared with nurses in other wards. Unfortunately, only five pairs of patient-nurse from the palliative setting took part in the first phase. This number is very limited to make a comparison between nurses in the palliative area and oncology wards regarding which setting has a better understanding of patients' QoL. Consequently, a comparison of cancer patients' and nurses' understanding of cancer patients' QoL between the palliative area and other wards can reveal if the purpose of QoL assessment, i.e. to support better palliation or to maintain expectations of recovery - can really make a difference in nurses' perceptions' of cancer patients' QoL.

Sixthly, this research study identified that nurses in outpatient chemotherapy oncology units have a better understanding of cancer patients QoL compared with nurses working in inpatient wards (specialist and non-specialist). This research study also found some underlying reasons for these differences. However, a research study that is conducted which compares only specialist inpatient wards with the outpatient chemotherapy units would address this question. Specialist oncology wards may focus more on QoL issues than non-specialist wards. This research needs to be followed up by an interpretive study exploring what kinds of facilitators and drawbacks exist in the context of specialist inpatient oncology wards and outpatient chemotherapy units.

Finally, this research study found that patients and nurses differ in their perceptions of cancer patients' QoL. However, this research study did not have enough time and resources available to completely understand, from patients' and nurses' perspectives, how such differences might impact on patients, particularly their QoL. For example, in this research study it was identified that nurses underestimated patients' QoL. Therefore, it would be very useful in an interpretive study to explore how nurses' underestimations of patients' QoL influenced patients' QoL and other related issues, like patients' coping styles, in more depth.

The QoL concept

With regard to the QoL concept, this research study confirmed that it is a broad and intangible concept. After many years of study and investigation there is still no universally agreed definition of QoL and no general consensus on those aspects that constitute it. The majority of individuals spend their lives without a deep consideration of what issues really contribute to their QoL unless their QoL is challenged. What sorts of things satisfy human beings and make them really happy? Is there anything in the physical world or the social world that can really feed the true sense of happiness or we do need to search for more than materialistic or secular answers?

These questions are important and need to be answered. A deep consideration about the 'taken-for-granted' aspects of life is quite necessary particularly for those whose lives are challenged. Answers to these questions at the individual level might then help researchers to make better definitions of QoL and thus enable health care professionals to be more therapeutic. It is suggested that discussions about the QoL concept focus more on issues like 'self-identification' (who we are?) and the 'meaning of life' (why we are here? and where do we go?). In other words, research results from this thesis suggest that discussion upon the QoL concept focus more on spirituality. It is most likely that such a focus on spirituality issues, which has been started recently, can resolve many ambiguities already existing in the field of QoL. It is predicted that future research studies will focus more on the notion of spirituality.

The researcher will conclude this thesis with the following statements written by a famous Persian poet, Molana Jalal-e-Din Mohammad Molavi Rumi, and translated into English by Shahriari (1998):

Everyday I meditate upon this, and every night I groan
Why is my own existence to myself the least known?
Whence have I come, why this coming here?
Where to must I go, when will my home to me be shown?
I am in desperate awe, why was I ever created?
For this, my creation, whatsoever was the reason?

Conclusion

This research study identified differences that exist between cancer patients and nurses about cancer patients' QoL. It found that such differences are mainly due to the individuality of the QoL concept – different for each person – and its breadth as well as QoL assessment being dependent on the strength of the relationship and rapport between patients and nurses. This research study used a mixed approach and an overlap in the findings of both phases of the research study was identified. The transferability of outcomes were found to have potential applicability. Some outcomes of the research study, particularly in the interpretive phase (see Chapter Seven) may have transferability to other populations, particularly the researcher's country of origin, Iran.

This research study accomplished its aims to understand nurses' perceptions about cancer patients' QoL. It addressed several important issues that may contribute to the current knowledge of QoL and push the boundaries of practice further. It also raised questions and opened doors for future researchers who are interested in this field of endeavour. The researcher hopes that the outcomes of the thesis make it more likely that those experiencing a life-threatening illness such as cancer will receive the support they need to maintain or improve their quality of life.

We must always keep in mind that cancer is not a disease that 'others' suffer from. We might be one of those future sufferers of this disease.

APPENDICES

Appendix A: The relevant article accepted for publication in *Contemporary Nurse*, vol. 29, no. 1, pp. 67- 69.

Patients' quality of life: A comparison of patient and nurse perceptions

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Background: Quality of Life (QoL) is a subjective perception a person has of their position in life. Tailoring care to a patient's unique needs requires nurses and patients to have a similar understanding of a patients' QoL.

Aim: This study aimed to identify: (a) the level of agreement between patients and nurses about cancer patients' QoL; and (b) variables that may affect the level of agreement between them.

² Masoud has a scholarship from Isfahan University of Medical Sciences, Isfahan, Iran (Islamic Republic), to complete his PhD in nursing.

Methods: Cancer patients (n=117) and nurses (n=49) from a public hospital were invited separately to complete the World Health Organisation Quality of Life Brief (WHOQoL-BREF) questionnaire. This assesses QoL in physical, psychological, social relationship and environmental domains, or dimensions.

Findings: Intraclass Correlation Coefficient (ICC) revealed a moderate agreement between nurses' and patients' scores in the physical QoL domain but lower agreement on other domains. A paired t-test identified patients' QoL domain scores were significantly higher than that of nurses in social relationship and environmental domains. Multivariate analysis using Standard Multiple Regression analysis demonstrated that agreement between patients and nurses was higher: (a) in the physical QoL domain with nurses who have greater clinical experience with cancer patients; (b) in the social relationship QoL domain when patients are treated in outpatient departments.

Conclusion: These results imply that differences exist between patients' and nurses' perceptions about cancer patients' QoL and nurses tend to underestimate patients' QoL in social relationship and environmental domains. Higher clinical experience with cancer patients may contribute toward a better understanding by nurses of cancer patients' QoL.

Keywords: nursing; quality of life; oncology patients; oncology nurses; World Health Organization Quality of Life Brief questionnaire; nursing care

INTRODUCTION

Quality of Life (QoL) issues have been of particular interest to many researchers, particularly in the area of oncology (Giesler 2000; He & Liu 2005). QoL has been researched with different purposes in mind such as curative, palliative, improving

symptom relief, care or rehabilitation, facilitating communication with patients, awareness of patient preferences, understanding of late problems of psychological adaptation, and for medical decision-making (Fayers & Machin 2000).

QoL is defined in this research project as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns” (WHO Group 1997: 1). Such a definition, implies that asking patients is an ideal way to assess this individual concept (Ballatori 2001; von Essen 2004). However, there are important reasons that perceptions of health care professionals, including nurses, about patients’ QoL are also important.

The main reason is that in the clinical area health care professionals usually form perceptions about QoL of patients based on different sources of information. Such perceptions might even be formed for those patients who can communicate, and whose QoL can be directly assessed by consulting with the patient. Such perceptions are used as a basis by health care professionals in order to make clinical decisions, modify or even change treatments or programs for patients (King et al. 2002).

Another reason is that when a research study is conducted in the clinical area, some patients may not personally want to take part in the research study. Another group may wish to be part of the study but be unable to adequately communicate so that an assessment of their QoL may be carried out (McPherson & Addington-Hall 2003). Therefore, health care professionals might be asked to assess a patient’s QoL. In these situations, where a person other than the patient assesses a patient’s QoL, the person is identified as a proxy. There are numerous QoL research studies (Slevin et al. 1988; Fisch et al. 2003) that have described situations in which health care professionals were requested to act as proxies for such patients.

Even though family members or significant others can also fulfil a proxy role, for purposes of this research study only nurses were chosen. Nurses play a key role in the process of making decisions about patients' care. Their significance is derived from the fact that nursing care is holistic in its approach – a necessary characteristic when it comes to assessing a patient's QoL (Rebollo et al. 2004; Tallis 2005). A nurse's care is also supportive in nature (Gray et al. 2002), particularly in oncology settings where physicians are very busy and may rely on nurses for information about the patients' QoL.

Whatever the circumstances or reasons, nurses need to make such assessments of patients' QoL to provide better supportive care for patients. In other words, if they have a better understanding of patients' QoL, it may contribute to better support for patients (Pickard & Knight 2005) otherwise the assessments might lead to negative consequences for the patients. It follows that a reasonable degree of agreement between patients' and nurses' perceptions of cancer patients' QoL may improve health outcomes. Given this, assessing the level of agreement between the patient and the nurse over the patient's QoL is considered important and worthy of investigation.

Previous research studies, which mainly used 'proxy rating', identified some general trends (McPherson & Addington-Hall 2003; Pickard et al. 2004a). For example, proxies appear to have a better understanding of objective aspects of QoL, like the physical QoL, rather than subjective aspects such as the psychological QoL. However, there are still some inconsistencies in the findings, particularly when the effect of patients' and proxies' characteristics on the level of agreement were assessed (Sneeuw, Sprangers & Aaronson 2002; Tang, ST & McCorkle 2002b). For example, in one research study, the degree of QoL agreement between patients and

their proxies was influenced by the patients' performance status (Horton 2002). Another study yielded an inconsistent pattern of such a relationship (SneeuwAaronson et al. 1997a).

A literature search yielded no Australian research that compared nurses' perceptions of patients' QoL with cancer patients' own perceptions of their QoL. Nor is it clear whether the findings of studies carried out in other countries hold true for Australia due to the culturally influenced nature of QoL (The WHO Group 1995; WHO Group 2000). Moreover, only a few research studies assessing the level of agreement between patients and proxies used more accurate statistical tests like Multivariate analysis. Therefore, the current investigators were interested to know how accurately nurses perceive and report patients' QoL in the clinical area of cancer patients in an Australian population.

AIMS OF THE STUDY

The primary aim of this study was to (a) measure the level of agreement between patients' and nurses' perceptions of the patients' QoL as the patients' proxies³. This study also sought to address the following secondary aims: (b) the reliability of patients' and nurses' QoL scores using the World Health Organisation Quality of Life Brief (WHOQoL-BREF) questionnaire; and (c) the influence of patients' and nurses' variables on the level of agreement between patients and nurses.

METHODS USED IN THE STUDY

Research Participants

A convenience sample of cancer patients and their nurses were recruited from one inpatient oncology ward, one outpatient chemotherapy unit and one radiotherapy centre at a large Australian teaching hospital. Any adult cancer patients undergoing

³From hereon, the term 'nurse' or its variations will be used to refer to the nurse as a proxy, except where specifically stated.

treatment were able to take part in the study provided that they could read the WHOQoL-BREF questionnaire and write their responses. Patients differed in their health status, disease severity and treatment modalities. This increased the variability in QoL ratings and allowed outcomes of agreement to be generalised to a wider group of patients. Nurses selected for the research were those who provided the primary care for a patient and were, therefore, familiar with them.

Instrument

The WHOQoL-BREF questionnaire was used for this research. This test uses 26 items which assess the QoL for four domains or dimensions, including physical (7 items), psychological (6 items), social relationship (3 items), and environmental (8 items) domains, and 2 items measuring overall quality of life and general health. All 26 items are rated on a 5-point Likert-type scale (The WHO Group 1998a).

The WHOQoL-BREF questionnaire was selected for this study as it was considered suitable by WHO to assess QoL in different situations such as routine clinical work, epidemiological studies and clinical research trials (WHO Group 1996). In this study, the Australian version of the questionnaire was completed in the framework of a clinical research study.

Two other separate forms, Patients' and Nurses' characteristics forms, were also created by the investigators. They were used as main instruments to collect demographic and clinical variables of patients and nurses.

Data Collection

The research study was completed during a six month period from July 2005 to December 2005 in a major public hospital in Adelaide, South Australia.

In the majority of cases, the principal researcher introduced the research study to each patient-nurse pair. If they agreed to take part in the study, demographic

and clinical variables of each patient-nurse pair such as age, gender, patient's cancer diagnosis, and nurse's clinical experience were recorded. The principal investigator gave the patient the WHOQoL-BREF questionnaire to complete and the nurse then filled out a WHOQoL-BREF separately, based on his/her understanding of the patient's QoL. These were collected by the researcher and placed in an envelope. There were a few cases when, due to practical issues, nurses gave questionnaires to the patients. However, the nurses were well informed beforehand about the research process and that completion of the questionnaires should be done on their own without asking the patient any questions.

Ethical Considerations

This research was approved by the appropriate Clinical Research Ethics Committees. The same number was recorded on a Patient's and Nurse's characteristic form as well as the WHOQoL-BREF questionnaire, to be completed by patients and nurses, so that the information from the patient's and nurse's forms were able to be properly matched and the data compiled, while participant anonymity was assured. Verbal and written information about the research project was provided for both patients and nurses. Agreement to complete the questionnaire was considered as consent for both patients and nurses and they were informed this was the case, as well as of their right to withdraw from the study at any time if they so desired. In order to deal with patients' possible emotional distress, supportive care in the form of counselling was negotiated with the Clinical Nurse Consultant. Nurses were not expected to experience any emotional stress by filling out a QoL questionnaire for patients.

DATA ANALYSIS AND FINDINGS

To calculate the sample size, the standard deviation of differences between patients and proxies from two previous research studies that used the WHOQoL-BREF

questionnaires with a sample of people with psychosis (Herrman, Hawthorne & Thomas 2002) and schizophrenia (Becchi et al. 2004) was calculated. This provided a standard deviation range from 1.00 to 1.50 units on the total WHOQoL instrument. Setting a significance level of 5% and power 80%, a sample of 117 was considered sensitive enough to detect a difference in means of 0.30-0.40 units.

The data were entered into SPSS 12 software and analysed using a syntax recommended by the World Health Organization (WHO) for use with this specific questionnaire (The Australian Centre for Posttraumatic Mental Health 2003). The patients' and nurses' QoL mean domain scores were calculated by multiplying the mean of all items included within the domain by four to be directly comparable with scores derived from WHOQOL-100, giving domain scores ranging from 4 to 20.

Patients' and nurses' clinical and demographic variables

Demographic variables of patients are shown in Table 1.

Table 1: Patients demographic variables

	Patients	
	No.	%
Patient's gender		
Male	60	51.3
Female	57	48.7
Patient's age		
Mean	59.8	
Standard Deviation	15.3	
Patient 's first language		
English	102	91.1
Other	10	8.90
Patient's marital status		
Single	12	10.5
Married	76	66.7
Divorced/widowed	22	19.3
Other	4	3.5

One-hundred and seventeen patients took part in this study with the mean age of 59.8 (± 15.3 SD) years. The highest percentage of patients were married (66.7 %), male

(51.3%), used English as their first language (91.1%), and secondary school was their highest level of education (71.7%). Patients had a range of cancer diagnoses, with breast cancer (23.1%), colorectal cancer (12.0%), and non-Hodgkin lymphoma (10.2%) being the most prevalent. The highest percentage of patients completing the questionnaire were from outpatient departments (54.8%), with chemotherapy (68.2%) as their major treatment. The highest percentage of patients (42.5 %) were classified as 'restricted but ambulatory' in their performance status.

Results also indicated that from the 49 nurses who took part in the study, the highest percentage of them were female (96.6%), married (61.3%), and had English as their first language (90.3%). Nurses had a range of qualifications with Registered Nurse certificate (30.8%), Graduate Diploma (26.5%) and Bachelor of Nursing (20.5%), being the most prevalent. The mean age of nurses was 37.4 (± 7.10 SD) with a range of 21-55 years. The mean time nurses spent providing care for a given patient (hour/shift) was 2.45 (± 1.50 SD) hours with a range of 0.08-6.00 hours. The mean of nurses' clinical experience was 15.5 years (± 8.90 SD) with a range of 0.16-30 years. The mean of nurses' clinical experience with cancer patients was 9.40 years (± 7.00 SD) with a range of 0-22 years.

In the nurses' Characteristics Form, nurses were asked to rate their own quality of life against one question (How would you rate your quality of life?). The aim was to assess the effect of nurses' QoL on the level of agreement. The highest percentage of nurses (53.5%) rated their own quality of life as 'very good'.

Reliability of patients' and nurses' QoL scores using the WHOQoL-BREF

To assess the reliability of the tool, internal consistency was measured using the Cronbach alpha coefficient for patients' and nurses' QoL mean domain scores. The

ideal acceptable level was 0.70 (Pallant 2004). The results of Cronbach alpha are shown in Table 2.

Table 2: Test of reliability of the WHOQoL-BREF

QoL domain	Cronbach alpha	
	Patients	Nurses
Physical (7 items)	0.84	0.87
Psychological (6 items)	0.76	0.80
Social Relationship (3 items)	0.35	0.60
Environmental (8 items)	0.67	0.86
Overall (26 items together)	0.90	0.93

Agreement between patients and nurses on patients’ QoL mean domain scores

Different tests were used to measure the level of agreement. Firstly, Pearson Correlation (r) and Intraclass Correlation Coefficient (ICC) were calculated. The criteria to judge the results of correlation coefficient and ICC were as follows: less than or equal to 0.20, poor; 0.21-0.40, fair; 0.41-0.60, moderate; 0.61-0.80, substantial; 0.81-1, almost perfect (Tang, ST & McCorkle 2002b; von Essen 2004).

The results of agreement between patients’ and nurses’ QoL domain scores using correlation statistical tests are reported in Table 3. The correlation (r) between QoL domain scores of patients and nurses ranged from 0.16 to 0.50. With the exception of the physical QoL domain, Intraclass Correlations were lower than the correlations ranging from 0.14 to 0.50.

Table 3: Patient-Nurse agreement on the WHOQoL-BREF using correlation tests

QoL domain	Patient-Nurse Correlation	
	r	ICC
Physical	0.50	0.50
Psychological	0.26	0.24
Social relationship	0.16	0.14
Environmental	0.37	0.29

Secondly, a graphical approach described by Bland and Altman (1986) was conducted. In this test the difference between the patient and nurse QoL scores was

plotted against the average of two scores for each patient-nurse pair. The main point is the acceptability of the overall width of the scatter (upper and lower levels of agreement). This is an interval in which 95% of patient-nurse differences would fall. Another point to be considered is whether there is a pattern in the scatter of points.

Figure 1 shows that for the physical QoL domain the location of the upper and lower limits of agreement of patients and nurses differs by around 6 points. For other QoL domains, the scatter plots (not included) were relatively similar to the physical QoL domain. Moreover, there is not an obvious pattern between the difference and the mean of physical QoL domain scores.

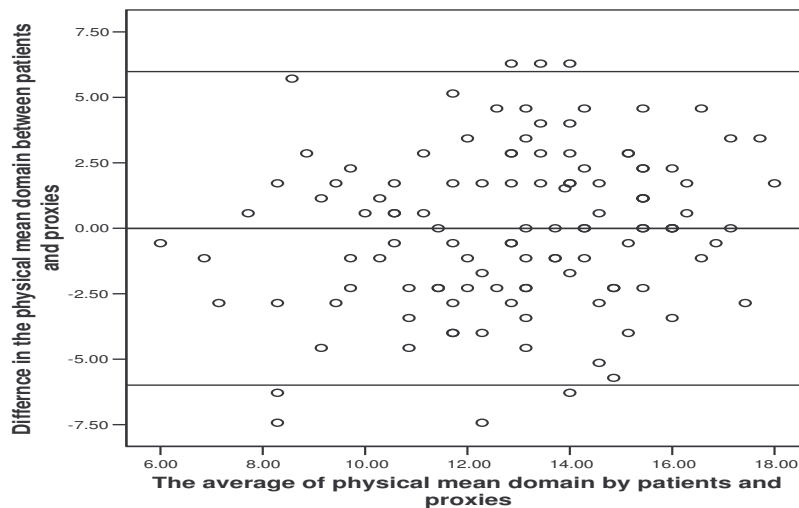


Figure 1: Bland-Altman plot between average of physical QoL mean domain scores of patients and nurses and difference between patients and nurses physical QoL mean domain scores

Thirdly, the QoL mean domain scores of nurses were compared to those of the patients using a paired t-test. The significance level was set at 0.05. The results of paired t-tests between physical, psychological, social relationship, and environmental domains of patients and nurses are reported in Table 4. Findings revealed that there were significant differences between social relationship domain scores of patients and nurses ($t=2.33$, $p < 0.005$) ($d.f=114$) and between environmental domain scores of patients and nurses ($t=4.78$, $p < 0.005$) ($d.f=116$). In these two domains, patients'

QoL domain scores were significantly higher than that of nurses, suggesting that nurses rated their patients as having an inferior QoL to what the patients rated themselves.

Table 4: Patient-Nurse agreement on the WHOQoL-BREF using t-test

QoL domain	Patients		Nurses		Patient-Nurse difference	
	Mean	SD	Mean	SD	Mean	SD
Physical	12.93	3.21	12.93	2.73	0.00	3.00
Psychological	14.58	2.63	14.03	2.35	0.55	3.05
Social relationship	15.64	2.73	14.92	2.26	0.72*	3.26
Environmental	15.85	1.86	14.84	2.17	1.01*	2.28

*Statistically significant difference between patient and nurse score ($P < 0.05$) using paired t-test

Influence of patients' and nurses' characteristics on the level of agreement between patients and nurses

At first, a Pearson correlation was conducted between patient-nurse absolute QoL mean domain differences (as the dependent variable) with patients and nurses' variables (as the independent variable). In line with a similar research study (Sneeuw et al. 1998) those with significant correlations (p value 0.05 or less) were then entered simultaneously into the equation and analysed using Standardized Multiple Regression analysis. Beta coefficients with p values of 0.05 or less were considered significant.

At the bivariate level using the Pearson correlation, several variables were identified to be significantly associated with the absolute difference between patients' and nurses' QoL domain scores. This is represented in Table 5. Larger differences between patient and nurse physical domain scores were noted when the nurses had less clinical experience with cancer patients, and for patients receiving non-chemotherapeutic treatments. In the psychological domain, greater differences between nurses and their patients were found to exist for inpatients, and patients who

were either in the level of ‘ambulatory but unable to do work activities’ or in the levels other than ‘restricted but ambulatory’ in their performance status. In the social relationship domain, greater differences were found for inpatients.

Finally, larger differences between patient and nurse environmental domain scores were noted for inpatients, non-married patients, younger nurses and nurses with less clinical experience. However, with Multivariate analysis, the nurses’ length of clinical experience with cancer patients ($\beta=-0.20$), where the patients were receiving treatment ($\beta=0.20$), and the patients’ marital status ($\beta=-0.20$) were the only statistically significant predictors of differences between patients and nurses scores obtained for the physical, social relationship and environmental QoL domain scores, respectively.

DISCUSSION

The major aims of this study were to identify the level of agreement between patients and nurses on patients’ QoL and to identify those variables that could affect the degree of agreement between patients’ and nurses’ QoL scores.

First, the WHOQoL-BREF questionnaire was identified as a reliable tool for assessing cancer patients’ QoL. Cronbach alpha of both patients’ and nurses’ QoL domain scores (except the social relationship domain) approached or was above the acceptable level of 0.70. In general, a high internal consistency may not be necessary for a multi-domain tool (Cella & Tulsky 1990) like WHOQoL-BREF questionnaire. The low internal consistency of the social relationship domain might be related to the low number of items (only three) and the content of the items (sex life, personal relationships, and friends) which was reported in another research study (Hanestad et al. 2004).

In general, results r and ICC support that there is no substantial agreement between each patient and nurse about a patient's QoL. This can be confirmed by checking the Bland-Altman scatter plots which shows around 6 points of difference (out of 20) between a patient's QoL score and a nurse's score.

Table 5: Bivariate(r) and Multivariate (β) correlation coefficients between patients and nurses characteristics and absolute difference between patients' and nurses' QoL mean domain

Patients' and nurses' characteristics	Absolute difference							
	Physical		Psychological		Social relationship		Environmental	
	r	β	r	β	r	β	r	β
Patient's gender Male (R) Female	0.02		0.10		0.02		-0.01	
Patient's age	0.02		-0.01		0.03			-0.01
Patient 's first language English(R) Other	0.13		-0.03		0.10			0.02
Patient's marital status• Single Married Divorced/Widowed Other (R)							-0.23*	-0.20*
Patient's current treatment• Chemotherapy Radiotherapy Surgery Other therapy More than one treatment (R)	-0.19*	-0.20						
Patient's treatment setting Outpatients (R) Inpatients	0.15		0.20*	0.14	0.20*	0.20*	0.27*	0.10
Patient performance status• Fully active Restricted but ambulatory Ambulatory but unable to do work activities Limited capability or disabled (R)			-0.20* 0.24*	-0.10 0.20				
Nurse's gender Male (R) Female	0.08		-0.05		0.03		-0.08	
Nurse's age	-0.15		-0.09		-0.09		-0.25*	-0.10
Nurse's language English(R) Other	-0.12		0.04		0.07		-0.09	
Time nurse spends with patients/shift	0.01		0.11		-0.02		0.05	
Nurse clinical experience	-0.18		-0.11		-0.06		-0.27*	-0.14
Nurse clinical experience with cancer patients	-0.23*	-0.20*	-0.18		-0.09		-0.13	

•As these categorical variables had more than two categories, they were entered into the equation after creating dummy coding variables. To simplify the table, patients' and nurses' characteristics where none of their dummy coding variables showed any significant relationship with difference between patients and nurses QoL mean domain scores at the bivariate level were deleted (patients' highest level of education, patients' current cancer diagnosis, nurses' marital status, nurses' educational level, nurses' QoL)

*significant; R: Reference group; r: Bivariate correlation; β : Beta coefficient

As other research studies have also reported (McPherson & Addington-Hall 2003; von Essen 2004) nurses had better agreement with their patients in QoL domains that consisted of more objective items such as the physical domain. In contrast, in the social relationship and psychological domains, which consisted of more private and subjective items such as questions about the patient's 'sex life' or 'friends', nurses were less successful in correctly rating patients' QoL. This may also show that the QoL is very subjective and individual in nature and might change from time to time according to patients' expectations, hopes and desires. It may not be achievable for nurses to accurately assess the patients' level of QoL because it might change frequently. However, other reasons such as how the QoL of patients may be important to them and their level of skill and expertise in relation to the assessment of patients' QoL may also be considered.

Moreover, nurses have different professional responsibilities as well as time limitations in providing nursing care. These time limits might prevent nurses from becoming adequately familiar with some aspects of patients' QoL like psychological and social relationships and environmental ones (Frost, Brueggen & Mangan 1997; Mohan et al. 2005).

A comparison of QoL domain scores of patients with nurses also revealed two important points. Firstly, except for the physical and psychological domains, nurses significantly underestimated patients' QoL. A reason might be that nurses do not have a clear understanding of these aspects of patients' QoL like social relationship and environmental domains and assumed the worst situation for the patients in these areas. This has been reported in many other research articles in which proxies reported lower levels of QoL than patients themselves did (Pierre et al. 1998; Sprangers, M.A.G. & Aaronson 1992). Nurses are usually around the patients

during their cancer journey. Patients may try to adapt themselves to the cancer, and underestimations in QoL by nurses might postpone this process, thus their role may not be as supportive as it may be otherwise.

The second point is that, except for the environmental QoL domain in which a large effect size between patients and nurses was identified, the QoL mean domains of nurses were the same or very close to those of patients (particularly the physical and psychological domains). Therefore, in line with the suggestion made by (Sneeuw et al. 1999), for those researchers who are interested in preventing missing data in QoL clinical trials comparing groups rather than individuals, means of QoL rating from nurses may provide a useful source of information.

No obvious pattern was identified from the scatter plot that may have implied that agreement between patients and nurses was better for a patient group with a specific level of QoL. This result differed from a study by Sneeuw et al. (1998) who reported more scatter (poorer agreement) at moderate levels of patient' QoL, with less scatter at either extreme. In this latter study outcomes indicated that proxies had a better understanding of QoL in those patients with either higher or lower rating of their QoL compared with those at the middle.

Several variables that may have influenced the level of patient-nurse agreement were also explored using Multivariate analysis. There was greater agreement between nurses with more clinical experience with cancer patients and patients in the physical QoL domain. Why a nurse who has more experience with cancer patients has a better understanding of a patients' QoL needs to be explored more. However, these nurses may have developed better assessment and communication skills in order to provide closer ratings on patients' QoL.

In the social relationship domain, there was more agreement between patients and nurses for patients treated in outpatient departments compared with inpatients. Despite the fact that a close and prolonged relationship with the patient (for example in inpatient departments) might increase the agreement (Magaziner et al. 1988) it could also lead to disagreement when a nurse was under the pressure of care giving (von Essen 2004). Outpatients might be coming to the clinic on a regular basis and this might allow nurses to get to know them quite well due to the continuity of care. In general, outpatients also had a better health status than inpatients and, as noted earlier, the level of agreement between patients and nurses might be better either when patients were very sick or very healthy (Sneeuw et al. 1998; Sneeuw et al. 1999). There may, of course, be other variables that are unique to the outpatient department that influenced the agreement.

Implication of findings for nursing practice and research

The main implication of the findings of this study is that nurses may need to enhance their understanding of patients' QoL. Nurses have an important supportive role toward cancer patients which includes physio-psycho-social concerns and needs. For achieving holistic health support, nurses need to understand a patient's QoL to assist them to make appropriate decisions in relation to patient care. For example, in decision making about what supportive services may suit a patient's needs, the following strategies may help nurses.

Firstly, if nurses are aware that their perceptions of QoL may differ to patients, then providing tools such as the WHOQoL-BREF questionnaire in the clinical area, may allow nurses to fully assess all aspects of patients' QoL instead of relying on their perceptions about QoL. This may lead to a better understanding of patients' QoL and a better standard of care.

Secondly, nurses may need to consider other sources of information about patients' QoL such as family, particularly their spouse, friends, and other health care professionals like doctors and social workers. Such sources may provide complementary information or may be useful when clients are not able to communicate appropriately with nurses. Of course, nurses need to consider the congruency between all sources of information.

Finally, the results that more experienced nurses have higher rating agreement with patients' QoL rating may be due to better communication and assessment skills. Therefore, to facilitate quality nursing care, training that allows nurses to develop a better understanding of the QoL concept, its importance to patients' QoL and how these tools may be used to facilitate systematic assessment of patients' QoL, may be useful. Alternatively, nurses may be able to help family care givers use the QoL tools to maximise standard of care in this area as well.

Study Limitations

The findings of this research study must be interpreted within its limitations. Firstly, an attempt was made to include as many nurses as possible in the research study (Broberger, Tishelman & von Essen 2005) however, like other research studies (Molzahn, Northcott & Dossetor 1997; Sneeuw et al. 1998) the number of nurses included was less than half of patients (42%). Nurses were well informed about the importance of the research and the need to complete the questionnaires as accurately as possible. However, the study was conducted in a very busy oncology environment and on some occasions this may have affected the nurses' concentration while completing the questionnaires.

Secondly, while some important variables of patients and nurses that may influence agreement were identified as significant, there may be other variables influencing this that were not included in this study.

Future research

This study needs to be conducted further with larger samples, particularly with a more representative sample of nurses. How nurses may have a better understanding of cancer patients' QoL, and how such perceptions may affect patients' QoL in either positive or negative ways, need to be explored further. These questions are presently being investigated in an interpretive study with oncology patients and nurses. Why nurses sometimes underestimate patients' QoL, why those nurses who work in outpatients cancer clinics and those who have more clinical experience with cancer patients may have a better understanding of patients' QoL may also be further investigated.

CONCLUSION

This study shows that differences exist between nurses' and patients' perceptions of cancer patients' QoL which may impact on the quality of patient care and support. To address this, strategies need to be devised that increase nurses' understanding of patients' QoL, particularly in the most neglected areas of psychological, social relationship, and environmental QoL domains. It is also important that nurses learn how to assess cancer patients' QoL thoroughly, possibly by using standardised QoL tools instead of relying heavily on their own intuitive perceptions which may lead to misunderstandings and misjudgements of a patients' QoL. Ultimately, increasing the level of agreement between nurses and their patients about patients' QoL makes it more likely that those experiencing a life-threatening illness will receive the care they need to maintain or improve their quality of life.

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Appendix B: The detailed process of one strategy for data collection in the first phase

1. Introduction

Dear Nursing staff member,

Thank you for your cooperation and also for your participation in this research study which is called: **‘A comparison of patients’ and nurses’ perceptions of cancer patients’ Quality of Life (QoL)’**

Any adult cancer patient (above 18 years old) with diagnosis of any kind of cancer (haematology or oncology) inpatient or outpatient and under any cancer treatment is welcome to participate in the research study provided that she (he) can read and circle the items in the questionnaire.

Any nurse is eligible to take part in the study if he (she) is familiar with the patient and is happy to complete the forms and the questionnaire as mentioned below. Your voluntary completion of the forms and questionnaire will be considered as **consent**.

2. Method: what you need to do

Please do the following steps:

A) If your patient has met the above inclusion criteria, would you please give him (her) **‘The patient information sheet’** which introduces the research study and ask if she (he) is prepared to fill out a questionnaire.

B) If the patient **verbally** confirms her (his) consent to participate with this survey, would you please complete **‘The patient clinical and demographic characteristic form’** and pass this form **‘The WHOQoL-BREF questionnaire’** to the patient from the set that has the **same number**.

C) Please ensure that the **questionnaire is completed by the patient on their own without any help** and returned to you together with **‘The participant information sheet’** on that day.

D) Please ask the patient to fold and staple the questionnaire before giving it back to you.

E) Please complete ‘**The nurse characteristic form**’ and the nurse survey ‘**The WHOQoL-BREF questionnaire**’ yourself from the set with the **same number** for the patient based on your perception about patient’s quality of life. Please do this **without** seeking the patient’s opinion.

F) You can complete the questionnaire immediately after the patient has done so or at any time on that day which is convenient for you.

G) Please return the completed set (The patient information sheet read by patient + The patient clinical and demographic characteristic form completed by you + The WHOQoL-BREF questionnaire completed by patient + The nurse characteristic form completed by you + The WHOQoL-BREF questionnaire completed by you for a patient) preferably as a stapled set to the principal researcher. Alternatively, you can deliver it to the Clinical Nurse Consultant in your Unit.

If you have queries about this survey, you can always contact me on (08) 8201 2071.

Yours sincerely,
Masoud Bahrami,
Principal researcher

Appendix C: Participant Information Sheet (Patient specific for the second phase)



‘A comparison of patients’ and nurses’ perceptions of cancer patients’ Quality of Life (QoL)’

As a student at Flinders University, enrolled in a PhD degree, I am seeking your assistance to take part in a study to compare and contrast the evaluation of Quality of Life (QoL) of cancer patients and nurses and the implications of the findings for nursing clinical practice.

If you choose to participate, you will be asked to participate in an interview about Quality of Life and this interview will be no longer than 60 minutes (which can also be done in two parts). This interview will be at a time and place of your convenience. These are the kinds of questions I will be asking: What does the term QoL mean to you? How do you usually think about your own QoL? What things do you think affect the way you think about your own quality of life?

Your participation in the study is entirely voluntary and you have the right to withdraw at any time. If you decide not to participate in this study or if you withdraw, you may do this freely without prejudice to any treatment at

All records containing personal information will remain confidential and no information that could lead to your identification will be released.

If you, as a participant of this research, suffer injury, compensation may, at the discretion of Flinders University, be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment.

Study results may be published in scientific journals at a later date. It is possible that the results may not be published because of commercial, scientific or other reasons. Also, the research results can be delivered to responsible persons at theto be used as a source for better care and support of cancer patients.

Should you require further details about the project, before, during or after the study, you may contact me on (08) 201 2071. Any further queries concerning the project can also be directed to my supervisor, Dr Steve Parker on (08) 201 3402.

This study has been reviewed by theClinical Research Ethics Committee. Should you wish to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Administrative Officer - Research,

Yours sincerely,
Masoud Bahrami

Appendix D: Participant Information Sheet (Nurse specific for the second phase)



‘A comparison of patients’ and nurses’ perceptions of cancer patients’ Quality of Life (QoL)’

As a student at Flinders University, enrolled in a PhD degree, I am seeking your assistance to take part in a study to compare and contrast the evaluation of Quality of Life (QoL) of cancer patients and nurses and the implications of the findings for nursing clinical practice. Your participation in the study is entirely voluntary and you have the right to withdraw at any time.

If you choose to participate, you will be asked to participate in an interview about Quality of Life and this interview will be no longer than 60 minutes (which can also be done in two parts). These are the kinds of questions I will be asking: What does the term QoL mean for you? How do you usually evaluate patients’ QoL? What factors do you believe may affect your perception in evaluating a patient’s QoL? How do you incorporate evaluations of a patient’s quality of life in your practice?

This interview will be at a time and place of your convenience. You may also be asked to participate in a focus group (no longer than one hour duration) to discuss finding ways to improve the Quality of Life for patients with cancer and the results of this study.

All records containing personal information will remain confidential and no information that could lead to your identification will be released.

If you, as a participant of this research, suffer injury, compensation may, at the discretion of Flinders University, be paid without litigation. However, compensation is not automatic and you may have to take legal action in order to receive payment.

Study results may be published in scientific journals at a later date. It is possible that the results may not be published because of commercial, scientific or other reasons. Also, the research results can be delivered to responsible persons at theto be used as a source for better care and support of cancer patients.

Should you require further details about the project, before, during or after the study, you may contact me on (08) 201 2071. Any further queries concerning the project can also be directed to my supervisor Dr Steve Parker on (08) 201 3402.

This study has been reviewed by theClinical Research Ethics Committee. Should you wish to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, your rights as a participant, or should you wish to make a confidential complaint, you may contact the Administrative Officer - Research,....

Yours sincerely,
Masoud Bahrami

Appendix E: The patient clinical and demographic characteristics form

Number of Form

1. Patient's gender Male Female

2. Patient's age.....years

3. What is patient's first language? (Please describe).....

4. Patient's marital status Single Married Divorced/Widowed Other

5. Patient's highest level of education Primary school Secondary school

Tertiary school

6 Patient's current cancer diagnosis (Please describe in full words).....
.....

7. Patient's most common current treatment (**tick more than one if applicable**)

Chemotherapy Radiotherapy Surgery Immunotherapy Other

8. Treatment Setting Outpatient Inpatient

9. Patient performance status (**Circle the appropriate Grade for the patient**)

Grade	Status
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities. Up and about more than 50% of waking hours
3	Capable of only limited self-care, confined to bed or chair more than 50% of waking hours
4	Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair

Appendix F: The WHOQoL-BREF questionnaire for patients

Number of Questionnaire

Instructions

This assessment asks how you feel about your quality of life, health, & other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the **last two weeks**.

Example:

	Not at all	Slightly	Moderately	Very	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

You would circle the number 4 if in the last two weeks you got a great deal of support from others

	Not at all	Slightly	Moderately	Very	Completely
Do you get the kind of support from others that you need?	1	2	3	4	5

but if you did not get any of the support from others that you needed in the last two weeks you would circle 1.

Thank you for your help.

Now turn to the back of this page

Please read each question and assess your feelings, for the last two weeks, and circle the number on the scale for each question that gives the best answer for you.

	Very poor	Poor	Neither Poor nor Good	Good	Very Good
1. How would you rate your quality of life?	1	2	3	4	5

	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
2. How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the **last two weeks**.

	Not at all	A Small amount	A Moderate amount	A great deal	An Extreme amount
3. To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5

4. How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
---	---	---	---	---	---

5. How much do you enjoy life?	1	2	3	4	5
--------------------------------	---	---	---	---	---

6. To what extent do you feel your life to be meaningful?	1	2	3	4	5
---	---	---	---	---	---

	Not at all	Slightly	Moderately	Very	Extremely
7. How well are you able to concentrate?	1	2	3	4	5

8. How safe do you feel in your daily life?	1	2	3	4	5
---	---	---	---	---	---

9. How healthy is your physical environment?	1	2	3	4	5
--	---	---	---	---	---

	Not at all	Slightly	Somewhat	To a great extent	Completely
10. Do you have enough energy for every day life?	1	2	3	4	5

11. Are you able to accept your bodily appearance?	1	2	3	4	5
--	---	---	---	---	---

12. Have you enough money to meet your needs?	1	2	3	4	5
---	---	---	---	---	---

13. How available to you is the information you need in your daily life?	1	2	3	4	5
--	---	---	---	---	---

14. To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
--	---	---	---	---	---

	Not at all	Slightly	Moderately	Very	Extremely
15. How well are you able to get around physically?	1	2	3	4	5

The following questions ask you to say how good or satisfied you have felt about various aspects of your life over **the last two weeks**.

	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
16. How satisfied are you with your sleep?	1	2	3	4	5
17. How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18. How satisfied are you with your capacity for work?	1	2	3	4	5
19. How satisfied are you with yourself?	1	2	3	4	5
20. How satisfied are you with your personal relationships?	1	2	3	4	5
21. How satisfied are you with your sex life?	1	2	3	4	5
22. How satisfied are you with the support you get from your friends?	1	2	3	4	5
23. How satisfied are you with the conditions of your living place?	1	2	3	4	5
24. How satisfied are you with your access to health services?	1	2	3	4	5
25. How satisfied are you with your transport?	1	2	3	4	5

	Never	Infrequently	Sometimes	Frequently	Always
26. How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

THE END

Appendix G: The nurse characteristics form

Number of Form

1. Nurse's gender Male Female

2. Nurse's age.....years

3. What is your first language? (Please describe).....

4. Nurse's marital status Single Married Divorced/Widowed Other

5. Nurse's highest level of qualification RN Certificate Dip.N B.N

Master PhD Other (Please describe).....

6. Approximate how much time you have spent providing care for this patient per shift? hour/s

7. How much clinical experience have you had?years

8. How much experience have you had with nursing patients with cancer?years

9. Please answer the following question in which you as a nurse ask to assess your own quality of life (**Please circle the appropriate number about your life for the last two weeks**)

	Very poor	Poor	Neither Poor nor Good	Good	Very Good
How would you rate your quality of life?	1	2	3	4	5

Appendix H: The WHOQoL-BREF questionnaire to be completed by nurses for a patient

Number of Questionnaire

Instructions

This assessment asks how you feel about your patient’s quality of life, health, & other areas of their life. We are asking you to complete this survey specifically about your patient and the quality of life (QoL) you believe this patient has. **Please answer all the questions.** If you are unsure about which response to give to a question, please choose the one that appears most appropriate. This can often be your first response.

Please keep in mind the patient’s standards, hopes, pleasures and concerns. We ask that you think about the patient’s life in the **last two weeks.**

Example:

	Not at all	Slightly	Moderately	Very	Completely
Does the patient get the kind of support from others that he or she needs?	1	2	3	4	5

You would circle the number 4 if you think in the last two weeks the patient received a great deal of support from others

	Not at all	Slightly	Moderately	Very	Completely
Does the patient get the kind of support from others that he or she needs?	1	2	3	4	5

but if you think the patient did not receive any support from others that he or she needed in the last two weeks, you would circle 1.

Thank you for your help.

Now turn to the back of this page

Please read each question and assess your feelings, for the last two weeks, and circle the number on the scale for each question that provides the best answer.

	Very poor	Poor	Neither Poor nor Good	Good	Very Good
1. How would you rate the patient's quality of life?	1	2	3	4	5

	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
2. How satisfied is the patient with his(her) health?	1	2	3	4	5

The following questions ask about how much the patient has experienced certain things in the **last two weeks**.

	Not at all	A Small amount	A Moderate amount	A great deal	An Extreme amount
3. To what extent do you feel that physical pain prevents the patient from doing what she(he) needs to do?	1	2	3	4	5

4. How much does the patient need any medical treatment to function in his or her daily life?	1	2	3	4	5
---	---	---	---	---	---

5. How much does the patient enjoy his or her life?	1	2	3	4	5
---	---	---	---	---	---

6. To what extent do you feel the patient's life to be meaningful?	1	2	3	4	5
--	---	---	---	---	---

	Not at all	Slightly	Moderately	Very	Extremely
7. How well is the patient able to concentrate?	1	2	3	4	5

8. How safe does the patient feel in his or her daily life?	1	2	3	4	5
---	---	---	---	---	---

9. How healthy is the patient's physical environment?	1	2	3	4	5
---	---	---	---	---	---

	Not at all	Slightly	Somewhat	To a great extent	Completely
10. Does the patient have enough energy for every day life?	1	2	3	4	5

11. Is the patient able to accept his or her bodily appearance?	1	2	3	4	5
---	---	---	---	---	---

12. Has the patient enough money to meet his or her needs?	1	2	3	4	5
--	---	---	---	---	---

13. How available is information that is needed for the patient's daily life?	1	2	3	4	5
14. To what extent does the patient have the opportunity for leisure activities?	1	2	3	4	5
	Not at all	Slightly	Moderately	Very	Extremely
15. How well is the patient able to get around physically?	1	2	3	4	5

The following questions ask you to say how good or satisfied the patient has felt about various aspects of his or her life over the **last two weeks**.

	Very Dissatisfied	Fairly Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
16. How satisfied is the patient with his or her sleep?	1	2	3	4	5
17. How satisfied is the patient with his or her ability to perform his or her daily living activities?	1	2	3	4	5
18. How satisfied is the patient with his or her capacity for work?	1	2	3	4	5
19. How satisfied is the patient with himself or herself?	1	2	3	4	5
20. How satisfied is the patient with his or her personal relationships?	1	2	3	4	5
21. How satisfied is the patient with his or her sex life?	1	2	3	4	5
22. How satisfied is the patient with the support he or she gets from his or her friends?	1	2	3	4	5
23. How satisfied is the patient with the conditions of his or her living place?	1	2	3	4	5
24. How satisfied is the patient with his or her access to health services?	1	2	3	4	5
25. How satisfied is the patient with his or her transport?	1	2	3	4	5
	Never	Infrequently	Sometimes	Frequently	Always
26. How often does the patient have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

THE END

Appendix I: Labelling the WHOQoL-BREF items and calculating the mean domains for patients and nurses as proxies

- W1 "Rate QoL"
- W2 "Health satisfaction"
- W3 "Pain prevents doing"
- W4 "Need medical treatment"
- W5 "Enjoy life"
- W6 "Life is meaningful"
- W7 "Concentrate"
- W8 "Safe in your daily life"
- W9 "Healthy physical environment"
- W10 "Energy for everyday life"
- W11 "Accept bodily appearance"
- W12 "Money to meet needs"
- W13 "Information available"
- W14 "Opportunity for leisure activities"
- W15 "Able to get around"
- W16 "Sleep"
- W17 "Daily living activities"
- W18 "Capacity for work"
- W19 "Satisfied with yourself"
- W20 "Personal relationships"
- W21 "Sex life"
- W22 "Friends"
- W23 "Conditions of your living place"
- W24 "Access to health services"
- W25 "Transportation"
- W26 "Negative feelings".

Physical domain consists of items: (W3, W4, W10, W15, W16, W17, and W18).

Psychological domain consists of items: (W5, W6, W7, W11, W19, W26).

Social domain consists of items: (W20, W21, W22).

Environment domain consists of items: (W8, W9, W12, W13, W14, W23, W24, and W25).

MD1 = 4*(Mean (W3r, W4r, W10, W15, W16, W17, W18)).

MD2 = 4*(Mean (W5, W6, W7, W11, W19, W26r)).

MD3 = 4*(Mean (W20, W21, W22)).

MD4 = 4*(Mean (W8, W9, W12, W13, W14, W23, W24, W25)).

MD=Mean Domain r=Reversed

nMD1 = 4*(Mean (nW3r, nW4r, nW10, nW15, nW16, nW17, nW18)).

nMD2 = 4*(Mean (nW5, nW6, nW7, nW11, nW19, nW26r)).

nMD3 = 4*(Mean (nW20, nW21, nW22)).

nMD4 = 4*(Mean (nW8, nW9, nW12, nW13, nW14, nW23, nW24, nW25)).

N=Nurse r=Reversed

Appendix J: Outcomes of SPSS for reliability testing (patients and nurses)

Reliability (Patients)

Reliability Statistics

Cronbach's Alpha	N of Items
.885	26

Item Statistics

	Mean	Std. Deviation	N
"Rate QoL"	3.6645	.96212	155
"Health satisfaction"	2.8774	1.19161	155
"Enjoy life"	3.6710	.97441	155
"Life is meaningful"	3.7032	.98807	155
"Concentrate"	3.5355	.83181	155
"Safe in your daily life"	3.6839	.86606	155
"Healthy physical environment"	3.7097	.82153	155
"Energy for daily life"	3.0000	1.09900	155
"Accept bodily appearance"	3.7484	1.09065	155
"Money to meet needs"	3.6194	1.09468	155
"Information available"	3.8387	.82560	155
"Opportunity for leisure activity"	2.9226	1.14832	155
"Able to get around"	3.3871	1.02809	155
"Sleep"	3.1419	1.22442	155
"Daily living activities"	3.0323	1.18661	155
"Capacity for work"	2.5806	1.22671	155
"Satisfied with yourself"	3.4452	1.11741	155
"Personal relationship"	4.1806	.92210	155
"Sex life"	3.1097	1.34632	155
"Friends"	4.3355	.82397	155
"Conditions of living place"	4.4516	.78288	155
"Access to health services"	4.4645	.74970	155
"Transportation"	4.3419	.79314	155
"Pain prevents doing"	3.4000	1.23583	155
"Need medical treatment"	3.0903	1.08931	155
"Negative feelings"	3.4194	.96612	155

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
"Rate QoL"	88.6903	170.436	.541	.879
"Health satisfaction"	89.4774	165.186	.599	.877
"Enjoy life"	88.6839	170.620	.525	.880
"Life is meaningful"	88.6516	171.865	.467	.881
"Concentrate"	88.8194	171.954	.564	.879
"Safe in your daily life"	88.6710	170.352	.612	.878
"Healthy physical environment"	88.6452	174.776	.437	.882
"Energy for daily life"	89.3548	163.932	.704	.875
"Accept bodily appearance"	88.6065	171.149	.442	.882
"Money to meet needs"	88.7355	177.131	.227	.887
"Information available"	88.5161	176.031	.376	.883
"Opportunity for leisure activity"	89.4323	166.273	.586	.878
"Able to get around"	88.9677	165.850	.681	.876
"Sleep"	89.2129	172.805	.331	.885
"Daily living activities"	89.3226	162.480	.696	.874
"Capacity for work"	89.7742	163.916	.622	.877
"Satisfied with yourself"	88.9097	164.992	.652	.876
"Personal relationship"	88.1742	176.833	.296	.885
"Sex life"	89.2452	176.277	.192	.890
"Friends"	88.0194	179.993	.193	.886
"Conditions of living place"	87.9032	178.322	.287	.885
"Access to health services"	87.8903	181.241	.156	.887
"Transportation"	88.0129	176.649	.364	.883
"Pain prevents doing"	88.9548	170.628	.396	.883
"Need medical treatment"	89.2645	174.196	.333	.884
"Negative feelings"	88.9355	172.282	.462	.881

Scale Statistics

Mean	Variance	Std. Deviation	N of Items
92.3548	184.945	13.59944	26

Reliability (Nurses)

Reliability Statistics

Cronbach's Alpha	N of Items
.918	26

Item Statistics

	Mean	Std. Deviation	N
Rate QoL (Nurses)	3.5130	.87251	154
Health satisfaction (Nurses)	2.6039	.89602	154
Enjoy life (Nurses)	3.4481	.80879	154
Life is meaningful (Nurses)	3.8831	.79169	154
Concentrate (Nurses)	3.7208	.82046	154
Safe in your daily life (Nurses)	3.6883	.75424	154
Healthy physical environment (Nurses)	3.7662	.73912	154
Energy for everyday life (Nurses)	2.9675	.85878	154
Accept bodily appearance (Nurses)	3.4221	.82274	154
Money to meet needs (Nurses)	3.5195	.77730	154
Information available (Nurses)	3.8506	.81475	154
Opportunity for leisure activities (Nurses)	2.8377	.92511	154
Able to get around (Nurses)	3.4805	.87239	154
Sleep (Nurses)	3.1169	.85519	154
Daily living activities (Nurses)	3.2273	.90404	154
Capacity for work (Nurses)	2.7792	.93757	154
Satisfied with yourself (Nurses)	3.2857	.86102	154
Personal relationships (Nurses)	3.9416	.82634	154
Sex life (Nurses)	3.0000	.89296	154
Friends (Nurses)	4.0909	.67990	154
Conditions of your living place (Nurses)	3.9805	.70914	154
Assess to health services (Nurses)	4.0195	.69987	154
Transportation (Nurses)	3.8377	.79599	154
Pain prevents doing (Nurses)	3.4805	1.02403	154
Need medical treatment (Nurses)	3.0130	.99664	154
Negative feelings (Nurses)	3.1299	.82209	154

Item-Total Statistics

	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Cronbach's Alpha if Item Deleted
Rate QoL (Nurses)	86.0909	141.312	.701	.912
Health satisfaction (Nurses)	87.0000	143.725	.562	.914
Enjoy life (Nurses)	86.1558	141.583	.747	.911
Life is meaningful (Nurses)	85.7208	145.248	.562	.914
Concentrate (Nurses)	85.8831	147.437	.426	.917
Safe in your daily life (Nurses)	85.9156	145.372	.586	.914
Healthy physical environment (Nurses)	85.8377	145.784	.576	.914
Energy for everyday life (Nurses)	86.6364	142.416	.656	.913
Accept bodily appearance (Nurses)	86.1818	146.385	.479	.916
Money to meet needs (Nurses)	86.0844	147.934	.427	.916
Information available (Nurses)	85.7532	148.658	.367	.917
Opportunity for leisure activities (Nurses)	86.7662	142.742	.588	.914
Able to get around (Nurses)	86.1234	143.194	.606	.913
Sleep (Nurses)	86.4870	147.899	.383	.917
Daily living activities (Nurses)	86.3766	140.707	.703	.912
Capacity for work (Nurses)	86.8247	141.178	.653	.912
Satisfied with yourself (Nurses)	86.3182	141.277	.713	.912
Personal relationships (Nurses)	85.6623	148.042	.392	.917
Sex life (Nurses)	86.6039	150.202	.256	.920
Friends (Nurses)	85.5130	149.585	.394	.917
Conditions of your living place (Nurses)	85.6234	148.498	.440	.916
Assess to health services (Nurses)	85.5844	149.003	.416	.917
Transportation (Nurses)	85.7662	146.102	.513	.915
Pain prevents doing (Nurses)	86.1234	143.285	.501	.916
Need medical treatment (Nurses)	86.5909	141.276	.605	.913
Negative feelings (Nurses)	86.4740	148.107	.391	.917

Scale Statistics

Mean	Variance	Std. Deviation	N of Items
89.6039	156.607	12.51426	26

Appendix K: The ICC between patients' and nurses' scores for all 26 items on the WHOQoL- BREF questionnaire

Number of item	ICC
Rate QoL	0.29
Health satisfaction	0.29
Pain prevents doing	0.32
Need medical treatment	0.24
Enjoy life	0.08
Life is meaningful	0.05
Concentrate	0.10
Safe in your daily life	0.14
Healthy physical environment	0.19
Energy for everyday life	0.44
Accept bodily appearance	0.04
Money to meet needs	0.18
Information available	0.19
Opportunity for leisure activities	0.15
Able to get around	0.30
Sleep	0.34
Daily living activities	0.28
Capacity for work	0.38
Satisfied with yourself	0.19
Personal relationships	0.12
Sex life	0.15
Friends	0.05
Conditions of your living place	0.05
Access to health services	0.07
Transportation	0.12
Negative feelings	0.05

Appendix L: The proportion of exact agreement between patients' and nurses' scores for all 26 items on the WHOQoL-BREF questionnaire

Number of item	Proportion of exact agreement between patients and nurses
Rate QoL	44.0%
Health satisfaction	32.0%
Pain prevents doing	35.0%
Need medical treatment	35.0%
Enjoy life	41.0%
Life is meaningful	33.0%
Concentrate	37.0%
Safe in your daily life	42.0%
Healthy physical environment	41.0%
Energy for everyday life	42.0%
Accept bodily appearance	31.0%
Money to meet needs	36.0%
Information available	36.0%
Opportunity for leisure activities	34.0%
Able to get around	36.0%
Sleep	32.0%
Daily living activities	30.0%
Capacity for work	34.0%
Satisfied with yourself	31%
Personal relationships	40.0%
Sex life	22.3%
Friends	39.0%
Conditions of your living place	33.0%
Access to health services	38.0%
Transportation	35.0%
Negative feelings	34.0%
Average	35.5%

Appendix M: Bland-Altman test for measuring agreement between patients and nurses

First, I create two new variables in the SPSS data file: 1-difference between mean domains as assessed by patients and proxies (say, diff) and 2- the average of the two mean domains as assessed by patients and nurses (say, mmean). I calculated this via Transform > compute.

Secondly, I calculate the standard deviation of the new diff variable via Analyse > Descriptive Statistics > Descriptive. The standard deviation (S) was 3.04, 3.16, 3.60, and 2.30 for physical, psychological, social, and environmental domains, respectively.

Thirdly, I create the scatter plot of the difference against the mean. I do this from Graphs > Scatter > Simple > Define. I put the diff in the Y-axis box and the mmean in the X-axis box. Then OK.

After creating the chart, it edits to include the limits of agreement. After a double click on the chart, the Chart Editor will be created. Then Chart >Add Chart Elements > Y Axis Reference Line > Reference Line. I need to add in Y Axis Position three numbers: mean - 2S, mean, and mean + 2 S. We would expect 95% of the differences to lie between mean plus two standard deviation and mean minus two standard deviation provided that differences are normally distributed. Such differences are likely to follow a normal distribution because we have removed a lot of the variation between subjects and are left with the measurement error. The averages of the difference for physical, psychological, social, and environmental domains were -0.27, 0.31, 0.64, and 0.79, respectively. Therefore, the other two “limit of agreement” calculates as below:

Physical domain:

$$\text{Mean} - 2S = -0.27 - (2 \times 3.04) = -6.35, \quad \text{Mean} + 2S = -0.27 + (2 \times 3.04) = 5.81$$

Psychological domain:

$$\text{Mean} - 2S = 0.31 - (2 \times 3.16) = -6.01, \quad \text{Mean} + 2S = 0.31 + (2 \times 3.16) = 6.63$$

Social relationship domain:

$$\text{Mean} - 2S = 0.64 - (2 \times 3.60) = -6.56, \quad \text{Mean} + 2S = 0.70 + (2 \times 3.26) = 7.22$$

Environmental domain:

$$\text{Mean} - 2S = 0.79 - (2 \times 2.31) = -3.83, \quad \text{Mean} + 2S = 0.79 + (2 \times 2.31) = 5.41$$

For each number I use the Apply > Close. After entering the three numbers, close the Chart Editor.

There is also an option which is named “precision of estimated limits of agreement (Bland & Altman 1986). It states that sometimes we want to use standard errors and confidence intervals to see how precise our estimates are. By then calculating 95% confidence intervals for the upper and lower limits of agreement we can derive the most optimistic (by using the lower confidence limit of the upper limit of agreement, and the upper confidence limit of the lower limit of agreement) and the most conservative (by using the upper limit of the upper limit of agreement, and the lower confidence limit of the lower limit of agreement) estimates of the range of bias. The standard error of the mean difference (i.e., the bias) is $\sqrt{S^2/n}$, where n is the sample size, and the standard error mean $- 2S$ and mean $+ 2S$ is about $\sqrt{3S^2/n}$. 95% confidence intervals can be calculated by finding the appropriate point of the t distribution with n-1 degrees of freedom, on most tables the columns 5% or 0.05. Then the confidence interval will be from the observed value minus t standard errors to the observed value plus t standard errors.

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