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# A shared revelation

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A comparative, triangulated study on  
Improving Quality of Life  
in the Terminally Ill

by  
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requirements for the degree of

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# Abstract

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This thesis examines the concept and measurement of quality of life (QOL) in the terminally ill and how this QOL can be improved within a hospice setting. Three threads are examined to help come to an understanding of how an improvement in QOL for the terminally ill can be achieved. These threads are: what effect present hospice care has on patients' QOL; how effective nurses are at understanding the patients' perspective of that QOL; and, whether nurses could contribute to an improvement in that QOL.

Seventy two patients and ten nurses participated in this comparative, triangulated research project. A control and intervention group of patients enabled comparison of the effects of an intervention (joint care planning by patient and nurse based on the patient's QOL assessment results) on patients' QOL. In the quantitative aspect of the study, a QOL questionnaire was used, by patients and nurses, to provide objective data. This quantitative data was illuminated and extended by qualitative methods namely, formal and informal interviews, written comments, field observations, and a nursing focus group.

The findings of the study reveal that a better understanding of the patient can be achieved if nurses have access to the patient's QOL perspective. This better understanding, when translated into meeting patients' QOL priorities and needs, results in clinically significant improvements in their QOL. Reflective practice in nurses, promoted by exposure to differences in patient/nurse perspectives, was demonstrated. Reflective practice resulted in behavioural changes in the participating nurses, increasing their awareness of QOL issues for subsequent patients and influencing their on-going palliative care.

The theme of 'revelation' encapsulates the insights gained from the research process for patients, nurses, and the researcher. Such revelation was personal and, in some cases, life-changing for the patients, and involved both personal and professional dimensions for the others. The study concludes by suggesting ways in which revelation can be sustained in the hospice setting. The recommendations cover personal, professional, and organisational dimensions. If implemented, the recommended changes would enhance patients' QOL through the continuing development of advanced palliative care nursing skills. The early pioneering philosophy of palliative care would thus be perpetuated in the development of new ways of caring. Palliative care could then confidently continue to demonstrate its unique place within the health services.

## Preface

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Palliative nursing is both extremely rewarding and infinitely challenging. The privilege of being part of such a significant event as death, is preceded by the responsibility to contribute meaningfully to the journey that comes before it. All nurses have experienced a “good death” where patient and family are at peace with themselves and the world. All nurses have also experienced death where all our medical and nursing skills, diligently and conscientiously applied, have failed to bring about the dignity of death that we try so hard to achieve. Sometimes this deficit is because symptoms are unable to be satisfactorily controlled; sometimes a reflection of where the patient is in their world, (and anger and frustration are a natural part of this world); and, sometimes because we have not accessed what is really meaningful for that patient and addressed their need.

It is this latter dimension that has prompted this study. Nursing can always be improved and palliative care, along with all other specialities, needs to continually seek new ways to do things that will benefit both patient and their ‘family’ (or whatever relationships are significant to the patient). Because new ways are only embraced when the old is seen to be inadequate, research and education in palliative care are best driven by practice issues. I was therefore anxious to complete a research project that would, perhaps, answer some of my own personal and professional concerns about palliative care nursing, and offer a new way of doing things in the hospice where I worked. Our Clinical Charge Nurse, Belinda Hodge, suggested that work on Quality of Life would be valuable. And so it proved. I hope that you, the reader, will also find value and learning from participating in the experiences that follow.

## Acknowledgements

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Behind every researcher's offerings are a treasure store of hidden contributors. This study is no exception. Chief of these contributors is *the* Word, the source of all creation and without whom none of these words would have come to pass.

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The Nursing Education Research Foundation and the Graduate Research Fund both contributed financially to this project. I thank them for their assistance.

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# Chapter One

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## INTRODUCTION AND OVERVIEW

Slowly, I learn about the importance of powerlessness.  
I experience it in my own life and I live with it in my work.  
The secret is not to be afraid of it - not to run away.  
The dying know we are not God.  
All they ask is that we do not desert them.

Twycross (1995, p.139)

### Introduction

Early in the 20th century, terminally ill people were dying in undesirable conditions. Modern hospice care was a dynamic response to this lack of care. The prevailing medical philosophy of being isolated and ignored once cure was not possible was replaced with an emphasis on total holistic care (rather than cure), alleviation of suffering, and a dignified death. In general this palliative care was seen as the domain of specialist hospital services and hospices. Palliative care is now defined as the active total care of patients whose disease cannot be cured (World Health Organisation (WHO), 1990, 1994). This total care involves control of physical symptoms, including pain, and also care of the psychological, social, and spiritual problems that are a part of every patients' total pain (Hanson & Cullihall, 1996; MacLeod, 1996; Strang, 1997). Schipper (1992) claims that with the acceptance of palliative care into mainstream medicine, this total care approach is no longer seen as being reserved for patients facing imminent death. Rather palliative care now represents a multidisciplinary approach to the reduction of suffering at any point of the illness trajectory.

There is, however, an inherent danger in this assimilation of specialist palliative care into the general medical milieu. Palliative care may lose its pioneering philosophy if it fails to retain its financial independence, loses its ability to challenge the status quo, and fails to educate and equip specialist staff to continually improve the standard of care provided. The goal of palliative care is to achieve the best possible quality of life (QOL) for patients and their families (Axelsson & Sjoden, 1998; Cohen, Mount, Bruera, Provost, Row & Tong, 1997; Hanson & Cullihall, 1996; WHO, 1990). If the philosophy of palliative care is compromised, that goal could then be at risk.

The education of specialist palliative care staff in assessing and meeting the needs of their patients is germane to achieving this goal of QOL and retaining the unique nature of hospice care. This study, therefore, seeks to discover how hospice nurses can improve



terminally ill patients' QOL through accurate assessment and jointly planned interventions. In addressing this broad aim, the QOL concept and measurement; nurses' ability to accurately assess their patients' QOL and work with the patient to increase that QOL; and, the effect of reflective practice in promoting advanced palliative care nursing, are all considered.

## **Quality of life**

A difficulty for palliative care health professionals, at a clinical and political level, arises from a lack of definitive understanding of how the best possible QOL may be achieved. Because QOL is a multidimensional, dynamic and subjective concept it is difficult to define and measure (Allison, Locker & Feine, 1997; Donnelly & Walsh, 1996; Gill & Feinstein, 1994; Holmes, 1998; King et al. 1997). There is general consensus that the patient's perspective (subjectivity) is essential in measuring QOL (Bredart & Razavi, 1997; Cella, 1994; Gill & Feinstein; McGregor, 1994). There is, however, less unanimity about what specific dimensions should be included and how these dimensions are defined (Cella; Clinch, Dudgeon, & Schipper, 1998).

## **Measurement of QOL**

Early assessments of QOL focussed on physical symptoms and functioning and used a 'standard needs' (all patients have similar needs and priorities) approach. In the last decade assessments have been broadened to include four dimensions: physical, psychological, social/role functioning and symptoms (Bredart & Razavi, 1997; Cohen, Mount, Strobel & Bui, 1995; King et al. 1997). These more recent QOL assessments vary between a standard needs and an idiographic design. While this more comprehensive approach reflects a greater understanding of the holistic nature of QOL, these revised QOL instruments still ignore the existential (philosophical, moral, spiritual) domain, a domain of much importance for those with a life threatening illness (Axelsson & Sjoden, 1998; Cohen et al.; Donnelly & Walsh, 1996; Hamilton, 1998). Most recently, tools specific to QOL assessment in advanced cancer and palliative care populations, have endeavoured to both include the existential domain and provide for identification of both negative and positive outcomes which contribute to QOL (Byock & Merriman, 1998; Clinch et al. 1998). Such an assessment enables patients to identify for themselves, and others, the areas of their lives where suffering is present.

QOL assessment has also been acknowledged as the most effective measure of patient satisfaction with care (Tierney, Horton, Hannan & Tierney, 1998), thus providing an important element in evaluating health spending. Despite the availability of suitable tools and the desirability of such measurement, there has been little research on the

effectiveness of hospice care on patients' QOL. Existing studies have largely compared the outcomes of hospital, hospice and home care on QOL. Those hospice studies which include QOL measurement reveal a stable QOL in terminally ill patients. There have been no comparative hospice studies seeking to evaluate the effectiveness of a nursing intervention on improving QOL.

This study will use a QOL assessment tool, specifically developed for the terminally ill, to measure the effectiveness of a specific nursing intervention on hospice patients' QOL.

### **Nursing assessments of patient needs**

Hospice nurses contribute to terminally ill patients' QOL by providing multi-dimensional care through nursing interventions. The effectiveness of nurses in assessing and responding to patients' QOL needs is crucial to providing such care. Evidence suggests that, although nurses endeavour and succeed in making their care patient-centred, there may well be a discrepancy between what the patient needs for maximum enhancement of QOL and what they receive (Bottorff et al. 1998; Heaven & Maguire, 1997; McMillan, 1996; Rathbone, Horsley & Goacher, 1994). Despite the acknowledged discrepancy between patient and nurse in assessing the patient's QOL needs, there has been no comparative research on differences between patient/nurse assessment of QOL in palliative care and how this assessment may be improved.

This study, therefore, compares patient and nurse assessment of patients' QOL both on admission and seven to ten days later to identify discrepancies and any change in the nurses' ability to accurately assess patient QOL.

In addition, as hospices become more dependent on the limited health dollar there is a constant pressure to cut down costs and to audit care. This drive for economy places considerable pressure on clinical staff to do more in less time. A smaller work force results in a decline in the quality time available to spend with patients. Under conditions of heavy workload and reduced staff numbers it is easy to focus on physical cares, namely symptom control and hygiene, although these may be less important to the patient in achieving QOL. Nursing assessments of patients may also be compromised and the consequent lack of appropriate interventions can negatively affect care and QOL. Individualised patient assessment through a valid and reliable QOL instrument may offer a clinically practical and time-effective way of achieving an accurate understanding of patients' current state of being. Using the questionnaire results as the basis for on-going discussion, nurses can move more quickly into a caring relationship which seeks to involve the patient in setting aims and priorities to meet their needs. Patient involvement and empathetic understanding from the nurse is essential to achieve QOL in the terminally ill. There has been no comparative research on the effect of using patients' QOL assessments to improve QOL.

This study, therefore, compares the QOL of two groups of patients. The control group of patients received normal hospice care and the intervention group received jointly planned care based on the insights and information gained from their QOL assessment. Comparison of the QOL of both groups will inform health professionals about the effect of joint care planning, (based on QOL assessment), on patients' QOL.

### **Achieving and verifying skilled palliative care nursing**

Aranda (1998) emphasises the need for nurses to identify their palliative care skills if palliative care is to be developed and continue as a recognised nursing speciality. Other authors also identify the challenge for nurses to justify their role and identify the skills, knowledge and specialist interpersonal care they provide (Duke & Copp, 1992; Jennings, 1991; Wilkes, 1998). Achieving such advanced palliative care nursing practice is difficult. Because of the abstract quality of patients' needs in the psychological, emotional and spiritual domains it is difficult to teach skills in this area. Professional skills, including medical and procedural knowledge, which are delivered with care and compassion, are essential and can be taught. However, *phronesis*, (i.e. practical wisdom) may be an equally necessary component of palliative care. *Phronesis* is utilised in the 'how, when and which' of professional skills are used, which leads to holistic caring (Randall & Downie, 1996). Although such wisdom will vary according to the individual nurse's personality and life experience, it could be argued that access to the patients' perspective will enhance the nurses' ability to understand and respect the uniqueness of each individual. When nurses are encouraged to evaluate their own assessment of the patient and reflect on identified differences between them, personal wisdom may be increased. Reflective practice on both the patient's understanding of their world and how accurately (or otherwise) the nurse is able to deduce this world may promote the skills and experience needed for advanced nursing practice in palliative care. In this study nurses received tangible feedback on their assessment skills, and the effectiveness of their interventions in promoting patient QOL, to help promote such reflective practice.

The broader context of resource rationing, as governments and funding agencies strive to achieve a balance between utility (greatest good for the greatest number), justice (equality of access and treatment) and finite health care fund allocations (Schipper, 1992; Stewart, Teno, Patrick & Lynn, 1999), also affects palliative care nursing. As part of the justification for health care funding, health authorities are demanding objective, measured service outcomes (Bullinger, 1992; Rathbone et al, 1994). As already identified, many aspects of palliative care nursing are not easily able to be standardised or quantified since much of the data are subjective and personal, and concerned with high order outcomes (Cooper, 1991; MacLeod & James, 1997; Robbins, 1998). When nurses can practice advanced palliative care they increase patients' and their own satisfaction with the care provided, become more competent and confident in challenging the organisational culture

in which they work, and potentially evolve a stronger professional position from which to debate health reforms.

Deep reflection, which seeks to extend the bounds of clinical practice, is important in extending the skills of palliative care nurses (Duke & Copp, 1994; MacLeod & James, 1998). Yet there has been no comparative research on the use of reflective practice to help improve palliative care nursing. It is suggested that a QOL instrument is able to help identify and quantify what would otherwise be invisible nursing interactions, promote reflective practice and, thus, both validate the positive outcomes of skilled palliative care nursing and provide stronger justification for funding this service.

This study, therefore, addresses the goal of improving hospice care to maximise terminally ill patients' QOL. Research steps to achieve that goal involve examining:

- \* the effectiveness of joint patient/nurse care planning in improving QOL;
- \* the ability of palliative care nurses to accurately assess their patients and provide holistic care; and,
- \* the development of advanced palliative care nursing skills through the use of reflective practice.

## **Study design**

Nurse researchers are increasingly using both quantitative and qualitative methods to better understand participants' experience (Coyle & Williams, 2000). Such was the case in this study. A combination of research paradigms was necessary because methodological and method divergence was required (triangulation) to gather the data needed to address the above three steps. In this study quantitative QOL assessments from both patient and nurse were achieved by a questionnaire survey. A psychometrically valid questionnaire, tested with a similar client group, was completed and the results statistically analysed. Qualitative semi-structured interviews were conducted with a sample of patients to validate the questionnaire findings. These interviews also sought to establish the cause of any changes in patients' QOL. Nurses also completed a semi-structured interview at the end of the data collection. This interview provided an opportunity for nurses to share their views on the research process and discuss any learning that had occurred as they reflected on their practice. A focus group of nurses, later in the study, enabled on-going changes in practice to be shared with colleagues. It also provided a forum for discussing what changes were needed in the Hospice<sup>1</sup> to maintain improved patient care through advances in palliative care nursing practice. Observations of patients and nurses, written comments and informal interviews also contributed to the qualitative data.

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<sup>1</sup> A capital letter is used to distinguish between hospice in general and the Hospice in which the study took place.



A comparative design was used in this research process. The control group of patients completed the questionnaire initially and then repeated it seven to ten days later. They received the usual Hospice care without reference to questionnaire results. In the intervention group, patients' questionnaire results again indicated areas of distress, strength and satisfaction, including those issues associated with dying. In this group, using the results of the patient's questionnaire as a basis for consultation, the nurse and patient worked together to create an individual care plan and discuss appropriate interventions. Those interventions may have been physiological, psychological, sociological, spiritual and/or environmental and may have involved other members of the interdisciplinary palliative care team. The simultaneous assessment of the patient's QOL by the patient and the nurse enabled the nurse to identify any disparities in their own assessment, and to reflect on why these differences had occurred. A further questionnaire was completed by both patient and nurse seven to ten days later, to identify QOL outcomes for the patient, and establish the level of agreement between patients' and nurses' assessment of those outcomes.

The researcher was present as an observer and also carried out numerous informal interviews throughout the data collection period. Extensive field notes captured the field observations and informal data.

Quantitative and qualitative data were then combined and analysed to ascertain if

- \* the intervention of a patient/nurse planning process, based on the patient's QOL assessment, resulted in improved patient care and consequent improvement in QOL;
- \* nurses' assessment skills in recognising patient's QOL were improved by this planning process; and,
- \* reflective practice in nurses was promoted by feedback on their assessment skills.

## **Conclusion**

Hospice care is about providing patients with QOL. QOL is a subjective, multi-dimensional concept unique to each patient. There are discrepancies between nurses' and patients' informal assessments of QOL (Cohen et al, 1995; King, Ferrell, Grant, & Sakurai, 1995). An effective QOL assessment tool has the potential to aid recognition of the patients' significant areas of contentment and dissatisfaction, promote co-constructed problem solving, and measure the outcome of interventions which positively contribute to the care of people who are dying. Despite the potential for tailoring care to patients' needs, and the support found in literature for a self assessed multidimensional measure of QOL, there has been minimal QOL research on the use of QOL assessment with hospice populations (Corner, 1996; McMillan, 1996). This study seeks to address (in a small way) this deficiency.

Palliative care as a speciality is under economic and philosophical threat. It is important that palliative care nurses can continue to develop advanced practice and prove to health providers and decision makers the professional and economic contribution they make. The use of a QOL instrument, particularly one especially developed for terminally ill patients, can alert nurses to patient concerns, help them to tailor care to those individual concerns, promote reflective practice, and measure the effectiveness of interventions. This study seeks to contribute to a better understanding of these issues. In particular it addresses QOL in the terminally ill and how nurses can more efficiently and effectively work with the patient to enhance this QOL.

## **Summary**

### **Chapter One**

In chapter one the key elements contributing to this study have been introduced. Beginning with a current description of palliative care, the reader is then presented with a brief outline of the issues concerning a definition of QOL and how this concept can be measured. Attention is drawn to discrepancies between nursing and patient assessment of QOL needs and the need to achieve and verify skilled palliative care nursing. A brief outline of the study design then follows. In the conclusion, the most salient points of the above discussion are summarised.

An outline of how the study is organised in the remaining chapters is now presented.

### **Chapter Two**

To provide a research context for this study, a literature review of relevant health related QOL studies and publications concerning palliative care was completed. Pertinent material from the literature review is presented in chapter two. This chapter examines the current thinking on QOL concepts and measurement, and considers the research which gave rise to this thinking. It then proceeds with a discussion of research using QOL instruments in the area of palliative care. The development of multidimensional, valid and reliable quality of life measures, is comparatively recent, particularly in the area of palliative care. For this reason only research done in the past decade is considered. Methodological issues that are of significant importance in research with the terminally ill, are briefly outlined. This outline is followed by a discussion of the QOL instrument chosen for this study and the justification for this choice. The limited amount of qualitative research on QOL issues is also examined. The chapter then looks at the implications of improving nursing care through reflective practice, as a way of improving patients' QOL. It concludes with the critical elements which have prompted this research study.

### **Chapter Three**

In chapter three the paradigms, methodologies and methods applied in this study are introduced. A discussion of the combined quantitative (post-positivist) and qualitative (ethnography) research approach used is expanded by describing the concept of multiple triangulation. The specific applications of triangulation in this study and their purpose are summarised in table form. This methodological discussion is followed by consideration of an additional concept from psychology (social validation) which is utilised in the research analysis. A general description of the study including setting, design, data collection and ethical issues (of particular significance in research with the terminally ill) follows. Quantitative data collection and analysis are then discussed in more detail. Modifications to the study design were necessary and these changes are outlined. The chapter concludes with a substantive section on how the qualitative data were obtained and analysed.

### **Chapter Four**

This chapter outlines the quantitative findings of the study. It begins with a description of the overall study sample and issues related to the gathering of the data. This description is followed by an outline of how the data were analysed. A description of the patient sample and data related to hypothesis 1 (change scores for the five QOL variables and overall QOL will be greater in the intervention group than in the control group) is then presented. This is followed by a biographical description of the nurses involved in the study and data related to hypothesis 2 (correlations between nurse and patient assessment of the five QOL variables and overall QOL will improve between Time 1 and Time 2). The chapter closes with a brief outline of patient status at the completion of data collection together with a summary of the quantitative findings.

### **Chapter Five**

This chapter outlines the qualitative data gathered from: formal and informal patient and nurse interviews; comments added to the QOL questionnaire by both patients and nurses; feedback from a focus group of nurses held five months after the study; and, field observations made by the researcher. Both patient and nurse interviews followed a semi-structured format with the interviewer free to follow any pertinent aspect raised by the participant, but sufficiently disciplined and defined to ensure coverage of areas relevant to the study. The material obtained was interpreted using content analysis. In the interests of clarity, patient data and nurse data are presented separately. In the section on patient data, taped and transcribed material from the twelve patient interviews is presented first, followed by secondary patient data, e.g. informal patient interviews, written comments and field observations. Because all ten nurses participated in interviews formal, informal, and observational data is matched and combined in this section as is material from the focus group. Pseudonyms are used to preserve patient and nurse confidentiality. The use of pseudonyms also enables the reader to both identify the participants and to develop a picture of participants' personal experience.

## **Chapter Six**

This chapter seeks to integrate data and distil the significance of the research findings. In particular it discusses the context of QOL; the usefulness of the QOL concept as an outcome measure of hospice care (particularly the questionnaire used in this study); and, how effective feedback on QOL assessment was in promoting improved patient/nurse understanding, and reflective practice. Quantitative and qualitative data, presented in chapters four and five respectively, are used to support and illuminate the discussion and to inform further theoretical consideration. The concept of hope is addressed as a rationale for identifying effective QOL nursing interventions. Additional material from the focus group, held five months after the research was completed, is integrated into the section on reflective practice. Throughout the discussion of the data, there is a constant tension evident between what is theoretically ideal and what is practicably possible.

## **Chapter Seven**

The final chapter seeks to highlight the main findings of the study. The implicit meaning of patients', nurses', and the researcher's experience is made explicit by drawing out the theme of 'revelation' from the research data. Included in these revelations are the limitations and strengths of the comparative, triangulated research process used. Recommendations are then made, in light of the research outcomes, on how improvements in terminally ill patients' QOL can be achieved through advanced palliative care nursing. These recommendations are presented as a potential framework for integrating a quality of care/QOL dimension into hospice-based palliative care in the form of a model of advanced palliative care nursing. The chapter concludes with a final statement which seeks to capture the essence of the research experience.



# Chapter Two

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## QUALITY OF LIFE CONCEPTS, MEASUREMENT AND RESEARCH: A LITERATURE REVIEW

### Introduction

This chapter examines current thinking on quality of life (QOL) concepts and measurement, and considers the research which gave rise to this thinking. Discussion of research using QOL instruments in the area of palliative care then follows. The development of multidimensional, valid and reliable quality of life measures, is comparatively recent, particularly in the area of palliative care. For this reason only research done in the past decade is considered. Methodological issues that are of significant importance in research with the terminally ill, are briefly outlined. This is followed by a discussion of the QOL instrument chosen for this study and the rationale for this choice. The chapter then looks at the implications of improving nursing care, through reflective practice, as a way of improving patients' QOL. It concludes with a consideration of the critical elements which have prompted this research study.

### Defining QOL

Death is the inevitable end-point of life. As death approaches, health care professionals are expected to provide patient care that enhances quality of life, enabling people to 'live until they die'. Despite this expectation of effective palliative care, there has been relatively little research into developing conceptual models and measurement tools for examining the QOL of terminally ill patients (Teno, Byock & Field, 1999; Turner, Payne, Jarrett, & Hillier, 1998). If the goal of palliative care is to optimise quality of life, then the outcomes of such care should be measured by how effectively this goal is achieved (Richards & Ramirez, 1997; Spicer, Jardine & Allan, 1999; Stewart, Teno, Patrick & Lynn, 1999). Two difficulties arise in defining and measuring QOL: the ambiguity of the QOL construct and the efficacy of instruments in measuring this theoretical construct. Because of the difficulties in defining QOL many researchers have equated the concept of QOL with QOL measurement, i.e. there is confusion between the theoretical concept itself and the measurement of theoretical constructs. Thus the question "What is QOL?" may merely be answered by "What QOL instruments measure". The equation of QOL with what is measured is not helpful. If we are to achieve improvement

in patients' QOL through effective palliative care we need to develop a deeper understanding of what QOL is and how it can be evaluated. A more detailed discussion of the issues involved (QOL concept and measurement) now follows.

## **The QOL concept**

Salisbury et al. (1999), state that difficulties in achieving QOL measurement arise from difficulties in deciding what compromises QOL. This view is supported by Gill and Feinstein (1994) who suggest that quality of life is a complex concept which may not have a distinctive or unique meaning within medical literature. In support of their argument they reviewed 75 articles relating to QOL, and found only eleven investigators defined QOL and less than half identified the dimensions they wanted to measure. This theoretical vagueness and definitional ambiguity is noted by many other authors (Axelsson & Sjoden, 1998; Cella, 1994; Clinch, Dudgeon, & Schipper, 1998; Donnelly & Walsh, 1996; King et al. 1997; Padilla & Grant, 1985; Richards & Ramirez, 1997; Salisbury et al. 1999). Even where the QOL construct is defined, there are frequently discrepancies between the purported dimensions to be measured and the actual item content (Cella). Conversely, Testa and Simonson (1996) claim that differences in the understanding of QOL do not lead to ambiguity in the measurement of a theoretical concept. Rather, they argue, variation among quality of life measurements is related to the extent they cover objective versus subjective dimensions, the coverage of domains and the format of the questionnaires. It could be argued, however, that the differences in the domains covered and objective or subjective measurement arise from differences in understanding about what comprises QOL. Such opposing views illustrate the equivocal nature of the QOL construct.

## **Dimensions of QOL**

In spite of this confusion over definition and measurement, four primary dimensions of health-related QOL have been generally supported by psychometric data. These are the physical, functional, psychological and social dimensions. In developing the World Health Organisation Quality of Life assessment (WHOQOL), the World Health Organisation (WHO), identify the key domains as physical, psychological, social and spiritual (The WHOQOL group, 1998). While the physical, functional and emotional dimensions are relatively straightforward, social well-being is the most difficult dimension to define, resulting in diverse content because of a lack of agreement among investigators (Cella, 1994). The lack of understanding over what this dimension measures and the consequent unease over its use is also reflected in the absence of a spiritual dimension in many QOL instruments. The WHOQOL group added this domain only after focus groups (comprised of health professionals, 'healthy' and 'impaired' persons from the general public) identified the need for a 'spiritual' facet. The omission of a spiritual or life-meaning dimension has been critically identified by researchers in the

palliative care field, where such a domain is of great importance to patients (Axelsson & Sjoden, 1998; Byock & Merriman, 1998; Cohen et al. 1995; Pratheepawanit, Salek & Finlay, 1999; Stewart et al. 1999 ).

Robbins (1998) and King et al. (1997), predict that definitions and descriptions of QOL will continue to change with advances in understanding and knowledge of the phenomenon. The best approach, they suggest, may be to document and use different definitions of QOL that are specific to the health care discipline (e.g. health research, nursing) or to a specific group of patients (King et al.). Even within cancer populations, different factors will be of importance in assessing QOL, reflecting the patient's perception of their position on the continuum between cure and terminal illness (Axelsson & Sjoden, 1998; Byock & Merriman, 1998; Cohen & Mount, 1992; Donnelly & Walsh, 1996; Rathbone, Horsley, & Goacher, 1994; Salisbury et al. 1999). This study seeks to explore the QOL of terminally ill patients. Therefore the instrument used in this study is based on a concept of QOL that is pertinent to patients who are in the terminal phase of their illness.

### **Theoretical understandings of QOL**

Various concepts and frameworks have been suggested as a basis for explaining how the phenomenon of QOL works, what influences it and why. Only those relevant to palliative care are addressed in this study. Included in these theoretical frameworks is the negative effect on QOL resulting from patients' perceived reductions in their ability to control life events. The direct relationship between a sense of control and QOL is identified in a case study by Russell (1997). Loss of control is closely related to uncertainty. Mishel's theory of uncertainty (Allison, Locker, & Feine, 1997; King et al. 1997) suggests that whether uncertainty is perceived as a challenge or as a danger (along with the coping strategies used), influences patients' QOL evaluations. That is, where the patient perceives uncertainty as a challenge and can utilise effective coping strategies, QOL is rated more highly.

Discrepancy theories propose that QOL outcomes are based on the gap or discrepancy between the individual's expectation of an experience and the reality, that is, what actually occurs (Twycross, 1995). Calman states that the smaller the gap, the better the quality of life. Thus, the individual's score does not reflect some absolute level of QOL but an assessment based on their expectation (Clinch et al. 1998; Cohen et al. 1995; Spicer et al. 1999). This model has considerable application in palliative care where symptom control, enhanced communication and reframing of attitudes can help develop mastery and adaptation by patients. Increased understanding and an ability to adapt reduces unrealistic expectations and closes the gap between expectation and experience, thus improving QOL (Stewart et al. 1999).

Internalised standards of QOL and personality traits are also recognised as significant in reframing attitudes and achieving adaptation to uncertainty and terminal illness (Allison, Locker, & Feine, 1997; Brown et al. 1997; Byock & Merriman, 1998; Cella, 1995; Cohen & Mount, 1992; Gibbons, 1999; King et al. 1997). The most important dimension affecting QOL, however, may be the ability to find meaning (Clinch et al. 1998; Jones, 1993; Street, 1998). King et al. note that few studies have considered the meaning of illness as a variable in QOL outcomes. Conversely, Cohen and Mount claim that the significance of meaning and transcendence (philosophical, moral and spiritual dimension) as determinants of QOL have been widely recognised. The positive effect of finding meaning in suffering enhances adaptation and coping with cancer pain. This important ability to make meaning of a seemingly negative experience and so increase QOL is well illustrated in work by Ersek and Ferrell (1994). Donnelly and Walsh (1996) report higher QOL in individuals who find meaning, even when their baseline reference points for QOL are changing. Roy (1993) also discusses the importance of helping patients find meaning in suffering, while in Axelsson and Sjoden's (1998) study of terminally ill patients and their spouses, "meaningfulness" ranked as the most important item in determining QOL.

It could be argued, therefore, that ability to find meaning should be included in any measurement of QOL. The inclusion of the domain of transcendence in both the McGill QOL questionnaire (Cohen et al. 1995) and the Missoula-VITAS Quality of Life Index (MVQOLI) (Byock & Merriman, 1998) acknowledges the importance of this dimension in QOL among palliative care patients. By balancing the suffering in one domain with an enhanced sense of personal meaning in another, QOL can be increased even when physical health and functioning are diminishing (Donnelly & Walsh, 1996).

## **QOL measurement**

As outlined above, confusion over the definition, construct and measurement of QOL makes research in this area a difficult quest. However, there is general agreement that QOL in palliative care should be measured so that the effectiveness and efficiency of care can be assessed and evaluated. This is easier said than done. The unresolved confusion regarding both the theory and measurement of that theory means that while much attention has been given to the measurement of health related QOL in the last two decades, there is still no one universal, acceptable measurement. In addition, many of the QOL instruments devised over this time were intended for use in evaluating different cancer treatments in clinical trials. The emphasis was on physical domains based on a 'standard needs' approach (i.e. an objective approach). Increasingly, a subjective approach is being accepted which recognises that the individual is the best judge of QOL and that individuals will vary in their QOL despite being in similar circumstances (Eischens, Elliott, & Elliott, 1998; Teno et al. 1999). There is a requirement in both approaches that QOL



instruments should be reliable, valid and sensitive (Cella, 1992; Fowler et al. 1999; Testa & Simonson, 1996) and, in the palliative care setting, brief, easy to read, understand and score (Cohen & Mount, 1992; King et al. 1997; Richards & Ramirez, 1997). An overview of both the objective (standard needs) and subjective (idiographic) approaches follows.

### **The Standard Needs approach**

Quality of life instruments based on the standard needs approach are designed to describe an individual's life through standardised numerical values. Such an approach (nomothetic) permits comparison between patients and a reference group or scale which is assumed to have universal validity (Browne et al. 1997; Richards & Ramirez, 1997; Spicer et al. 1999). Inherent in this psychometric measurement approach is the assumption that there are a universal set of needs which are the most important determinants of QOL and that these needs have been identified by the researcher. In a critique of this approach, Browne et al. identify the low level of consensus about the domains, criteria and weightings that should be used to assess QOL. This lack of consensus has led to the proliferation of QOL measures (Campbell & Whyte, 1999), and also to the comprehensiveness of many QOL instruments (Spicer et al.).

The debate over which domains should be included in QOL assessments has been addressed earlier. Browne and colleagues, in discussing the criteria used to evaluate QOL, point out that the criteria used will differ from individual to individual and, indeed, within the one individual at different times. The discrepancy in QOL as viewed through the eyes of the patient and their carer is clear evidence of the influence differing criteria have on QOL assessment. Within the individual a response shift (change in attitude) can change not only the criteria against which QOL is measured, but also the weighting of the life domains seen as germane to QOL. Standard needs measures assume that certain needs are more important to all individuals than others (Browne et al 1997). This approach ignores issues of inter-individual variability, referred to earlier, that need to be considered in weighting QOL domains. In palliative care, as mentioned previously, the physical and functional domains may become less significant while psychological and spiritual dimensions become increasingly important.

Examples of standard needs QOL assessments are the World Health Organisation QOL (The WHOQOL Group, 1998), European Organisation for Research and Treatment of Cancer (ECORT QOL C30) and the Sendera Quality of Life Index (SQLI).

### Sendeera Quality of Life Index

The SQLI was used in a study of the QOL of hospice patients carried out by McMillan and Mahon (1994). The purpose of the study was to identify changes in QOL, as identified by the patient and their primary carer, on admission and three weeks later, i.e. after hospice services had been implemented. The SQLI is a 25 item visual analogue scale (VAS) based on a standard needs approach. Although not specifically designed for hospice patients, the authors considered the SQLI addressed issues that would be relevant for terminally ill individuals. The SQLI had established validity and reliability for use with cancer patients. Results of the study revealed no statistically significant increase in patients' QOL between admission and three weeks later.

In discussing the limitations of the study, McMillan and Mahon noted that only 31 of the original 67 patients were able to complete the study. It could be suggested that, while some of these patients had died or become comatose, the demands of completing a 25 item questionnaire and a visual analogue scale are likely to have eliminated others who were becoming increasingly ill.

The difficulty for palliative care patients in completing visual analogue scales (VAS) is discussed by Cohen and Mount (1992, p.44).

### An example of Visual Analogue Scoring:

Please place a mark across the line at a position between the two extremes that indicates how often you have felt depressed in the past two days.

Never \_\_\_\_\_ Constantly

They suggest a numerical scale with verbal anchors at each end is preferable.

An example of Numerical scoring:

Please choose a number which best represents how often you have felt depressed in the past two days if 1 means never and 7 means constantly.

1 2 3 4 5 6 7  
Never Constantly

Visual analogue scales are also difficult to administer verbally. A palliative care assessment tool should be easy to administer orally when patients are no longer able to manage pencil and paper. A numerical scale which could have been completed orally with the patient may well have increased the number of patients in the study who were able to complete both assessments.

McMillan and Mahon (1994) also identify the lack of QOL assessments, specifically designed for hospice patients, as a limitation in their study. This perceived limitation may be related to the criticisms of the SQLI outlined above. Although the authors continued to

believe the SQLI has sufficient validity and reliability for use with hospice patients they did recommend future studies should use a tool specifically designed for hospice patients.

### **Hospice Quality of Life Index**

McMillan and Mahon subsequently developed the Hospice Quality of Life Index (HQOL) and used this 25 item questionnaire in a descriptive study similar to the one above (McMillan, 1996). Instead of a VAS each item was rated on a 1-10 scale. Higher scores indicated a higher self-rated quality of life. Four domains were covered: social/spiritual ; psychological/emotional; physical/functional ; and financial . The HQOL demonstrated reliability and validity (McMillan & Mahon, 1994).

Loss of participants was again an issue. The index was administered within 48 hours of admission and repeated three weeks later. One hundred and eighteen patients began the study but only 62 were able to complete it, although 74 patients survived the study period - an attrition rate of 52.5% compared to 44.4% in the earlier study. Thus the use of a numerical scale failed to produce a significant improvement in patients' response rates. This may have been due to the very detailed scoring system used - i.e. a 10 point scale applied to over 20 separate questions. As in the earlier study, overall QOL scores remained stable between assessments but did not increase, indicating little difference between the HQOL and SQLI in sensitivity to changes in QOL.

### **McGill Quality of Life Questionnaire**

The McGill Quality of Life questionnaire (MQOL) is a modified standard needs assessment instrument (Cohen et al. 1997), i.e. the domains, criteria and weightings of quality of life are already established in the instrument, and it can be used to compare QOL for different groups of patients. However, for the physical domains patients are asked to identify their three most troublesome symptoms and rate these. In Part D the questionnaire offers the patient the opportunity to write down the things that had the most effect on their QOL over the past two days and identify if these were negative or positive. Like the Hospice Quality of Life Index, the MQOL was designed for use with palliative care patients and so covers appropriate domains while avoiding issues that are not relevant, e.g. income producing capacity, employment status, sexuality (Eischens et al. 1998). The four subscales in the MQOL ( covered by 17 items) are: physical symptoms, psychological symptoms, outlook on life, and meaningful existence. Each item has a scale 1 - 7.

In a comparative study of two hospice QOL surveys, the Hospice Quality of Life Index-Revised (HQOL) and the McGill Quality of Life Questionnaire (MQOL) were administered by hospice home-care nurses to 22 patients (Eischens et al. 1998). A cross over design was used and the nurses were interviewed at the end of each week before using the alternative assessment. At the end of the survey the nurses were asked to

compare the two surveys. The MQOL was preferred over the HQOL because it was seen as easier to use, clearer for patients to understand and not as overwhelming for the patients. The main criticism of the MQOL was of inconsistent answer scales (reversal of 'most' and 'least'). The nurses also considered a scale of 1-10, rather than 1-7, would be an advantage. (The MQOL has since been modified and now has a 1-10 scale). The small sample size (22) was acknowledged as a limitation in the study but because the care of the patients improved through the use of the MQOL (nurses were alerted to areas of patient care that might otherwise have been overlooked) the service provider decided to adopt regular use of the MQOL form with its patients.

One could easily assume that in the MQOL, the ultimate standard needs QOL assessment tool for palliative care had been achieved. The MQOL has the desirable characteristics of a multidimensional approach, patient self-reporting, and the inclusion of both positive and negative factors in quality of life. It is easy to understand and use and has commendable psychometric properties. However, while acknowledging the significant improvements in QOL measurement achieved in this tool, Byock and Merriman (1998) identify two deficits. The instrument (like many others in this field) is designed for cancer patients at all phases of illness. The unique concerns of patients who are aware of their terminal prognosis may not be addressed. Also, the MQOL does not weight the domains according to the importance placed on them by the patient. Pratheepawanit and colleagues (1999) undertook a comparative study evaluating the MQOL and the Patient Evaluated Problem Scores (PEPS). Although they found the MQOL preferable overall, they noted that it took longer to complete (10-30 min) than the PEPS and was slightly more difficult. Two of the 25 patients found answering the MQOL questionnaire upsetting. The final disadvantage identified in the MQOL was a weakness in the coverage of the social dimension.

Critics of the standard needs approach would also identify the use of imposed domains and criteria as a deficit of the MQOL (Browne et al. 1997; Spicer et al. 1999). Browne et al. point out that individuals define life domains differently, use different criteria to evaluate these domains and give them varying importance in relation to QOL. They argue that the standards needs approach to QOL assessment is therefore inadequate at an individual level. Spicer and colleagues regard standardised, comprehensive assessment as applicable and useful in the research context; however, they too identify such an approach as unsuitable for the clinical setting, particularly palliative care. In addition to the deficiencies identified by Browne et al., they argue that terminally ill patients will have difficulty in completing long QOL measurements because of their physical and psychological state. The lack of a reference point against which to measure QOL also limits the usefulness of the standard needs assessment as a guide to care planning (Spicer et al.). What then, are the alternatives?



## **The Idiographic approach**

In idiographic measurement of QOL the individual is given the opportunity to choose their own domains, criteria and weightings. The amount of individual choice depends on the particular instrument involved. Some instruments provide domains (items) but allow individual weighting of their importance (Quality of Life Index; Ferans 1990). Others ask individuals themselves to identify the domains most important to their QOL.

### **Schedule of the Evaluation of Individual Quality of life**

Campbell and Whyte (1999) used an idiographic instrument, the Schedule of the Evaluation of Individual Quality of Life (SEIQoL) in their study of cancer patients participating in clinical trials. The SEIQoL allows patients to select, assess (according to their own criteria), and weight five domains contributing to their QOL (Browne et al. 1997; Richards & Ramirez, 1997). Based on the technique of judgment analysis, the SEIQoL is administered in a standardised, semi-structured interview. Where individuals find it difficult to nominate the five areas (domains) which are most important to their QOL, a standard list of prompts is used: family, relationships, health, finances, living conditions, work, social life, leisure activities and religion/spiritual life (Campbell & Whyte). The individual then rates each area on a vertical scale anchored at the two extremes by the labels 'best possible' and 'worst possible'. This allows individuals to use their own criteria based on the premise that the larger the gap between the current and the ideal state, the poorer the QOL in that domain (Browne et al.). The relative contribution of each item to the overall QOL is then quantified using the direct weighting instrument. An overall score of 100 is achieved by the sum of the weights (Campbell & Whyte).

Only 15 patients participated in this study which limits the importance of the findings. It is interesting to note, however, that most patients had difficulty in identifying five domains. The authors suggest that it may be inappropriate to require five domains if a patient feels that only three or four are important to their QOL at that time. As in other studies using the SEIQoL, there was a wide variety of domains chosen and varying weights allocated to these domains, confirming the need for individual choice in assessing QOL. While acknowledging the sensitivity of this instrument, Rathbone et al. (1994) point out that because the SEIQoL is very time consuming and requires considerable patient input, it would be inappropriate for terminally ill patients.

Spicer and colleagues, in their critique of the SEIQoL, identify the constraining nature of choosing five domains; the standardisation of scores so patients can be compared; and the lack of a reference point against which ratings can be judged. The authors also draw attention to the general lack of understanding of change assessment in QOL measures. Although such measures are designed to measure change, the type of change that may occur is seldom considered. This has important implications - for example when change is interpreted as arising from an intervention when a shift in the patient's attitude is

actually the catalyst for the change. This point is discussed in more depth later in the chapter.

### **Spicer, Jardine & Allan - Quality of life rating scale**

In a pilot study of 29 patients in a New Zealand hospice programme, Spicer et al. (1999, p.23) trialed a new idiographic procedure which would be “sensitive to the idiosyncratic and changing concerns of individual patients”. As in the SEIQoL, patients are asked to identify the most important aspects of their current lives but they are not limited to a set number. Prompts are available covering all QOL domains. Once identified, these items are written on cards which the patient sorts into order of priority. The patients are then asked to rate each item using a flight of steps with a left hand number indicating where they are at present and a right hand number to show where they would like to be. The difference between the two ratings, actual and ideal, reveals the patient’s QOL in that area. The reference points obtained by this procedure can be evaluated on future occasions enabling change related to response shift to be identified. As in other idiographic QOL studies, a wide number of items or domains were identified by patients as being of importance to their QOL. The procedure was successful in identifying the gaps between actual and ideal states and in revealing response shift (recalibration). Patients found the interview process helpful in identifying and communicating their concerns, a feature of other studies which involved interviews (Cohen & Mount, 1992; Greisinger, Lorimor, Aday, Winn, & Baile, 1997; Turner, Payne, Jarrett & Hillier, 1998). The authors claim that although this approach may not be based on psychometric principles, it can yield important information for health professionals on patients’ changing QOL needs. They suggest that:

the procedure could become an integral part of clinical assessment that serves to engage the patient, provide a structured but individualised mode of communication, focusses attention on salient issues to be explored and generates a record of change processes.

(Spicer et al., p.25).

The procedure developed by Spicer and colleagues has the desirable attributes of self-selection of domains, assessment according to patient criteria, self weighting and the providing of a reference point against which QOL can be measured. There are, however, some difficulties which need to be addressed. The authors criticise existing QOL instruments as being too demanding of patients and staff because of length (e.g ECORTC QOLQ C30 - at least 30 responses). However, their own procedure also requires considerable cognitive energy since patients may identify numerous domains and they are then required to establish an actual and ideal state for each domain. Indeed, the very effort of determining the most important domains and then ranking them in order, while very desirable for individual, subjective understanding of QOL, would be a considerable challenge for many terminally ill patients (Stewart et al. 1999).

Cohen and Mount (1992) suggest that because of the limited physical resources of palliative care patients, the ideal palliative care quality of life questionnaire should be able to be administered verbally in 10 -15 minutes. Spicer and colleagues (1999) state that interviews in their study ranged from 15 minutes to 3 hours. The time taken to complete their procedure appears to be greater than that advocated as suitable for such patients. Staffing constraints in a busy palliative care setting would also be an issue in administering such a time-consuming evaluation.

As previously noted, visual analogue scales are often too demanding for many patients. This particularly applies as patients become increasingly ill. Although the procedure developed by Spicer et al. (1999), is not strictly an analogue scale, the concentration required to understand the step concept and mark each item is at least as demanding. Such concentration may well be beyond those who are moving closer to death. Twenty-nine patients participated in the study but no demographic data were given so it is not possible to ascertain how ill the participants were.

To summarise, Spicer and colleagues (1999) have developed a responsive, patient-centred procedure for assessing patients' QOL based on discrepancy theory. The effort required to complete this procedure, however, may well be beyond the capabilities of many palliative care patients, particularly as they approach death. The time-consuming nature of administering the instrument would also be an issue for hospice staff.

### **Patient Evaluated Score**

Recognising patient difficulties in completing existing QOL assessments when they are terminally ill prompted Rathbone and colleagues (1994) to develop a self evaluated assessment for seriously ill hospice patients. The Patient Evaluated Score (PEPS) involves patients identifying and grading major problems as perceived by them and then grading problems previously identified by medical and nursing staff. Patients were asked to report any physical, emotional, social or spiritual problems and score them as mild, moderate or severe. They were then asked to similarly score problems identified by staff that were not on the self-assessment list. Where possible the PEPS assessment was repeated each week.

Results of the study revealed a high patient acceptance of the procedure even close to death; a considerable discrepancy in problem identification and weightings between patients and staff (particularly psycho/social); and the usefulness of the tool in guiding care to actual rather than perceived needs. The PEPS was also very useful for evaluating patient progress. As in other idiographic approaches, the value in this tool lies in intra-individual change comparison, not inter-patient evaluation. In their study, referred to earlier in connection with the MQOL, Pratheepawanit et al. (1999), found the PEPS was practical in the clinical setting but the psychometric properties were unknown and there was concern about its comprehensiveness as a true QOL measure.

### **Edmonton Symptom Assessment System**

A similar simple assessment approach is taken in the Edmonton Symptom Assessment System (ESAS) (Bruera, Kuehn, Miller, Selmser & MacMillan, 1991). In this tool, visual analogue scales (VAS) are used to assess pain, activity, nausea, depression, anxiety, drowsiness, appetite, sensation of well-being and shortness of breath. An empty VAS is available for a less frequent symptom that might be individually important, e.g. hiccoughs, pruritis. Patients were encouraged to complete the assessment twice daily either alone or assisted by nursing staff. When patients refused or were too unwell to complete a particular assessment this was done by a relative or nurse. Difficulties for terminally ill patients in completing VAS scores have been identified earlier. The tool proved effective in graphically displaying the intensity of symptoms and the efficacy of treatment interventions. However, while patients were able to subjectively respond to symptom intensity, the domains measured and the weightings of these domains were standardised. The effort needed to respond was obviously less than that required for the PEPS but the ESAS appears far less responsive to individual variability and therefore less useful as a measurement of QOL. Like the PEPS, the ESAS focuses only on problems or negative aspects of the patient's experience.

While problem identification is undoubtedly useful in improving QOL in terminally patients there is a real danger of equating QOL merely with the improvement or absence of such problems. Such an exclusively problem-based model is not appropriate in terminal illness where the experience of dying can be viewed as a normal and natural part of life with potential value for both patient and family (Byock, 1999). The need to identify and measure positive factors in palliative care assessments is also identified by other authors (Cohen et al. 1995; Greisinger et al. 1997). If patients are to be encouraged to view the dying process with hope and see it as an opportunity to adapt and grow, an opportunity to respond positively must be included in any QOL assessment.

### **Qualitative approaches**

Other approaches to assessing quality of life in the terminally ill include qualitative studies to understand the lived experience of cancer patients. Joyce (1998) claims that in order to understand patients' QOL it is necessary to enter and explore their world of cultural values and practices through Heideggerian phenomenology. McKinlay (1998) also used a phenomenological approach in her study of the patient's lived experience of receiving palliative care. A phenomenological hermeneutic study which examined the experiences of 12 patients in a Swedish hospice did not directly measure QOL but the findings have implications associated with QOL. Patients identified the kindness and individual care and attention received from staff, which created a consoling hospice spirit, as the most important element in reducing suffering and becoming-at-home in the midst of dying (Rasmussen, Jansson & Norberg, 2000).



Other research (at present unpublished) in this area includes postgraduate nursing students in Australia using narrative inquiry to establish how patients define/perceive QOL (Clark, personal communication, April 1999) and “a qualitative examination of a QOL questionnaire in palliative care - do respondents understand the questions?” (Devery, 1999). Such qualitative approaches, especially phenomenology, bring a depth of understanding difficult to achieve through quantitative assessment; however, the time involved and the small number of patients who could be assessed in this way render such an approach impractical in the clinical setting.

On the other hand, an ‘interview’, while assisting the patient to complete an appropriate palliative care QOL instrument, may yield significant, unique information about the patient in a relatively short time (Greisinger et al. 1997; Turner et al. 1998). The instrument can provide a structure which lessens the cognitive demands on the patient, reduces the time necessary to assess each dimension and yet permits exploration of the individual meaning of each domain to the patient. In caring for the terminally ill, a specifically designed quantitative assessment used within the context of a supportive qualitative interview may yield the most useful individual measurement of QOL.

Recognising the need for such a specifically designed, psychometrically reliable QOL instrument for use in the palliative care area, Byock and Merriman (1998) drew on their experience in this speciality to create a new QOL instrument. The Missoula-VITAS QOL index, which they developed, is a reliable and valid QOL measurement specifically designed for terminally ill patients. It has a defined construct, is multi-dimensional, easy to understand and score, allows the patient to weigh the importance of each dimension, is limited to 15 questions and can be used as the basis of a supportive interview. The only QOL instrument designed for use with terminally ill patients, it is therefore thought to be the most appropriate tool for use in this research study. The specific qualities of the MVQOLI are now addressed.

### **Missoula-VITAS quality of life index (MVQOLI)**

The dimensions of quality of life included in the MVQOLI (Byock & Merriman, 1998) are based on Cassell’s multidimensional model of personhood and the model of lifelong human development as applied to the terminally ill. Byock (1998) has identified a working set of developmental milestones at the end of life. These are:

- \* Sense of completion with worldly affairs
- \* Sense of completion in relationships with the community
- \* Sense of meaning about one’s individual life
- \* Experienced love of self

- \* Experienced love of others
- \* Sense of completion in relationships with family and friends
- \* Acceptance of the finality of life - of one's existence as an individual
- \* Sense of new self (personhood) beyond personal loss
- \* Sense of meaning about life in general
- \* Surrender to the transcendent, to the unknown - letting go.

The five dimensions of QOL to be measured were determined using Cassell's model of personhood and Byock's model of lifelong human development, a review of the literature, and informal interviews with hospice professionals, patients and their families. The five dimensions are shown in Table 1 (Byock & Merriman, 1998, p.234).

**Table 1: QOL dimensions of the MVQOLI**

Symptom:	the level of physical discomfort and distress experienced with progressive illness;
Function:	perceived ability to perform accustomed functions and activities of daily living and the emotional response, experienced in relation to the person's expectations;
Interpersonal:	degree of investment in personal relationships and the perceived quality of one's relations/interactions with family and friends;
Well-being:	self-assessment of the individual's internal condition. A subjective sense of wellness or unease, contentment or lack of contentment (the intrapersonal);
Transcendent:	experienced degree of connection with an enduring construct, and of meaning and purpose of one's life (the transpersonal).

As discussed in chapter three, Clinch and colleagues (1998), along with others (Gill & Feinstein, 1994; Fowler et al. 1999; King et al. 1997), identify that the weighting of the measured dimensions according to their importance to the individual, is important in achieving an accurate QOL score. Previous attempts to deal with this problem have resulted in long instruments which are difficult for terminal patients to complete and have unsatisfactory psychometric properties leading to an inaccurate total score of QOL (Byock & Merriman, 1998; Clinch et al.). The MVQOLI addresses this issue by weighting each QOL dimension according to its patient-reported importance. This is achieved by using three categories of items within each dimension of QOL. These three categories are:

Assessment:	subjective measurement of actual status or circumstance.
Example:	<i>I feel sick all the time.</i>
Satisfaction:	feelings or emotions in response to actual circumstances.
Example:	<i>I accept my symptoms as a fact of life.</i>
Importance:	the degree to which a given dimension has an impact on the quality of life.
Example:	<i>Despite my physical discomfort, I can enjoy my days.</i> (Byock & Merriman, 1998, p.234)

As previously discussed, there is no universal theoretical model for QOL. Clinch et al. (1998) point out that because of this there is a tendency to allow the construct to be defined by the instrument used to measure it. The difficulty here is the objective measurement of an abstract concept. In order to evaluate the efficacy of a QOL instrument, the definition of QOL and the conceptual approach adopted by researchers should be made explicit (Browne et al. 1997). Byock and Merriman (1998, p.233-4) explain the QOL construct measured in the MVQOL as follows:

QOL in the context of advanced, progressive, incurable illness, is defined as the subjective experience of an individual living with the interpersonal, psychological, and existential or spiritual challenges, that accompany the process of physical and functional decline and the knowledge of impending demise. A person's QOL can range from suffering, associated with physical distress and/or a sense of impending disintegration, to the experience of well-ness and personal growth arising from the completion of developmental work and the mastery of developmental landmarks.

A study of 257 hospice patients using standard statistical and psychometric analyses established the reliability and validity of the index. The MVQOLI demonstrated internal consistency (Cronbach's  $\alpha = 0.77$ ). MVQOLI total scores were correlated with scores on the Multidimension QOL scale - Cancer 2, and with patient-reported global QOL ratings. Byock and Merriman (1998) appear to have developed an index which effectively measures their construct, addresses the dimensions most pertinent to palliative care, is simple and easy to use, and thus yields an effective QOL measurement tool for the terminally ill (see Appendix A).

There has been little published research using the MVQOLI, although three questions in the McGill quality of life questionnaire (MQOL) are conceptually based on the MVQOLI (Cohen et al, 1995). A project evaluating palliative outcome instruments for use in Australia studied the MVQOLI and two other questionnaires: the Symptom Distress Scale, and the Enforced Social Dependency Scale (Mills, Webb, Stuart, Cooney & Leelarthapin, 1997). The study comprised a sample of 102 participants drawn from patients admitted to a large urban hospice over a period of six and a half months. Data were collected within 48 hours of admission and again 6-8 days later. None of the instruments, while reliable and valid, detected significant change in the sample between the first and second data collection.

In their comments Mills et al. (1997) noted that rather than the MVQOLI lacking sensitivity to change, no change may have occurred in this group. Issues that arose in completing the MVQOLI included the wording and meaning of certain items. These were questioned by some participants in the first administration of the index. While some participants found the index confrontational, others expressed appreciation of the pertinent questions asked. These issues of ambiguity, negativity and confrontation will be addressed in later chapters.

In the conclusion and recommendations of the report, the authors suggest that the MVQOLI be further investigated within Australian palliative care settings, particularly in regard to cultural differences and difficulties in completing the index. They note that:

while this instrument may be a potential burden for some respondents, it may provide an opportunity for others to review their life situation, the meaning and quality it holds for them. This has the potential to be growth promoting for these individuals.

(Mills et al. 1997, p.39)

This current New Zealand study will provide an additional critical evaluation of the instrument in a similar cultural context to that of the Australian study.

The MVQOLI has been designed to be used by patients. In terms of this design, there may be some limitations in its use by nurses for evaluating their patients' QOL. McMillan (1996), in adapting the HQOLI for use by caregivers, altered the index so that items referred to "the patient" rather than to "you". Although the MVQOLI was not modified in a similar fashion, it was made clear to the nurses in the current study that they were to "walk in the patient's shoes", and answer the questionnaire accordingly, i.e. they were to answer according to their understanding of how the patient viewed their QOL.

## **Undertaking QOL research in palliative care**

### **Current approaches**

While many researchers identify a dearth of research into the QOL concept and measurement in terminal care, a literature review looking at the impact of different models of palliative care on terminally ill patients' QOL (Salisbury et al. 1999) found 831 studies. The review excluded a large number of papers which were limited to development of scales or research instruments to assess QOL.



On analysis, only 86 of these papers were found to be relevant to evaluating different models of palliative care. The models of specialist palliative care addressed were primarily hospital based, hospice based, homecare based, or variations of the three. There were no comparative studies using an intervention to improve care within one setting. Twenty two articles were descriptive studies and 27 comparative. A wide range of research methodologies were used reflecting the complex problem of experimental research in this field. There were few randomised control trials and few directly comparable studies. Only 11 of these comparative studies took place in the last decade.

In their discussion of the project, Salisbury et al. (1999) noted that although a large quantity of published material was identified there was little good quality evidence on which to base any conclusions. Some of the deficiencies identified in the research which was assessed included weakness in methodology, small numbers of participants, inappropriate outcome measures to detect changes in QOL, and a tendency to rationalise negative results. While acknowledging that the ideal of randomised, controlled trials is not always possible in this research field, the authors point out that numerous small and inconclusive studies may be ethically and empirically dubious.

To strengthen future studies they suggest that outcome measures should assess separate components of QOL, the measure should be validated in a similar client group, and reflect the values of palliative care. In their conclusion, the methodological difficulties are acknowledged but there is a call for vigorous comparative research (both randomised and non-randomised) to evaluate all models of palliative care. Only then, they claim, can expansion of particular forms of care be justified by evidence of improvement in patients' QOL.

This scientific, comprehensive view of how palliative care research should be carried out is not shared by Sheila Payne, Director of Research in the Health Research Unit, University of Southampton. In encouraging small nursing research projects she states "my view is that research and the acquisition of new knowledge in palliative nursing are about numerous small footsteps towards the light rather than giant leaps in the dark" (Payne, 2000, p.56).

However, Salisbury et al.'s psychometric, objective approach is echoed in a paper by King and colleagues (1997). Their comprehensive article discusses the outcomes of a 1995 Oncology nursing conference which addressed the "state-of-the-knowledge" concerning QOL issues and the cancer experience. Aspects of their work have been referred to earlier. In their discussion of nursing research, they note the difficulty in defining QOL and claim that clinical and research interest in QOL may diminish without theoretically sound instruments that have established psychometric properties and clinical relevance. While acknowledging that qualitative research methodology may have "indirectly influenced the limitations of quantitative measures of QOL" (p.33), they consider that giving respondents an opportunity to supplement the item pool within the

instrument is sufficient to improve QOL assessments (such as in the MQOL). They note the usefulness of QOL research in reinforcing the holistic nature of nursing, assessing the human response to illness and establishing a common framework for inter-disciplinary understanding. They also identify the potential for partnership between nurses, researchers, and clinicians in testing nursing interventions to improve QOL. Despite this analytical and comprehensive account, the authors confine “true” nursing research to the positivist, quantitative research approach. Qualitative methods are briefly acknowledged as being of worth, but only with clinical nurses in the practice setting.

In an article based on her 1995 address to the UK Palliative Care Research Forum, Jessica Corner (1996) takes a very different approach to research when she addresses the question: is there a research paradigm for palliative care? In a review of 384 published research studies she established, like Salisbury et al. (1999), that both subject and methods in palliative care research differ widely. Wilkes (1998) makes a similar observation. Corner also critically identifies that the emphasis in palliative care research has been on describing activities and problems rather than actively evaluating existing and new approaches to care. Corner goes on to suggest that, in order to increase scientific acceptance of the new speciality, the original radical nature of palliative care (which rejected the traditional medical approach to dying) has declined. Instead of breaking new research ground, there is a tendency for researchers to become an accepted part of the conventional system with its paradigm of bio-medical science.

### **Future directions**

Where then does the future for palliative research lie? Corner (1996) suggests that the preoccupation with ‘self discovery’ may reflect the beginnings of an emergent research tradition, or palliative care research may be on the brink of a paradigm shift which will permit a “new, better fitting approach” to such research. She calls for much more creativity in method. In particular she advocates method that does not enter the quantitative-qualitative debate but uses both and develops new approaches appropriate to palliative care. Wilkes (1998) identifies a recent emergence of palliative care nursing research using this combined qualitative and quantitative method. Richardson and Wilson-Barnett (Wilkes), contend that such studies are a brave effort to gain in-depth, subjective and “particulate” objective pictures of palliative care nursing.

The importance of in-depth conversation in understanding the subjective well-being of individuals is acknowledged by Cohen et al. (1997). Despite their development of the quantitative McGill QOL questionnaire, the authors suggest the gold standard for QOL evaluation may involve the richness and depth of qualitative methodology. Cella (1994) states there is no gold standard QOL measures for use in palliative care and that the selection of an instrument should be based on the researcher’s interest and questions (ensuring that the measurement is reliable and valid). Gill and Feinstein (1994, p.7),

however, share Cohen's caveat on the efficacy of quantitative standard needs QOL measurements. They question "whether the academic psychometric principles, although perhaps elegant statistically, are satisfactory for the clinical goal of indicating what clinicians and patients perceive as QOL".

Corner (1996) concludes her discussion by asking whether the multi-method, multi-perspective, multi-subject, and multi-disciplinary research approach she sees as necessary for effective palliative care research can be combined within a single paradigm called 'palliative care'? The answer she offers is that it can, but only if the philosophy of research in palliative care can tolerate such a radical agenda about how such knowledge needs to be generated.

As well as the work by a range of health researchers, psychologists have also drawn attention to the complexity of measuring QOL. In particular, they urge researchers to become aware of the dynamics of change when interpreting QOL results (Gibbons, 1999; Norman & Parker, 1996; Sprangers & Schwartz, 1999). A discussion of change in response to QOL evaluations now follows.

### **Changes in QOL responses**

Where QOL is used as an outcome measure to evaluate interventions, the identification of the factors contributing to a change in QOL is a challenging undertaking. It is not sufficient to equate positive changes in QOL with a successful intervention nor to assume that a negative response shift indicates failure of the intervention. If we are to gain a better understanding of why QOL research often yields findings which do not make sense, are paradoxical, or non-conclusive about the effect of interventions, and fail to give insight into how individuals perceive their QOL over time, a response shift construct may be useful. Response shift refers to a change in peoples' attitudes, values, conceptualisations or priorities that may occur in addition to a change in health status (Schwartz & Sprangers, 1999).

### **Typology of change**

Norman and Parker (1996) also suggest that an understanding of the typology of change (response shift) has important implications in interpreting questionnaire results in intervention studies. Their interpretation of change is based on work by Golembiewski, Billingsley and Yeager (1976), who defined change as a threefold construct comprising 'alpha, beta and gamma type' change.

Briefly, alpha change (e.g. changed health status) occurs when change has occurred within an otherwise stable individual state. For example, a patient's assessment of function is related to their ability to walk to the bathroom independently. Supplying a

walking frame (intervention) enables this goal to be reached with a consequent improvement in the patient's evaluation of function.

Beta change (e.g. a recalibration of the respondent's scale for assessing health status) occurs when there has been a recalibration of the measuring scale between assessments. For example, the patient's original measurement of function had been based on getting to the bathroom independently but between measurements the patient's response to physiotherapy has changed the patient's goal to walking to the lounge independently. The assessment of function is now based on a recalibrated scale. If the patient can walk independently to the bathroom but not to the lounge, function may be reported as negative on the second assessment.

Gamma change (e.g. a reconceptualization of the meaning attached to health) occurs when there has been a redefinition of the concept being measured. For example, the patient no longer views function as physical ability to get to the bathroom but as being able to communicate their physical needs in a way that enables these needs to be met. Measurement of function is now being assessed in relation to two different concepts. The authors suggest that only alpha changes are an accurate measurement of intervention.

### **Attitude structure**

A more comprehensive and complex discussion of alpha, beta and gamma change within a model of attitude and structure is carried out by Thompson and Hunt (1996). Although this work concentrates on management issues, it has application to changes in QOL evaluation by terminally ill patients, i.e. a change in attitude may change assessment of QOL. The effect of attitude, although more generally regarded as an individual characteristic, is acknowledged as being significant in evaluations of QOL. For new behaviours to endure (i.e. effective change), the authors argue that interventions to change attitudes are necessary. The cognitive processes to achieve gamma change are thought to be the most challenging and result in the most effective attitude change.

To simplify (perhaps over-simplify) the cognitive processing model Thompson and Hunt (1996) have devised, there are three levels of information or knowledge in each individual attitude. These are:

- (a) underlying values; and
- (b) beliefs; which are combined to form the
- (c) background knowledge used by a person to evaluate an object (i.e. determine the attitude towards that object).

To achieve gamma change, exposure to new information is followed by integration into an existing attitude structure (c). If the belief or value is new, it is compared to other beliefs and added or excluded based on consistency with present attitudes. Comparison and thought about existing beliefs and values may also yield gamma change culminating



in new attitudes.

### **Response shift**

Sprangers and Schwartz (1999) also use the dynamic change concept in a model integrating response shift into health-related QOL research. This response shift model appears to integrate concepts from change typology and attitude structure. While acknowledging that the components defined as making up a response shift are interconnected and perhaps hierarchical, they are presented as distinct entities by the authors for the sake of clarity. It should be noted that because alpha change does not, by definition, include a response shift in the individual, it is not part of the response shift concept.

Response shift, then, as adopted by Sprangers and Schwartz (1999, p.1508).

“refers to a change in the meaning of one’s self-evaluation of a target construct as a result of:

- (a) a change in the respondent’s internal standards of measurement (scale recalibration, in psychometric terms);
- (b) a change in the respondent’s values (i.e. the importance of component domains constituting the target construct); or
- (c) a redefinition of the target construct (i.e. reconceptualization)”

As discussed in previous change models or constructs, (a) could also be identified as beta change, (b) a change in attitude structure and (c) gamma change which necessarily involves attitudinal change.

The authors identify many research studies which appear to support the concept of response shift in patients faced with life-threatening or chronic disease. These studies include stable QOL despite the above, comparable QOL to healthy people and a higher QOL than estimated by health care providers or significant others (McMillan, 1996).

Another prompt for response shift may be social comparison.

### **Social comparison as a mediator of response shift**

Significant life events, such as terminal illness, prompt response shifts. Changes in social comparison, that is comparing oneself, one’s status and/or one’s situation with others, are also likely to occur in this situation. The basic proposition of social comparison theory is that comparison with others significantly influences self knowledge (Gibbons, 1999). According to Gibbons, when the amount of social comparison increases and the level at which the individual compares is lowered, changes in one’s perspective on self will often change. This change in self perception may result in change in beliefs, change in internal standards of measurement, and possible

reconceptualization, i.e. response shift. She identified research studies on social comparison which, although they do not directly address response shift, produce evidence of a change of focus which results in individuals changing their perspective on their current life situation. Often this change consists of a change in priorities or the extent to which different aspects of one's life are valued and others are not. Changes in one's perception of QOL may thus be the result of a social comparison-mediated response.

Gibbons notes that the role of social comparison in response shift may vary according to the dispositional outlook of the individual concerned. Where an individual is negative or depressed in outlook or has a terminal illness, downward comparison with others (i.e. those who are worse off) may result in a negative response shift. Conversely, optimism or a positive outlook can act as a buffer against the deterioration in self-concept, or negative response shift that can accompany significant loss. The effect of personality or outlook on life on a patient's perception of their illness has been discussed previously, and will be referred to again in chapters five and six.

The use of the response shift concept would address many of the research results perceived as unreliable by Salisbury et al. (1999) and also support the concept of QOL as a dynamic construct (Allison et al. 1997). More positively, as the authors suggest, integrating response shift into health-related QOL research could promote the sensitivity and relevance of such research.

We now move to consider the impact that research might have on affecting change, both in the patient and the nurse, with a consequential improvement in patients' QOL.

## **Reflective practice**

Carefully constructed instruments are required to measure and quantify individuals' particular perceptions of their QOL. Nevertheless, such instruments necessarily provide a limited summary of the individual patient's story. Effective palliative care nursing involves accurate patient assessment (including QOL variables) but also the ability to use such assessment to facilitate a deeper discussion and understanding of the patient's narrative. Nurses need to practice reflection if they are to increase their skill level in assessment and understanding.

### **Reflective practice - a definition**

What is reflective practice? Various definitions have been used both in education and nursing. Durgahee (1996, p.22) offers this definition. "Reflection is a method of learning and teaching nursing through critical analysis of experience". Reflection on



practice has been used to understand and improve the work of nursing for generations (Benner, 1984). It has been of critical importance in the development of palliative care as a discipline (Lee, 1998), because of the reflexive (adaptable, responsive, individual) approach needed to provide holistic care (Yates, 1998). Atkins and Murphy (1993), in a review of the literature on reflective practice, identify two crucial elements. Reflection must involve the self and result in changed thinking. Osterman and Kottkamp (1993) echo this understanding seeing reflection as a means of change through self awareness and discovery.

### **Social, psychological and spiritual care - the challenges**

There are no developed prescriptive frameworks for providing social, psychological and spiritual care. Indeed, even communication skills training has been shown to be ineffective in enhancing nurses' ability to effectively interact with their patients in these areas (Heaven & Maguire, 1996; Wilkinson, 1991). Rather, the personal characteristics of the nurse have been identified as the most significant factor in meeting the patient's psychosocial and spiritual needs. These personal qualities are defined as an awareness of the spiritual dimension in their own lives, a personal search for meaning (including attitude to death), a personal experience of crises, perception of psychological, social and spiritual care as part of their role, and a particularly sensitive/perceptive nature (Ross, 1997; Wilkinson). Randall and Downie (1996) describe these characteristics as *phronesis* - practical wisdom - and argue that there is little professional expertise in the areas of emotional, social and spiritual care. While acknowledging the importance of these areas in achieving "total good" for and with the patient, they suggest the health professional achieves practical wisdom only through development of their own personality, and professional and personal experience.

Chapman (1998) and Yates (1998) also develop this theme of persistent self-exploration and reflection which leads to the development of a repertoire of therapeutic, supportive interventions. When nurses reflect on "What is it that I do?", "Why do I do it?", and, "Can I do it better?", the way is opened to developing new knowledge. This receptiveness to change encourages the development of creative, reflexive ways to help terminally ill people reduce uncertainty, gain control and find meaning. Appropriate, sensitive, individualised nursing interventions are likely to result in improved QOL for patients.

### **Social, psychological and spiritual care - development of skills**

If then, much palliative care knowledge lies in the hermeneutic/interpretive, the moral-ethical and the personal domain (MacLeod & James, 1997), how can we improve nursing effectiveness in the social, psychological and spiritual areas? Sheldon and Smith (1996) suggest that it means a shift from the positivist paradigm with its quantitative research,

educational practice and medical model, to human and co-operative inquiry from the critical thinking paradigm. Learning would then reflect the philosophy of palliative care involving a holistic approach that is *with* and *for* people rather than *on* people. They suggest critical reflection and analysis with problem based learning as the most effective form of advanced palliative care education. Other authors too (Chapman, 1998; MacLeod & James), emphasise the need for questioning-in-action and questioning-on-action to inform practice. By critically reflecting on their own experience, practitioners (and educators) can facilitate reflection by others and so achieve some measure of personal effectiveness.

In a New Zealand study exploring reflective thinking in nursing practice, Teekman (2000, p.1125) identified three hierarchical levels of reflective thinking:

- reflective-thinking-for-action (immediate in order to act)
- reflective-thinking-for-evaluation (seeking understanding of complexities)
- reflective-thinking-for-critical-inquiry.

Teekman thus differentiates two levels of inquiry when nurses reflect on action: evaluation and critical inquiry.

Nurses in this study were able to compare their assessment of the patient's QOL with that of the patient. Any discrepancies which were revealed between the nurses' and patients' QOL assessments offered the nurse an opportunity to critically reflect on her assessment skills and ponder on the reasons for these differences. The subsequent reassessment, 7-10 days later, revealed how successful any reflection, change in approach or use of problem solving skills had been in achieving a closer correlation with the patient's QOL assessment, i.e. developing a greater understanding of the patient. Because nurses were asked to reflect on questionnaire results after completion of the questionnaire, this study addresses reflective-thinking-for evaluation (reflection or questioning on action), and reflective-thinking-for-critical-inquiry. Reflection in action may be deduced from nurses commenting, after the study, about changes in practice arising from the research process.

### **Reflective practice - the process**

According to Atkins and Murphy (1993, pp.1189-90) the reflective process is characterised by three stages:

1. inner discomfort or an awareness of uncomfortable feelings and thoughts;
2. a critical analysis of the situation which has caused these, including examination of feelings and knowledge. Application of other inherent knowledge may yield an explanation or the examination or generation of new knowledge may be required;

3. development of a new perspective, (affective and cognitive changes) which may lead to changes in behaviour.

Teekman (2000) identifies self-questioning as the key to reflective thinking while others identify the skills needed as self-awareness (analysis of feelings); description (ability to accurately recall the situation); critical analysis (identifying, challenging and exploring) and synthesis (integrating new knowledge with previous knowledge) (Atkins & Murphy, 1993; Ostermand & Kottkamp, 1993).

### **Reflective process - context needed**

In addition to the processes identified above, Osterman and Kottkamp (1993, pp.46-47) state that there are key assumptions that must be met before reflective practice can be undertaken and encouraged. They call these beliefs about professional development a:

#### **Credo for Reflective Practice**

1. Everyone needs professional growth opportunities.
2. All professionals want to improve.
3. All professions *can* learn.
4. All professionals are capable of assuming responsibility for their own professional growth and development.
5. People need and want information about their own performance.
6. Collaboration enriches professional development.

In order to promote improvement in terminally ill patients' QOL, it is therefore necessary to both know what is involved in reflective practice and have an environment which promotes nursing self-awareness and capacity to change.

## **Critique of QOL literature, a summary**

Outcome measures in palliative care need to reflect the goals of palliative care. These goals can be encapsulated as seeking to improve the patient's QOL. Quality of Life measurement is therefore crucial in obtaining detailed information about the patient to guide and inform patient care; to audit the care provided; to compare services or care before and after an intervention; and to inform purchasers of the service (resource allocation), (Hearn & Higginson, 1997).

QOL is a dynamic concept which is subject to psychological phenomena, e.g. adaptation, coping, self-concept and optimism, and is therefore difficult to define. A productive,

legitimate partnership of appropriate QOL measurement tools and rigorous research has yet to be consummated, especially in the area of caring for the terminally ill. Confusion over the concept of QOL and how this concept can then be accurately measured contributes to the complexity of this relationship and the gestation of conflicting views on outcome measures. The positivist approach of objective data gathering through standard needs assessment is now seen as reductionist (Schipper, 1992) and inadequate to capture the subjective nature of QOL. Idiographic measurement, while creating opportunity for a unique perspective of patients' QOL, tends to be time consuming and cognitively intensive requiring more energy than many terminally ill patients can offer. The resolution of methodological challenges - the ability to subjectively establish the most important QOL domains, assess these and weight their importance to the patient in a simple, easily completed, reliable and valid patient assessment tool - continues to elude researchers.

The existing research into QOL in the terminally ill has largely focused on evaluating different methods of care (home, hospital, hospice). Most of these studies have been criticised as being of poor quality and yielding inconclusive results (Salisbury et al. 1999). A number of other palliative care studies have been undertaken to create or establish the validity and reliability of different QOL measures. While such studies reflect the absence of a universally accepted QOL measurement tool they have not successfully created such a measure or contributed to evidence-based practice. On-going QOL assessment tools (such as the PEPS and ESAS) are being used in clinical practice but these measures are standardised and concentrate on problem identification only. They evaluate patient progress but have not been psychometrically validated and are considered insufficiently comprehensive to truly measure QOL.

Where comparative QOL studies have been completed, these have largely been to evaluate the use of different QOL instruments, none of which were considered ideal (Hearn & Higginson, 1997). Few studies have used QOL assessment to actually evaluate hospice care, i.e. the difference in patients' QOL between admission and a subsequent time (Turner, Payne, Jarrett, & Hillier, 1998). Those studies that have been completed have found no statistically significant improvement in patients' QOL although the patients' QOL remained stable and reasonably good throughout (McMillan, 1996; Mills et al. 1997; Turner et al.). The studies were hampered by difficulty in obtaining and/or maintaining sufficient patient numbers to retain study power (Bretscher et al. 1999; McMillan & Mahon, 1994). An Australian study involving 42 hospice patients looked at relationships between symptom relief, QOL and satisfaction with hospice care (Tierney, Horton, Hannan, & Tierney, 1998). The main finding was that satisfaction with care was more associated with QOL than symptoms. The authors suggested that improving hospice care will require focussing on QOL, especially existential and support concerns. Despite this clear indication of the need to increase QOL in patients to improve satisfaction with palliative care there have been no published studies within a hospice setting, which measure the effectiveness of nursing interventions on patients' QOL.

## Conclusion

If we are to improve care of the dying, audit the care provided and inform funding authorities, comparative studies evaluating the efficacy of hospice care and the value of specific interventions are essential. To date there is no perfect instrument for evaluating the QOL of palliative care patients. This makes gathering such evidence difficult. The MVQOLI, specifically designed for terminally ill patients, offers a compromise between standard needs and idiological instruments. A limited number (16) of defined items which can be weighted according to their importance to the patient offers a relatively simple, readily completed QOL assessment for such patients. It was therefore the preferred (quantitative) instrument for this study to identify changes in patients' QOL. Understanding the reasons underlying changes in patients' QOL is also an important part of evidence gathering. The rationale behind such change can only be ascertained by speaking with the patient (qualitative). To help develop an understanding of the complexity which can underlie patients' QOL change, the concept of response shift is applied.

Quality of care is extremely important in achieving QOL in terminally ill patients. To develop advanced nursing practice in palliative care, nurses need feedback on their assessment and caring skills enabling them to engage in reflective practice. To date there have been no research studies on how objective assessment can promote nurses' clinical understanding of the skills and behaviours needed to promote patients' QOL in terminal illness.

## Present study

This study seeks to address, in some small way, the complex research question of improving QOL in terminally ill patients.

The formal aims of the study are:

1. To identify if the patient/nurse care planning process, based on QOL assessment, results in improved patient care and consequent improved QOL.
2. To determine whether the patient/nurse planning process improves nurses' assessment skills in recognising patients' QOL status, i.e. increases understanding between nurse/patient.
3. To promote reflective practice in nurses by providing feedback on their assessment skills.

The first two aims are addressed by the following hypotheses:

1. Change scores for the five QOL variables and overall QOL will be greater in the intervention group than in the control group.
2. Correlations between nurse and patient assessment of the five QOL variables and overall QOL will improve between Time 1 and Time 2.



This research study will utilise both quantitative and qualitative data in a triangular (multi method) approach to establish whether the use of QOL assessments by hospice patients and nurses in planning care improves terminally ill patients' QOL, nurses' understanding of patients, and nurses' reflective practice. Rather than using a single, simple methodology, a variety of approaches are used. Quantitative data from the MVQOLI, qualitative semi-structured interviews, a focus group and facilitating nurses' reflective practice will inform and, potentially, influence palliative care nursing practice. It is proposed that a clearer understanding of the individual needs of terminally ill patients and corresponding changes in nurses' palliative care practice will lead to improved QOL for patients. The dimension of this proposition is such that it can only start to be explored in this study.

## **Summary**

This chapter reviewed the literature concerning the definition of QOL and the theoretical understandings which underlie this dynamic concept. A discussion on how QOL can be measured followed with a critique of the current instruments and approaches. The reader was then introduced to the QOL instrument to be used in this study, the Missoula-VITAS quality of life index. In discussing the call for more research into palliative care the scientific objective approach was contrasted with the challenge to find a new research paradigm. This was followed by a discussion of changes in QOL responses. Understanding the type of change which may underlie sequential QOL questionnaire findings is particularly important when one is seeking to evaluate an intervention. The chapter closed with a critique summary of QOL literature and a brief outline of the research study that is presented in subsequent chapters. The next chapter begins the research component by outlining the methodologies and methods that were used to gather and analyse the data.



# Chapter Three

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## METHODOLOGY and METHOD

### Introduction

During the past decade there has been increasing recognition that not only is scientific knowledge found in different research paradigms but that varying methodologies can be used within these paradigms to enhance research findings (Corner, 1996; Coyle & Williams, 2000; Crotty, 1998; Ford-Gilboe, Campbell, & Berman, 1995; Le Fort, 1993; Patton, 1999). De Santis & Ugarriza (2000), however, sound a note of caution in combining distinct research methods in a way that compromises methodological rigour. Foster (1997) goes further in claiming that an eclectic approach still requires each methodology to be guided by the paradigmatic assumptions which underlie each mode of enquiry. This view is not shared by Ford-Gilboe and colleagues who suggest that combining strategies across paradigms could create new methodologies to better meet the health needs of all people. Shih (1998) too, notes the need for new perspectives, new priorities and a new spirit to be found in existing philosophical paradigms if nursing researchers are to conceptualise complex human responses to health issues. A similar view is put forward by Maggs-Rapport (2000, p.223) who describes the nature of nursing as “many layered, multifaceted and perhaps unknowable in its entirety”. Such a phenomenon defies single research approaches to understand its totality. Rather than a rigid commitment to distinct methodologies, these authors suggest single or multiple triangulation provides a possible way to overcome present research deficiencies. Such an approach would address, at least in part, Corner’s call for a new responsive, collaborative, inclusive, multi-method and well-disseminated palliative care research paradigm.

In keeping with the search for a new palliative care research paradigm this study goes beyond a single lens to describe reality, interpret research results, and contribute theory. Two different but equally important paradigms (post-positivist and interpretive) are applied in combination to guide the methodology and methods used, and to examine the data obtained (via multiple triangulation). Thereafter, as Shih (1998) and Patton (1999) postulate, rather than expecting the multiple sources of data to confirm one another, each source will contribute a different shape and colour contributing to a multidimensional model (Maggs-Rapport, 2000).

Each paradigm used is now briefly discussed followed by a description of how these are combined to meet the aims of this study.

# Methodology

## Post-positivist paradigm

A modification of the traditional scientific approach to conducting research, the post-positivist paradigm seeks to discover a reality that can be studied and known (Polit & Hungler, 1997). This objective reality is assumed to exist regardless of human observation and is made up of regular patterns which can be used to describe, understand and predict phenomena. The context in which patterns occur is acknowledged to be of importance but the environment is controlled to examine the phenomena under study (Ford-Gilboe et al. 1995). Control of the environment includes holding the researchers' personal beliefs and biases in check to avoid contamination of the phenomena being observed (Polit & Hungler). The patterns are captured by structured quantitative methods, ideally using randomised clinical trials (Jennings, 1991). Quantitative data is obtained through questionnaires, interviews and observations, and records. The most common quantitative approach is the questionnaire used as a survey (Clifford, 1990; Crotty, 1998).

Research using quantitative approaches ranges from descriptive to experimental and quasi-experimental research designs, depending on the research question or hypothesis. An hypothesis proposes a relationship between two variables or factors being studied (Clifford, 1990). Evidence is gathered to prove or disprove hypotheses (Ford-Gilboe et al. 1995). An experimental design with randomisation of the sample, manipulation of the dependent variable by the researcher and control to eliminate the influences of other variables is the most powerful method of testing hypotheses (Clifford). Randomisation of participants was not practical in this study because of the limited numbers of suitable participants available and the difficulty in recruiting and retaining such participants. A quasi-experimental research design where the independent variable was manipulated and other variables controlled without randomisation was therefore used. A pre-test, post-test data collection involved participants answering a valid (measuring what it is supposed to measure) and reliable (consistent in measurement) QOL questionnaire prior to and following the intervention (joint patient/nurse care planning). Initial QOL baseline data was thus obtained, the intervention introduced and patients' QOL again measured to ascertain possible influences of the intervention (Clifford). Pre-test, post-test data collection was also used to examine the ability of nurses to assess patients' QOL. An initial comparison of patient/nurse QOL assessment was followed by exposure of the nurse to the patients' own QOL assessment and a period of working with the patient on joint care planning. A further comparison of patient/nurse assessment of the patients' QOL was then made.

Quantitative data are analysed statistically, i.e. formulas and rules are followed (Patton, 1999). However, Ford-Gilboe and colleagues (1995) note that subjective data such as self-reports and observable behaviour may also be used as evidence to support or negate an hypothesis. Subjective data allows clinical significance, rather than just statistical

significance to be considered (Smith, 1993), an important issue in health-related research. Self-reporting of QOL and observations were used to further examine hypotheses in this study. Use of such between-methods triangulation (Kimchi, Polivka & Stevenson, 1991) in quantitative research brings stronger support for a hypothesis or promotes new insights which allow refinement of existing explanations of the phenomena (Ford-Gilboe et al.).

## **The Interpretive paradigm**

In contrast to the objective reality world view of positivism, the interpretive paradigm is based on constructionalism where meaning is not discovered, but constructed by subject and object (Crotty, 1998). The interpretive paradigm is also referred to as *humanistic* and *naturalistic* (Ford-Gilboe et al. 1995). In the interpretive approach, rather than keeping separate from the phenomena being studied, the researcher consciously interacts with participants, seeks to discover values and subjectivity, and uses an inductive process to interpret created patterns (Polit & Hungler, 1997). The researcher thus becomes the data collection instrument (Maggs-Rapport, 2000; Sorrell & Redmond, 1995) working with participants to discover meaning from their on-going experiences. This emphasis on the subjective, contextual meanings of a phenomena to individual participants is captured by qualitative methods (Ford-Gilboe et al.). Interviews, observations and written records are sources of data in qualitative research.

Methodologies associated with the interpretive paradigm include phenomenology, grounded theory and ethnography (Lowenberg, 1993). The two interpretive methodologies used within this study draw from ethnography and interpretive phenomenology. In ethnography (originally developed in the discipline of anthropology and sociology) the goal is to achieve a holistic understanding of the group of people being studied (Hughes, 1992). The researcher aims to identify the day-to-day experiences and the meaning given to these experiences by group members (Crotty, 1998). The two cultural groups investigated are terminally ill patients in a hospice setting and the palliative care nurses who care for them. Observations, documents and interviews are used to obtain an emic (insiders) group view (Polit & Hungler, 1997).

Interpretive phenomenology (drawn from philosophy and psychology) seeks to gain deeper individual insights by focusing on the subjective world that the study's participants experience (Maggs-Rapport, 2000). Interaction between the participants and the researcher is inherent in both methodologies to jointly construct a deep, rich and authentic reality (Ford-Gilboe et al. 1995), but the emphasis in the phenomenological interview is on encouraging stories or narratives to explore the essence of the individual experience of the participant (Polit & Hungler, 1997; Sorrell & Redmond, 1995). Patients and nurses often told stories during the research interviews to illustrate their experiences. Nurses also shared stories informally, with the researcher and each other.

Qualitative analysis is a creative process depending on the insights and conceptual capabilities of the researcher. Astute pattern recognition arising from immersion in the data and a well-informed mind are necessary. In addition the qualitative researcher has to report sufficient details of data collection and the processes of analysis for others to judge the quality of the research product (Patton, 1999). Maggs-Rapport (2000, p.222) notes that ethnography and interpretive phenomenology “both look for commonalities and shared themes within the narratives and both reduce data to uncover the essence of participant meaning or to clarify cultural meaning”. Thus, she suggests, ethnographic data analysis techniques (content analysis) can be used to search for interview themes with the extra process of cognitive reasoning to understand the phenomena under study.

The interpretive paradigm in this study is used to discover and describe the QOL of terminally ill patients, from their lived experience. Ethnography and interpretive phenomenology are again used to describe and examine the experiences of nurses as they seek to assess their patients’ QOL, initiate interventions that will improve this QOL, and reflect on their own practice. Participants responses, both individually and as a group, are analysed and interpreted to identify cultural meaning and common themes.

As indicated previously, the combination of methods used in this study is a recognised research process called triangulation. The concept and process of triangulation are now addressed more fully.

## **Triangulation**

Triangulation is a technical term taken from land surveying and navigation. Two landmarks or visible points enable the individual to take their bearings from two directions to plot the location of a third point or intersection (Patton, 1999; Shih, 1998). Triangulation in research is based on the premise that no single method adequately reveals or explains reality. This is particularly so in the complex area of palliative care where the limits of traditional science are exposed (Thorne, 1999). In fact Liossi and Mystakidou (1998, p.133), suggest that most of the questions in palliative care “require the explorations of processes still to be identified and encompassed in theory.” By using different methods of data collection and analysis the researcher can explore phenomena more fully (Maggs-Rapport, 2000; Patton), yielding a more comprehensive understanding and explanation. The use of triangulation within method (interview and observation); between method (qualitative and quantitative) and in analysis (statistical and content analysis), thus seeks to overcome the deficiencies of a single theory, single methodology and single method study (Kimchi, Polivka & Stevenson, 1991; Shih). However, attention has been drawn to the different meanings of triangulation in research and the need to specify the meaning and the purpose and type of triangulation used (Bergin & While, 2000; Kimchi et al.). The meaning of the different forms of



triangulation used in this research is therefore outlined followed by an explanation of the type and purpose of the triangulation applied in addressing the aims of the study.

### **Methods triangulation**

Methods triangulation involves using two or more research methods in one study. Between methods triangulation occurs when qualitative and quantitative data are used to measure the same phenomena (Kimchi et al. 1991; Patton, 1999). Within methods triangulation involves the combination of two or more similar data collection approaches to measure the same variable, e.g. observation and interview (Kimchi et al.). Patton calls within method triangulation "triangulation of data sources" and defines such an approach as comparing and cross-checking the consistency of information received at different times and by different means. In addition to comparing observational and interview data he adds further dimensions including comparing what people say in public with what they say in private; checking the consistency of what people say about the same thing over time; and, comparing the perspectives of people from different points of view, e.g. staff, clients, funders and people outside a programme.

### **Analyst (Investigator) triangulation**

Investigator triangulation (Kimchi et al. 1991) or Triangulation through multiple analysts (Patton, 1999), involves two or more researchers exploring the same phenomenon. This approach may involve several field workers or observers doing fieldwork to reduce potential individual bias or having two or more researchers analyse the same data set and compare their findings (Patton). Kimchi and colleagues state that researchers should be trained and have divergent backgrounds so biases are compared or neutralised throughout the study. Patton suggests that another approach to analytical triangulation is to have those who were studied review the findings. The credibility of the study is established by the extent to which the participants can relate to the description and analysis. Analysis of data in this study was subjected to review by the nurse participants.

### **Theory triangulation**

Theory triangulation involves looking at the same data using different theoretical perspectives. The theories can be seen as competing, i.e. which theory provides the better explanatory model of the phenomena (Kimchi et al. 1991) or as a way of providing a better understanding about how findings are affected by different assumptions and fundamental premises (Patton, 1999). In the latter case (as applied in this study), ethnography and phenomenology are two theoretical frameworks that can be used to examine qualitative data to gain a different perspective. Maggs-Rapport (2000) suggests that using this combined approach enables the phenomenon to be considered in terms of the participant group and its cultural background, together with the individual experience of participants. In another application of theory triangulation, the concept of response

shift is applied to quantitative data to give additional insight into statistical results.

### **Multiple triangulation**

Multiple triangulation, as the name suggests, occurs when two or more types of triangulation are used in the same study (Kimchi et al. 1991). Within-methods and between-methods or investigator and within-methods triangulation used in the same study are examples of multiple triangulation.

The aim of triangulation is to reduce or circumvent the personal or systematic bias in the research data, thus increasing the study's validity (Kimchi et al. 1991; Patton, 1999). The purpose in using within and between method triangulation in this study is to *confirm* the quantitative data generated by the QOL questionnaire by interviewing and observing participants. This enables theories concerning QOL assessment to be critically examined. The consistency of information derived and review of analysis by participants enhances the validity of the research process by triangulation of data sources. By adding different forms of analysis to method triangulation a more *complete* understanding of the effectiveness of nursing interventions in promoting QOL is obtained. The development of reflective practice through feedback on assessment skills is also interpreted, generating new theory (Bergen & While, 2000).

The concept of clinical versus statistical significance is also pertinent to this study. Clinical significance can be captured through a process of social validation.

### **Social validation**

Social validation is a concept drawn from psychology. In broad terms it refers to the extent to which the goals of an intervention process, the interventions used to achieve those goals, and the outcomes of the efforts to meet those goals are acceptable to the community concerned (Gresham & Lopez, 1996; Lloyd & Heubusch, 1996). Lefort (1993), in addressing the statistical versus clinical significance debate, argues that the proportion of improved subjects is a more valid indicator of clinical significance than statistically significant results such as means and standard deviations. She notes that because what is meaningful depends, in part, on who is asked, social validation is appropriate in assessing clinical significance in nursing research.

In the current study, the researcher suggests social validation is particularly appropriate when seeking to evaluate changes in such a complex phenomenon as QOL. Patient participants were asked their views on the significance of their QOL results, thus accessing the importance of any change from a values as well as statistical perspective (social validation).



Clearly conveying the use of multiple triangulation in this study presents a challenge. A tabulated overview of the type, method, and purpose of triangulation applied to the research aims of the current study is therefore presented (see Table 2). This summary is followed by details of the study method as specifically applied to the three aims.

**Table 2.**  
**Multiple triangulation used in this study - a summary**

Type of triangulation		Method	Purpose
Method	Quantitative	questionnaire used in survey	*testing hypotheses - pre-test/post-test measurement of QOL to evaluate the intervention effect on patients' QOL and nurses' QOL assessment
	Qualitative	interviews & observations & written comments & focus group	* subjective evaluation of QOL *social validation of an intervention *describing & interpreting patient and nurse experiences *describing & interpreting changes in reflective practice
Data		observational & interview	*check what participants say with what they do (separate analysis)
		nurse interviews & focus group	*check consistency of information over time
Analytical		participating nurses review write up of qualitative data analysis	*check the validity of data and the analysis framework used to present the data
Theoretical	Quantitative	descriptive & inferential statistics	*describe sample *Evaluate interventions - improvements in patient QOL and improvements in nurses' assessment skills
	Qualitative	ethnography- descriptive content analysis	*describe cultural experience of patient & nurse
		interpretive phenomenology -	*interpret the lived experience of patient & nurse
		interpretive content analysis	
		response shift	*describe & explain anomalies in statistical results

## **Aims of the study**

The first aim of this study: *To identify if the patient/nurse care planning process, based on QOL assessment, results in improved patient care and consequent improved QOL*, is examined by post-positive quantitative analysis (questionnaire) addressing the hypothesis:

Change scores for the five QOL variables and overall QOL will be greater in the intervention group than in the control group.

Interpretive qualitative analysis (interviews, written comments, observations and social validation) is also used to discover subjective data which contributes to a wider understanding through clinical, rather than just statistical, significance. The dynamic concept of response shift is applied to paradoxical QOL findings in an endeavour to make sense of the data obtained. Between and within method; data; and theory triangulation are applied to discover the degree of convergence and consistency of findings and to achieve a greater understanding of differing assumptions.

The second aim: *To determine whether the patient/nurse planning process improves nurses' assessment skills in recognising patient's QOL status, i.e. increases understanding between nurse/patient*, is again examined by post-positive quantitative analysis (questionnaire) addressing the hypothesis:

Correlations between nurse and patient assessment of the five QOL variables and overall QOL will improve between Time 1 and Time 2.

This aim is similarly addressed in methodology and method but seeks to describe and find new patterns both within each group (ethnography) and individually through narratives and stories (interpretive phenomenology). Between and within method; data; theory; and also analysis triangulation are applied. This research approach is also used in pursuing the third aim: *To promote reflective practice in nurses by providing feedback on their assessment skills*.

It is anticipated that such a triangulated approach can expand the clinical significance of this study and increase the validity of the findings (Bergen & While, 2000; Kimchi et al. 1991; Patton, 1999; Shi, 1998).

## **Conclusion**

As stated in previous chapters, the broad aim of this study is to improve the QOL enjoyed by terminally ill patients in a hospice setting. To achieve this aim, description, explanation, understanding and interpretation are all required within and arising from the research process. Different methodologies and methods, drawn from the post-positive and interpretative paradigms outlined above, are therefore utilised. Quantitative data (via survey research) were obtained through a pre-validated QOL questionnaire administered to patients and their nurses. These data are statistically and comparatively analysed.

Qualitative data were obtained from patient and nurse participants through semi-structured formal interviews, unstructured informal interviews, written comments, field observations and a nursing focus group. The data are analysed in chapters four (statistical) and five (content analysis). Data are presented separately to interpretation to minimise researcher bias (Mays & Pope, 1995 a). Discussion of the data is presented in chapter six.

## **Method**

### **Study setting**

The present study was conducted within an urban hospice in-patient unit comprising eighteen patient beds. The Hospice serves the Wellington region, including the Kapiti Coast (excluding Lower Hutt). Other services provided by the Hospice include outpatient clinics, day therapy and community care co-ordinators. The Hospice works closely with patients' general practitioners. Criteria for admission to palliative care services are an estimated life expectancy of not greater than a year and cessation of curative treatment, i.e. the patient has been informed about the non-curability of their disease and limited life expectancy. Patients are admitted to the Hospice for symptom relief, respite care and terminal nursing care. Over the ten month period of the study (21 June 1999 - 21 April 2000) there were 302 new admissions to the Hospice inpatient unit and 251 deaths. The average stay was eleven days.

### **Study design**

This was a two-staged comparative study involving ten consenting nurses and two groups of five consenting patients for each nurse. Stage one involved the creation of a control group of patients who completed the QOL questionnaire two-three days after admission and again seven to ten days later (quantitative methodology). A random sample of these patients were interviewed to validate the findings of the QOL questionnaire and explore their experiences (qualitative methodology). Stage two involved an intervention group where the patients' QOL results were utilised by the patient and the nurse to create a joint care plan. Again, as in stage one, a random sample of patients were interviewed. To avoid exposure of the control group to the experimental group it was necessary to separate data collection. Thus, a pre-test/post-test experimental methodology was used which involved assessments being made on the control group prior to implementation of the intervention followed by assessments being made on the intervention group. Nurses were interviewed on completion of the QOL data collection and a focus group of nurses met some five months after data collection. Throughout the study field observations, informal interviews and written comments also contributed to the qualitative data obtained.

### **Rationale for study design**

Nursing staff at the Hospice were a cohesive team who discussed patient care and concerns, including effective and non-effective interventions, as part of their nursing practice. Duty handovers between nurses were detailed and comprehensive. Nurses often cared for other patients as well as those for whom they were the primary nurse. Because there was a high proportion of part-time and on-call staff it was impossible to randomly assign patients to nurses. It was also thought to be impossible to separate the nurses into two different research groups that did not discuss the results of patients' QOL assessments or the interventions that were planned to address any deficits, i.e. nurses and patients in the control group would have been exposed to the changes that were being made by nurses and patients in the intervention group. The study groups were, therefore, run sequentially. Although this introduced the possibility of history effects (environmental change occurring between stage one and stage two), this design was the only practical and ethical way to undertake the research.

### **Data collection: Stages**

In stage one, the first five patients for each nurse comprised a control (non-intervention) group where the MVQOLI was administered by the researcher but not used as the basis for joint construction of the care plan. This stage was anticipated to take approximately three months. Semi-structured interviews with randomly selected patients (after the second questionnaire), informal interviews, written comments and field observations yielded qualitative data.

In stage two, each nurse worked with a further five patients using the MVQOLI as the basis for joint development of a care plan and to compare patient/nurse assessments for congruence. Semi-structured interviews with randomly selected patients, informal interviews, field observations and written comments again yielded qualitative data. Stage two was also estimated to take approximately three months i.e. a total of six months involving 10 nurses and 100 patients (Table 3). Following completion of the quantitative data collection, taped, transcribed interviews were carried out with all the nurses.

**Table 3.**  
**Summary of data gathering process**

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#### Stage 1 control (non-intervention) group

1. Administration of the MVQOLI by the researcher to the patient only, at two to three days and then seven to ten days after admission.
2. Interviews conducted a day after the second MVQOL assessment, using a semi-structured format, with a sample of patients (one from each nurse's group of five) to explore the accuracy of the QOL assessment and why patients had experienced any change in their QOL over their period of care.

### Stage 2 (intervention group)

1. Administration of the MVQOLI by the researcher to patients and nurses, two to three days after patient admission.
  2. Nurse receives her own and the patient's QOL assessments enabling her to identify differences in nurse-patient perceptions.
  3. Nurse uses patient's QOL assessment to draw up a care plan, jointly with each patient.
  4. Recompletion of MVQOLI for both patients and nurses seven to ten days after first assessment.
  5. Taped interviews conducted a day after the second MVQOL assessment, using a semi-structured format, with a sample of patients (one from each nurse's group of five) to explore the accuracy of the QOL assessment and why they have experienced any change in their QOL over their period of care.
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### **Focus group**

Five months after the completion of the quantitative data collection, a focus group of eight of the ten participating nurses was facilitated by the Hospice Education Co-ordinator. This focus group allowed shared debriefing on the process of the study, evaluation of the effectiveness of the questionnaire, exploration of the continuing effects of the study on practice, and tentative suggestions for changes in practice within the Hospice context. The session was taped and transcribed by the researcher. The time lapse between being interviewed about the research process and contributing their thoughts in the focus group, brought any lasting changes in nursing behaviour (reflective practice) into sharper focus. This material is included in the discussion on reflective practice in chapter six.

### **Participants**

#### **Patients - Eligibility criteria for study**

All patients admitted to the hospice over the study period, and assigned to nurses participating in the study, were considered eligible for inclusion unless they were:

1. unable to understand and communicate in English;
2. confused or disorientated on admission assessment;
3. experiencing psychological symptoms that, in hospice staffs' opinion, might be exacerbated by completing the questionnaire;
4. near death.



## **Nurses**

Registered nurses with permanent positions, who had worked in the hospice field for at least a year, and who were assigned to the patient as the 'named' or 'associate' nurse were eligible for inclusion in the study. Loss of registered nurse participants early in the study necessitated the inclusion of two very experienced enrolled nurses in the study to restore the number of nurse participants to ten.

## **The researcher**

The researcher is a mature nurse who has taught research and palliative care modules to under-graduate nurses; undertaken post-graduate study in 'understanding death' and palliative care; and worked in the Hospice as an on-call registered nurse for two and a half years prior to undertaking the study. She therefore brings a theoretical and clinical understanding of palliative care and a knowledge of the hospice context (culture) which motivates and informs the research (Hughes, 1992). Her familiarity with the milieu and nursing participants enabled direct observation of behaviours which could be defined as typical or atypical (Mays & Pope, 1995 b). Although not officially "nursing" during the data collection phase, the researcher often adopted a "participant observer" role (minimising the impact on the environment being studied) during busy times while at other times she was a "participant as observer". Cohen and Mount (1992) note that QOL data should be collected by an independent person who is not part of the care giving team. The researcher was careful to avoid giving care to patients participating in the study. A possible difficulty arises out of the researcher's familiarity with the participants and the context of the study. It is suggested that such in-depth familiarity can result in failing to identify how data is discovered and/or the principles underlying such identification (Silverman, 1993). To minimise such a risk, observations were systematically recorded in field notes as soon as possible after the event.

## **Recruitment**

### **Nurses**

Prior to the field-work phase of the study, the researcher was employed as a member of the nursing staff at the hospice. She had frequently spoken, informally, of the impending research study to her colleagues. Detailed information about the research project was given formally at a nurses' meeting where nurses were also invited to answer the QOL questionnaire to be used, and to give feedback. An information sheet (see Appendix B) was available for those interested. Presenting the information at a nurses' meeting enabled all in-patient nursing staff (including enrolled nurses and nurse aides) to be aware of what was involved in the study. A presentation to the Clinical Services Committee ensured that all the multi-disciplinary hospice staff involved in both in-patient and outpatient services were aware of the research and were able to co-operate with the study's requirements.



The Hospice has a considerable number of on-call nurses as staffing requirements can vary considerably. The number of permanent Registered Nurses on day duties at the commencement of the study was only fifteen. Two declined to participate and ten agreed, the other three being undecided or ineligible because of prospective leave during the study period. Early in the study, three nurses were lost to the study because of resignation, pregnancy and promotion. They were replaced by two experienced Enrolled Nurses and one of the previously undecided Registered Nurses (see consent form, Appendix C).

### **Patients**

The researcher attended daily hand-over meetings (involving discussion of each patient by their assigned nurse with doctors and other members of the multidisciplinary team), Monday - Friday. She was also either present or rang the Hospice to check on admissions at the weekend. This enabled prompt identification of any suitable prospective participants. The researcher always consulted members of the health care team before approaching any patient.

### **Ethical issues**

In addition to the usual ethical concerns of informed consent, confidentiality, right to participate and withdraw from research, and non-wasting of participants' time, research with the terminally ill raises some special issues. These ethical issues are related to patients' vulnerability, the potential for distress, the sensitivity needed to obtain informed consent and the patients' relationship with their carers. These will now be discussed in more detail.

### **Vulnerability and potential for distress**

Patients who are terminally ill may be feeling vulnerable as a result of experiencing pain and discomfort (Randall & Downie, 1996), and through their lack of normal defences against intrusion (Aranda, 1995). Many palliative care patients are old. Elderly patients are doubly vulnerable as they experience both aging and illness, two factors which may diminish their autonomy (Moore & Miller, 1999). Terminally ill patients' poor physical condition and short life expectancy is likely to further increase researchers' reluctance to make demands on them (Rathbone et al. 1994). Tierney et al. (1998), however, suggest that research shows limited agreement between caregivers' and patients' assessments and advocates patient-centred assessments as important in improving hospice care. Where overall benefit (either to the individual or for the clientele as a whole) can be expected to be derived from participating in the research, such research can be considered ethical (Aranda).

The present study sought to benefit the patients involved (intervention group) by providing an opportunity to increase their personal QOL. This potential for improvement in QOL was achieved by defining areas that resulted in patient distress and satisfaction and those that gave strength. Hospice staff were able to work with the patient to enhance the positive dimensions of the patient's QOL and discern interventions that would reduce the areas of distress. The opportunity for participants to express emotions, including distress and grief, was seen as positive, and has been identified as a benefit of undergoing research by participants in other studies (Aranda, 1995; Mills et al. 1997; Moore & Miller, 1999; Rathbone et al. 1994). Such expressions of emotion were regarded as positive by the nurses who, as experienced palliative caregivers, understood the appropriateness of this reaction in discussing death and dying and sought to share the patient's suffering as described by Salt (1997).

### **Informed consent**

Jeffrey (1993) points out the need to protect patient autonomy in obtaining informed consent. Persuasion to participate in research by providing information is considered ethical, while coercion through manipulation to undermine the patient's independent reasoning is not. In this study a sensitive, careful approach was followed to achieve informed consent. Aranda (1995) also emphasises that the consenting process is not completed with the signing of the consent form but is one of ongoing collaboration. One patient in the study declined to complete his second assessment, revealing his awareness that such an option was quite acceptable.

The researcher discussed with the participants the study's purpose, risks and benefits and the right to withdraw from the study at any time. This information was provided on an information sheet (Appendix D). Participants indicated informed consent by signing a disclosure document (Appendix E) or, where such a procedure was outside their physical strength, by giving verbal consent. Nurses were reminded of the need for on-going informed consent from patients when psychological, social and spiritual dimensions are discussed. Evidence of distress in these areas does not necessarily mean the patient wishes intervention by hospice staff. Some patients may choose to deal with such issues in their own way and in their own time (Randall & Downie, 1996; Ross, 1997). It is essential that the patient's right to reject offers of care is respected. Again, the experience of the nurses participating in this study and their relationship with the patient helped to protect participants from inappropriate interventions.

### **Researcher/participant relationship**

To avoid any potential pressure to participate (fear of negative consequences if the patient/nurse refuses), the researcher took leave of absence from active nursing for the ten months of data collection. All research was done outside the researcher's normal working hours.

The nurses working in the hospice were known to the researcher and to each other as work colleagues. The conditions set out regarding confidentiality of both their QOL patient assessments and their transcribed interviews on completion of the study encouraged free and honest feedback.

It is important to measure both quality of care and QOL in a palliative care setting (Aranda, 1995; Randall & Downie, 1996; Rathbone et al. 1994). The MVQOLI is an easily completed, well designed instrument that is expected to enable both of these aspects to be evaluated. In both the immediate context and over the longer term, it was expected to help nurses and patients identify the most appropriate, responsive interventions to meet patients' subjective, and constantly changing, needs. The ethical grounds justifying this study are therefore based on both the practical benefit to the patients involved and the potential for on-going improvement in palliative care nursing.

A detailed description of the methods used in this research now follows:

## **Quantitative data**

The next section provides a description of the research process used to obtain quantitative data including the measures used, patient and nurse procedures, and modifications to the study design. Analysis of the quantitative data is found in chapter four.

### **Measures**

#### **The Missoula-VITAS Quality of Life Index**

The MVQOLI was originally a 25 item tool specifically developed by Byock and Merriman (1998) for use with terminally ill patients. The 15 item version was created later by removing one of the assessment and one of the satisfaction items from each dimension of the 25 item version (see Appendix F). For a group of 157 patients who completed 25 items, total scores were calculated using the 15 items only, and compared with total scores calculated using all 25 items. The totals were correlated and found to have high agreement, i.e. a correlation co-efficient of greater than 0.90. The authors, therefore, recommended use of the 15 item version because it is easier on patients and staff (Merriman, 1998).

The five dimensions: symptom, function, interpersonal, well-being, and transcendent are designed to measure both positive and negative aspects of patients' multi-dimensional QOL. Data were summarised into positive and negative scores for the five dimensions, allowing easy identification of the degree of distress, strength and satisfaction of the individual patient.

Each dimension was assessed by three questions which established (1) how the patient evaluated their present position (assessment), (2) how satisfied they were with this position (satisfaction), and (3) how important the particular dimension was to them (importance). Assessment (A) and satisfaction (S) responses were scored on scales ranging from negative to positive. Assessment items were scored from -2 to +2 and satisfaction items from -4 to +4. Satisfaction scores were based on a different scale to reflect the important role of mastery and adaptation inherent in the developmental construct underlying the MVQOLI. The average (A) scores plus the average (S) scores provide the unweighted dimensional scores which range from -6 to +6. Weighted dimensional subscores were calculated by multiplying the assessment plus the satisfaction score by the importance (I) score (an integer between 1 and 5) in that dimension. Weighted subscores range from -30 to +30. Because total scores are a modified sum of the weighted subscores, they reflect the individual patient's identification of the most important dimensions, i.e. an individualised, subjective, multidimensional QOL score. Total scores are calculated by summing the five weighted dimensional scores, dividing the sum by 10, and adding 15 to yield a positive score between 0 and 30 (Byock & Merriman, 1998).

Scores are given in both numerical and graph form to help promote ease of understanding, particularly for energy-compromised patients (see example, shown as Figure 1). This was helpful in the intervention group where nurses used the printout to discuss the results with the patient and to plan care interventions.

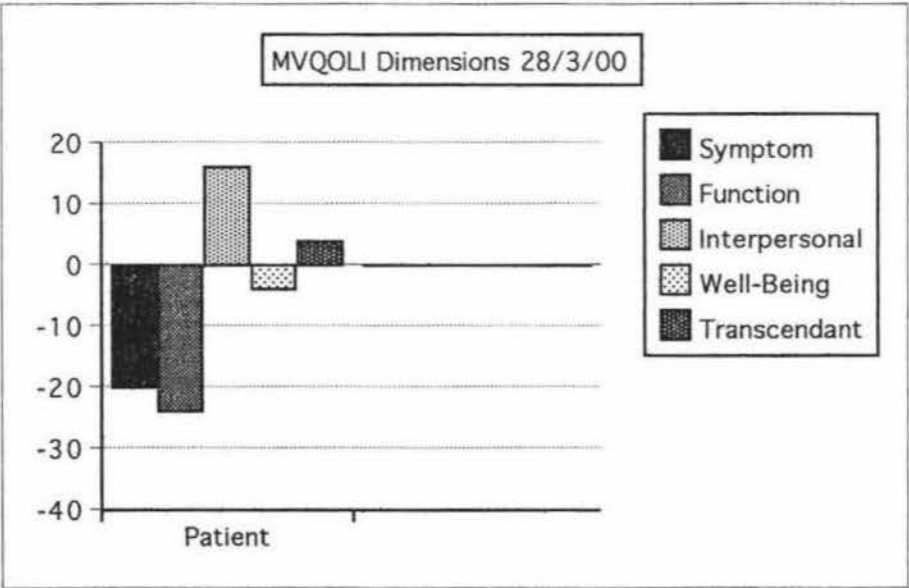


Figure 1. MVQOLI Dimensions, Patient Time 1.

The patient and nurse assessments (intervention group) were also printed in graph form (see Figure 2) which allowed the nurse to quickly identify any discrepancies between assessments.

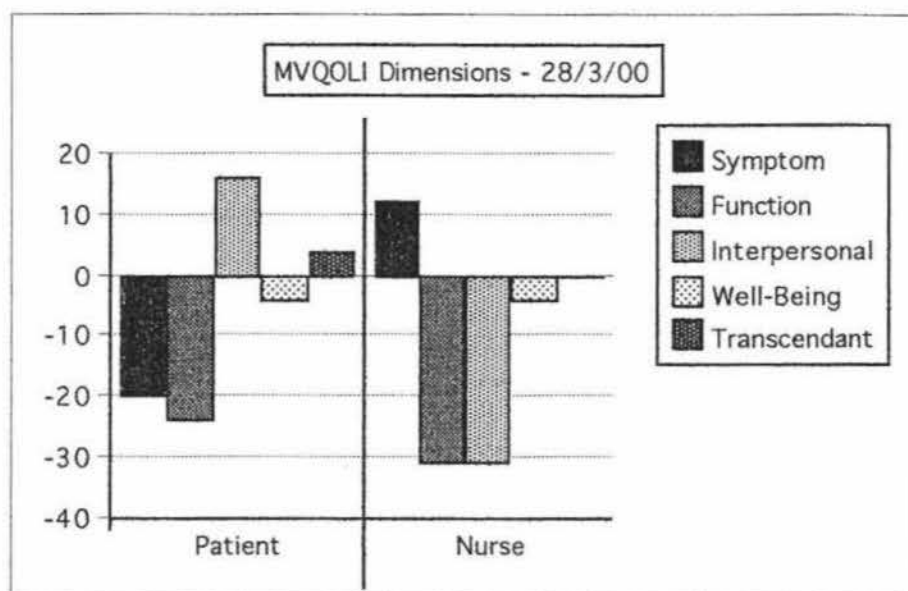


Figure 2. MVQOLI Dimensions, Patient and Nurse, Times 1.

### Piloting of MVQOLI questionnaire

The researcher piloted the 15 item questionnaire with a nursing/lecturer group within Massey University. Changes to the presentation of the questionnaire were made, (i.e. removing scoring numbers which the group found confusing and simplifying directions on how to indicate the preferred answer). The questions and patient scoring key were unchanged. An extra page inviting (optional) written comments was added to provide the opportunity for participants to make additional, individual responses to issues not covered by the questionnaire (see Appendix G).

## Procedure

### Patients

In both stage one and stage two, patients were approached, where possible, soon after admission or within 48 hours of being admitted to the hospice. It has been observed that patients are often emotionally drained on admission to hospice care (McMillan, 1996). Hence, leaving the administration of the questionnaire until they had settled down in a new environment was expected to have resulted in less stress for the patient and a more accurate self-assessment of their baseline QOL status. The initial approach to the patient was made either by the researcher or the assigned nurse. A brief verbal outline of the study was given and, if the patient was interested, an information sheet was left with them. Sometimes the patient requested to see (or it was thought appropriate to show them), the QOL questionnaire itself so the type of questions being asked could be identified. The patient was asked to advise their nurse or the researcher, the next day, if they had decided to participate. Either written or oral consent was obtained prior to the questionnaire being completed. Oral consent was sought when patients' energy levels



were low and the effort required to understand a further detailed form (which repeated much of the material contained in the information sheet) made seeking written consent inappropriate. Demographic data were collected by the researcher from patient's records, with their permission. The precoded MVQOLI was given to the patient to complete. Patients were given the option of completing the questionnaire alone or with the assistance of the researcher. Where assistance was sought, items were read verbatim by the researcher as necessary. Cohen et al. (1997) found that 84% of participants in a palliative care QOL study required questionnaires to be read aloud. In this study, 57% of participants required some form of help in answering the questionnaires.

### **Nurses**

Following the completion of stage one of the data collection (nurses were not involved in stage one), a reminder letter was sent to participating nurses (see Appendix H) and a training session on how to interpret the MVQOLI assessment was given to the participating nurses who attended the meeting. Those who could not attend the meeting received subsequent one-on-one briefings. Individual guidance was then provided, wherever possible, at the point of each nurse/patient questionnaire completion until the nurse seemed to be proficient in understanding the questionnaire and its use. (The researcher assisted the nurse to compare her own and the patient's assessment. Areas of difference were highlighted, discussion of why such differences may have occurred followed and, initially, the researcher suggested where the nurse should seek clarification from the patient. Occasionally interventions that might be appropriate to improve or maintain QOL were considered.) Nurses were not given the patient's results until the nurse had completed her own assessment of that patient's QOL. In nearly all cases, nurses and patients were able to complete their patient assessment on the same day so that the context was relatively constant.

After the MVQOL was completed by both the patient and the nurse, the patient's data were analysed and the results were used, at the first available opportunity, to provide the basis for a discussion between the patient and the nurse. It was intended that the nurse use this discussion to explore more fully the patient's areas of distress, strength and satisfaction. Together they devised a care plan and decided on what interventions would be helpful in improving the patient's QOL, and who should initiate these interventions.

Both the patient and the nurse completed a second MVQOLI, 7 - 10 days later. It was anticipated that this time frame was appropriate to ascertain the impact of the intervention. The second assessment evaluated the success of any interventions undertaken to improve the patient's QOL, and also indicated any change in the nurse's ability to accurately assess QOL for the particular patient, i.e. whether there was improved assessment agreement between the patient and nurse. The second MVQOLI also provided further opportunity for patient and nurse to discuss QOL outcomes and any on-going or unresolved needs. After the second assessment, the researcher conducted a semi-structured interview with a

randomly selected sample of patients to validate questionnaire findings with qualitative data and to identify the factors which led to any change in the patient's QOL.

Informal feedback to the researcher, mid-way through the intervention phase, indicated that two or three nurses were experiencing some difficulty in following the research process. A further letter was sent (see Appendix I) and the researcher again endeavoured to go through the research process, individually, with each participating nurse.

## **Modifications to study design**

As other research studies have found, palliative care is a difficult area to research because patients are generally very sick, leading to low recruitment and high attrition (Jordhoy et al. 1999; McMillan, 1996; Rinck et al. 1997). In practice, the limited availability of suitable applicants and a high rate of attrition between patients completing the first and second questionnaire necessitated modifications to the research design. For example, in the first three months 21 June 1999 to 21 September, there were 116 admissions to the Hospice. Of these 116 admissions, 76 did not meet the criteria for inclusion, nine declined to participate, five were unable to complete the second questionnaire, four agreed to participate but then deteriorated before the first questionnaire was administered, two were not allocated to nurses participating in the study, and 20 completed both questionnaires. By the end of March 2000 (21 weeks into the second (intervention) phase of the study), 43 participants had completed questionnaire one in the intervention group, but only 31 had been able to complete questionnaire two, i.e. a 38% attrition rate.

The difficulty in recruiting sufficient participants to retain the power of the study, but still keep the study within a reasonable time-frame, necessitated both an extended period of data collection and a reduction in the number of study participants. These modifications meant that a total of 36 patients in the control and intervention groups completed both assessments over a ten month period (i.e. 72 in all). The reduction in total numbers was considered to have a minimal effect on the quality of the study.

The researcher's approach to prospective participants was also modified. Patients who indicated they wished to participate, and were ready to do so immediately, were given the opportunity to complete the QOL questionnaire at that time rather than waiting till the next day. After discussion with the Palliative Care Director, Community Care Co-ordinators and nursing staff a letter was drafted, outlining the research study, to be sent to suitable patients who were booked to come in for a week's respite care (see Appendix J). As with already admitted patients, the suitability of these patients to participate in the study was checked by reading their medical notes and consulting their Care Co-ordinator or Hospice doctor. The prior contact enabled these patients to have already considered whether or not they wished to take part in the research study before arriving at the Hospice. For those who decided in the affirmative, the questionnaire was available on admission and

could thus be repeated on the day of discharge 7 days later, or if the patient stayed longer, 7-10 days later. Prompt answering of the questionnaire, where patients wished to do this, as well as alerting respite patients to the study beforehand, decreased the number of patients lost to the study through deterioration of health status or too short a stay.

### **Additional research involving nurses: Their experience in using the research intervention**

Despite the efforts taken to provide instruction and feedback to the nurses on the study's procedures, it became clear to the researcher, from field observations, that nurses were using the QOL research process in different ways. To gain a clear understanding of how nurses actually used the QOL questionnaire to plan patient care and how effective they thought this process was, additional modification to the research was proposed. Taped interviews were conducted with the participating nurses on the completion of data collection, using semi-structured questions (see Appendix K).

#### **Objectives**

This part of the modified study had two objectives (which were extensions of the original aims two and three):

1. to describe, interpret and understand the experiences of nurses in using the QOL assessment approach to plan patient care; and
2. to offer nurses an opportunity to reflect on their experiences and voice their opinions about the research process and the objectives of the intervention.

#### **Procedures**

If the nursing interviews were undertaken by the researcher there would be a likelihood of bias. It was anticipated that in this situation the nurses might be uncomfortable in commenting negatively on the use of the QOL questionnaire and the research process. Thus to remove any barriers to openness, the research co-ordinator at the Hospice, who was not involved in clinical work, conducted the interviews with the nurses after obtaining informed consent.

The tapes were given a code number and were transcribed by a receptionist at the Hospice who worked closely with the research co-ordinator to ensure consistency in the interpretation. The receptionist signed a confidentiality form to 'protect' the information provided by the nurses. Tapes were kept in a locked cupboard in a secure location. Transcripts were kept in a locked filing cupboard separate from tapes. Nurses were offered their tapes and given an opportunity to read and edit their transcripts. The coded, edited transcripts were then given to the researcher.

## **Analysis of quantitative data**

Quantitative data were analysed using the Statistical Package for Social Sciences. Descriptive statistics were used to summarise the characteristics of the patient and nurse sample and provide means (averages) and standard deviations (which express the variability of a measurement) of change in QOL scores. Pearson's correlation was used to measure the relationship between nurses' and patients' ratings of QOL (Polit & Hungler, 1995). Inferential statistics, namely parametric statistical tests (the t test and analyses of variance (ANOVA)) were used to determine whether the means of the control and intervention groups (matched-groups) and pre and post-test (within-subject) scores were significantly different (Skodol Wilson, 1993). The Chi-square, a non-parametric test which assesses whether a relationship exists between two nominal level variables, was used to discover if there was a relationship between biographical factors and health status (Polit & Hungler).

## **Ethical committees**

Permission for the study was obtained from the Palliative Care Director of the Hospice, the Central Health Wellington Ethics Committee and Massey University Human Ethics Committee.

Ethics permission to modify the research design was subsequently obtained from the Wellington Ethics Committee and the Massey Human Ethics Committee, upon further application by the researcher.

A discussion of how qualitative data was gathered and processed follows.

## **Qualitative data**

Qualitative data were obtained through formal semi-structured interviews with twelve patients (see Appendix L) and all the participating nurses; informal non-structured interviews with both patients and nurses; written comments from both patients and nurses; and field observations.

## **Formal interviews**

Interviews for both patients and nurses were 'pilot tested' before the actual research interviews were carried out. Pilot testing was important to try out a variety of openings and questions (Sorrell & Redmond, 1995), and to ensure the researchers were technically familiar with the recording equipment. Respondents were also prepared by being reminded of the purpose of the interview, the confidentiality of the data and by ensuring

that the interview took place in an environment where the participants felt comfortable. As Carspecken (1996) suggests, the interviews were semi-structured (see Appendix L). Formal interviews took place with twelve patients (six from each group) and all of the participating nurses.

### **Informal interviews**

There were frequent informal interviews (discussions) with both patients and staff throughout the research process. Informal patient interviews usually occurred while assisting patients to complete their QOL questionnaires or on collecting the answered questionnaires. Occasionally they were at the patient's request (usually to check their understanding of a particular question) and sometimes where the researcher found an unanswered question or one where the answer was not clear. Interaction with staff was a daily occurrence and yielded important insights into staff attitudes and experiences with the research process.

### **Field notes (observations)**

The researcher also made field notes throughout the study, including after each patient interview. These notes included observations of both patients and nurses (verbal and non-verbal); cameos which captured attitudes or behaviours; and, insights into possible research outcomes. The notes provided a context in which to place both the patient and the nurse interviews and identified differences between what was said and what participants did. Field notes and written comments on the questionnaires were analysed separately but by using the same method as for the transcriptions. Written comments from the questionnaires and field notes were written in different colours from interview transcriptions so the origin of the material was always apparent to the researcher.

## **Analysis of qualitative data**

Analysis of qualitative data was based on the method of analysing interview transcripts suggested by Burnard (1991). Burnard adapted his method of content analysis from the works of other authors including Glaser and Strauss' 'grounded theory' approach; the literature on content analysis; and from other sources concerned with the analysis of qualitative data (Burnard, p.461). His method was used to categorise and codify qualitative material through various phases or stages.



## **Phase one**

All taped formal interviews (both patient and nurse) were fully transcribed. The transcriptions included other important communication details such as silence, tone of voice, and laughter. Noting silence was particularly important in understanding the subjective experience of the participant where silence may indicate ideas or feelings that cannot be expressed (Sorrell & Redmond, 1995). The researcher also listened to each tape several times, making additional notes on non-lingual cues on the transcript. This approach attempted to ensure that the meaning behind the words was encapsulated when the words used were open to differing interpretations. For example, some nurses spoke light-heartedly at times and, when this occurred, it was important not to take their words literally. One nurse, in discussing the appropriateness of certain QOL questions, commented "*the sort of very moral ones about meaning of life and things: it's almost as if you had to have a bad diagnosis or visitation to suddenly do a personality change...*". A throw away line she later described as "facetious".

## **Validity of transcripts**

All nurses were given their transcripts to correct, confirm and comment on. Occasional difficulties with the tape recorder were experienced during interviews and one nurse felt this interrupted her train of thought, particularly when she was asked to "redo questions". Because surviving patients were already compromised in concentration, energy and cognition they were not asked to read their transcripts, but these were available to them if they so desired. No patient wished to read their comments. One family requested the tape of their mother's interview, after she had died: "*It is just so good to hear her voice again.*"

## **Phase two**

Patient and nurse interviews were analysed separately but the same analysis process was used for both. The tapes were listened to and transcripts read several times with patterns being identified and noted on the transcript. These individual patterns were then clustered to obtain general categories. The categories were noted under several headings and colour coded. The transcripts were then re-read and colour coded according to the identified categories. Almost all the material in the interviews was categorised although divergence from the research topic occurred with some patients (discussion of family history and reminiscences which were not immediately relevant to the present situation). This material was not included.

The eleven categories initially identified for patient qualitative data were: developmental growth; insights from participating; accuracy of QOL results; changes in QOL; deficits in questionnaire; faith/hope; negative QOL; importance of attitude; factors affecting

QOL; variability of QOL; and miscellaneous.

Initial analysis of the nurses qualitative data yielded twenty-one categories. These were: effect of research process; time; deficiencies in questionnaire; poor preparation for study; reflective practice; positive outcomes from use of questionnaire; positive use of assessments; areas not usually assessed; difficulties of research process; variability of QOL; future use; aspects of QOL not asked about; issues that would have taken longer to get to; knowledge of differences in assessment nurses/patient; effect on patients; affirming of nurses' expertise; response shift; patient personality; nurses' attitude; workload; rostering.

### Phase three

The identified categories were reduced by combining similar categories together, sometimes under broader headings, and the transcripts re-coded accordingly.

Patient categories became: (content analysis) accuracy of QOL results; deficiencies in the MVQOL Index; changes in QOL; and, (common threads) developmental growth; attitude (hope and faith); variability in QOL; and no change or negative changes in QOL. Thus the initial categories of attitude, faith and hope were combined as were insights from participating and developmental growth. Changes in QOL and factors affecting QOL were likewise combined to reduce the number of categories to seven (see Table 4).

**Table 4.**  
**Patient categories at stage two and stage three**

Stage two	Stage three
Accuracy of QOL results	Accuracy of QOL results
Deficiencies in the questionnaire	Deficiencies in the questionnaire
Changes in QOL Factors affecting QOL }	Changes in QOL
Attitude Faith and hope }	Attitude (faith and hope)
Insights from participating Developmental growth }	Developmental growth
Variability in QOL	Variability in QOL
No change/negative changes in QOL	No change/negative changes in QOL

The initial categories established for coding nurse interviews were reduced from twenty to eleven (see Table 5). In part this was achieved by placing sub headings under broader categories e.g. the effect of time constraints, rosters and workloads were discussed under the category of the Hospice Context. The category 'Positive outcomes of the research process' included: use of assessments, areas not usually assessed, aspects of QOL not asked about, issues that would have taken longer to get to, effect on patients, and affirming of nurses' expertise. The initial category of response shift was combined with variability of patient QOL to form one category. Where categories (e.g. attitude and differences in assessment) applied to both patient and nurse these were discussed separately within the Patients Context and the Nurses Context.

**Table 5.**  
**Nurse categories at stage two and stage three**

Stage two	Stage three
Preparation for the research process	Preparation for the research process
Difficulties in completing the research process	Difficulties in completing the research process
Deficiencies in the QOL questionnaire	Deficiencies in the QOL questionnaire
Time Rosters } Workload	Hospice Context
Attitude (patient) } Differences in assessment	Patient Context
Attitude (nurses) } Differences in assessment	Nurse Context
Variability of QOL } Response shift }	Variability of QOL
Use of assessments Areas not usually assessed Aspects of QOL not asked about Issues that would have taken longer to get to } Effect on patients Affirming of nurses' expertise	Positive outcomes of research process
Reflective practice	Reflective practice
Future use	Future use

## **Phase four**

Each coded section of the interviews, field notes and written comments were then transcribed on to a page headed with that category. Certain quotes could be placed under more than one category, e.g. My affairs are in order/not in order:

*See, that's a brilliant question to ask because quite often that gets missed. That's something people are thinking about but maybe not verbalising and so that's a brilliant one to ask because then you can..., all sorts of things lead on from that... You find out whether they need to be at home to die or to get home for, even if it's a matter of a few hours, whatever, yeah.*

This quote was cross referenced under both 'Positive outcomes of the research process', and 'Future use'. Care was taken to ensure comments were not taken out of context.

## **Phase five**

The interview, comments and field observation data were then written up under the category headings and sub headings. It was necessary to refer back to the full transcript from time to time to confirm the context of the quotes. Sufficient quotes were used in each section to convey the variety or depth of responses from patient and nurse participants. The quotes used in writing up were identified on each category sheet. This enabled those quotes or observations that were not used to be checked to see all significant aspects had been identified and written into the text.

## **Phase six**

### **Validity of analysis**

All participating nurses were sent a letter (see Appendix M), given a draft of the qualitative results chapter, and asked to verify how their quotes were used, i.e. to check whether the way the quotes were categorised changed the meaning of what the nurse was intending to say. One nurse identified a quote which she felt was incorrectly categorised, and this was re-coded to her satisfaction. The other nine nurses were satisfied with the analysis of their material. Nurses were also asked for comment and insights on their combined, categorised material. No critical comment or insights were received although several nurses expressed appreciation of how their data had been integrated.

As previously noted on validating interview transcripts, it was not felt to be appropriate to ask the few patient participants who were still alive at this stage of the study, to read and verify the patient interview analysis.

## **Phase seven**

Quantitative data were compared with qualitative data and the results verified. Patient qualitative data were analysed for clinically significant improvement in QOL (method triangulation). Observational, written and interview data were coded separately to enable data triangulation. Descriptive content analysis and interpretive content analysis were then applied to the data to describe, understand, interpret and put forward new theories (theoretical triangulation).

A clear unifying theme emerged from a careful analysis of the various data sources included in the study. The theme of 'revelation' made explicit the implicit meaning contained in interview transcripts, informal interviews and observed, recurrent behaviours. Important aspects of and issues in the lives of the patients, nurses and the researcher were represented by this theme (DeSantis & Ugarriza, 2000). 'Revelation' may be seen as a foundational component in any future development of effective palliative care interventions.

## **Summary**

This chapter has addressed the foundations of social research and how they have been applied in this study. Multiple triangulations - a combination of methodologies and methods applied across accepted paradigms - have been outlined as appropriate for the study's complex research aim of improving the QOL of terminally ill patients in a hospice setting. Details of the study design, modifications, and the methods used to obtain and process the quantitative and qualitative data followed. The validity of research studies can be enhanced by separating data and analysis, enabling the reader to compare their own interpretation of the data with that of the researcher. Thus to minimise researcher bias in the presentation of results, quantitative and qualitative data are separated from the discussion section as recommended by Mays & Pope (1995 a). The following chapter presents quantitative data while qualitative data are covered in chapter five. Discussion of the data is found in chapter six. The unifying theme of revelation that emerged as patterns came together, broke up, and reformed during reflection on the study's findings is presented in chapter seven.



# Chapter Four

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## QUANTITATIVE RESULTS

### Introduction

This chapter outlines the quantitative findings of the study. It begins with a description of the overall study sample and issues related to the gathering of the data. This is followed by a description of how the data were analysed. A description of the patient sample and data related to hypothesis 1 (change scores for the five QOL variables and overall QOL will be greater in the intervention group than in the control group) is then presented. This is followed by a biographical description of the nurses involved in the study and data related to hypothesis 2 (correlations between nurse and patient assessment of the five QOL variables and overall QOL will improve between Time 1 and Time 2). The chapter closes with a brief outline of patient status at the completion of data collection followed by a summary of the quantitative findings.

### Sample

Ninety-four of the targeted 100 participants completed the first questionnaire in the (extended) ten month period of the study. Another six patients had agreed to participate but deteriorated before actually completing the first QOL questionnaire. Of the 94 participants who entered the study, only 72 were able to complete both the first and second questionnaires. Twenty-two patients were lost to the study: five patients were discharged before the seven to ten day interval between questionnaires one and two, sixteen deteriorated or died, and one declined to complete the second questionnaire. The rate of attrition was higher in the intervention group. Thirteen patients were unable to complete the second questionnaire in the intervention phase (27%) compared with nine from the control group (20%). Partly because of the greater loss of patients, reflecting the higher number of very ill patients admitted, it took longer to achieve the required 36 completed participants for the intervention group; 19 weeks for the control group and 33 weeks for the intervention group. Similar methodological problems in recruitment and retention have been identified in other palliative care studies (Jordhoy et al, 1999; McMillian, 1996; Mills, Webb, Stuart, Cooney & Leelarthapin, 1997). Nineteen patients required assistance in completing the questionnaire in the control group (53%) compared with 22 patients in the intervention group (61%). The total number of patients needing help was 41, (57%).

On average seven participants completed both questionnaires each month (range 2 - 12). The lowest completion rates were recorded in July 1999 and December 1999. This was consistent with a lower number of suitable admissions. Of the 24 patients who declined to participate (19%), the main reasons given were recent participation in a hospital survey, feeling too tired, or reluctance to address the issues raised in the questionnaire. Those patients prepared to participate often made comments such as “delighted to do anything that might help someone” or “anything I can do to help”. The final sample consisted of 72 participants, 36 in each of the two groups, achieved over a period of ten months.

### Data analysis

The MVQOLI was scored by algorithm, supplied on a disc by the VITAS Healthcare Corporation. Dimensional subscores and total scores are calculated according to the following formulas using custom paradox calculation scripts (see Table 6).

**Table 6.**  
**MVQOLI algorithm**

Unweighted dimensional subscore = average assessment + average satisfaction =		
$\frac{DA1 + DA2}{2}$	+	$\frac{DS1 + DS2}{2}$
= $\frac{DA1 + DA2 + DS1 + DS2}{2}$		
Weighted dimensional subscore = $[DA1 + DA2 + DS1 + DS2] / 2 \times (DI)$		
Total score = $[(\text{sum of weighted dimensional subscores}) / 10] + 15$ ; This is a mathematical conversion to generate total scores between 0 and 30.		
Where D is one of the five dimensions, A is an assessment item in the specified dimension, S is a satisfaction item in the specified dimension and I is the importance item for the specified dimension. Subscripts indicate the first (1) or second (2) item of that type.		

Byock & Merriman (1998, p.236).

All analyses were performed using the statistical computer package SPSS PC for Windows, Statistical Package for Social Sciences (version 9.0). Descriptive statistics were used to analyse demographic data. T-Tests were used to examine differences in group means on the variables. In these analyses, an F test of sample variances was carried out. If the probability of F was >.05, then it was assumed sample variances were equal and pooled variance estimates were used. If the probability of F was <.05 then it was assumed sample variances were unequal and separate variance estimates of t were used (Snedecor & Cochran, 1980). When cell expected frequency were less than 5, Fishers exact was calculated. Pearson correlations were calculated to examine relationships between demographic data and QOL, and to compare patients’ and nurses’ assessments of QOL. T-tests compared QOL subscale and total QOL difference scores between the control and intervention groups for the first and second administration of the questionnaire.

## Patient sample description

Detailed biographical and health information for the patient sample are provided in Table 7.

**Table 7.**  
**Summary of Biographical and Health information for Whole Group (N=72).**

	Control	Percentage of respondents	Intervention	Percentage of respondents	Chi Square
<b>Gender</b>					
Female	16	44	20	56	ns
Male	20	56	16	44	
<b>Age (Years)</b>					
20-29	1	2.8	1	2.8	ns
30-39	0	0	1	2.8	
40-49	2	5.6	1	2.8	
50-59	5	13.9	2	5.6	
60-69	7	19.4	12	33.3	
70-79	9	25.0	8	22.2	
80-89	12	33.3	11	30.5	
<b>Marital Status</b>					
Never married/divorced	4	11.0	1	2.8	ns
Widowed	9	25.0	18	50.0	
Married	23	64.0	17	47.2	
<b>Ethnicity</b>					
N Z European	32	88.8	31	85.9	ns
Other European	1	2.8	2	5.6	
Maori	2	5.6	1	2.8	
Pacific Islander	1	2.8	2	5.6	
<b>Reason for admission</b>					
Symptom control	20	55.5	20	55.5	ns
Terminal nursing	2	5.6	5	13.9	
Respite	14	38.9	11	30.6	
<b>Diagnosis</b>					
Cancer	31	86.1	35	97.2	ns
Respiratory/cardiac	3	8.3	1	2.8	
Other	2	5.6	0	0.0	

Analyses found no significant differences between the control and intervention groups in gender, age, marital status, ethnicity, reason for admission, number of admissions to the Hospice or diagnosis.

# Hypothesis 1

Change scores between Time 1 and Time 2 for the five QOL subscales and overall QOL will be greater in the intervention group than in the control group.

## 1.1 QOL change scores across groups

Table 8 presents Means and Standard Deviations for the change in scores from Time 1 to Time 2 for the control and intervention groups on the five QOL subscales and overall QOL. There was no statistically significant change in the QOL subscales or overall QOL scores across Time 1 and Time 2 between the control and intervention groups.

**Table 8.**  
**Change in QOL scores from Time 1 to Time 2 for Control and Intervention groups (N=72).**

	Group	N	Mean	Std. Deviation	t
Symptom	control	36	3.83	7.33	ns
	intervention	36	4.75	13.81	ns
Function	control	36	.52	17.04	ns
	intervention	36	7.58	18.02	ns
Interpersonal	control	36	1.41	11.88	ns
	intervention	36	.16	12.04	ns
Wellbeing	control	36	4.13	14.55	ns
	intervention	36	2.72	10.15	ns
Transcendent	control	36	.97	9.69	ns
	intervention	36	1.30	12.04	ns
Overall QOL	control	36	10.88	33.58	ns
	intervention	36	16.52	39.05	ns

## 1.2

Means and standard deviations on QOL subscales and overall QOL Time 1 and Time 2 for the control group are presented in Table 9. Within group change in QOL scores in the control groups' first and second assessment were statistically significant for symptom.

**Table 9.**  
**Within group change in QOL scores from Time 1 and Time 2 for Control Group (N=36).**

		Mean	Std. Deviation	t
Symptoms	QOL T1	3.63	6.84	**
Symptoms	QOL T2	7.47	5.41	
Function	QOL T1	-4.52	17.06	ns
Function	QOL T2	-4.00	17.11	
Interpersonal	QOL T1	11.69	13.02	ns
Interpersonal	QOL T2	13.11	13.34	
Well-being	QOL T1	1.11	13.60	ns
Well-being	QOL T2	5.25	13.92	
Transcendent	QOL T1	12.19	12.56	ns
Transcendent	QOL T2	13.16	13.01	
Overall	QOL T1	24.11	33.70	ns
Overall	QOL T2	35.00	40.10	

\*\* p<.01

**1.3** Means and Standard Deviations on QOL subscales and overall QOL for the intervention group are presented in Table 10. Within group change scores between QOL scores in the intervention groups' first and second assessment were statistically significant for symptoms and function and overall QOL.



**Table 10.****Within group change in QOL scores from Time 1 to Time 2 for Intervention Group (N=36).**

		Mean	Std. Deviation	t
Symptoms	QOL T1	1.44	11.01	*
Symptoms	QOL T2	6.19	9.17	
Function	QOL T1	-5.00	16.40	*
Function	QOL T2	2.58	15.28	
Interpersonal	QOL T1	13.83	12.01	ns
Interpersonal	QOL T2	14.00	12.64	
Well-being	QOL T1	6.30	12.02	ns
Well-being	QOL T2	9.03	12.17	
Transcendent	QOL T1	14.31	11.95	ns
Transcendent	QOL T2	15.61	9.58	
Overall	QOL T1	30.88	41.88	**
Overall	QOL T2	47.41	39.22	

\*\* p&lt;.001

\* p&lt;.05

**Nurse sample description**

The ten nurses participating in the study were all female, european and experienced in palliative care nursing. The nurses involved in the study ranged in age from 36 to 56 years. Eight were Registered Nurses and two Enrolled Nurses. All had completed some additional form of tertiary education including B.A., Palliative Care Modules, and relevant short courses, e.g. massage, alternative therapies, counselling, spiritual development/healing touch, loss and grief. Years in nursing ranged from seven to 36 and years in palliative care nursing from one to nine (see Table 11).

**Table 11.**  
**Summary of Biographical information for Nurses (N=10).**

	Number of Respondents
<b>Gender</b>	
Female	10
<b>Age (Years)</b>	
35-39	3
40-44	1
45-49	5
>50	1
<b>Ethnicity</b>	
European	10
<b>Education</b>	
RGON, R(COMP)N, RGN	8
EN	2
B.A.	1
Palliative Care Modules	9
Relevant short courses	6
<b>Years in nursing</b>	
5-9	1
10-14	3
15-19	2
20-24	1
25-29	1
30-34	1
>35	1
<b>Years in palliative care</b>	
<4	2
5-9	8

## Hypothesis 2

Correlations between nurse and patient assessment of the five QOL subscales and overall QOL will improve between Time 1 and Time 2.

### 2.1 Correlation at Time 1.

Nurses and patients ratings of two of the five QOL subscales were correlated at Time 1. Positive correlations were found in the subscales interpersonal and well-being, and overall QOL. There were no significant correlations between nurses and patients in the subscales symptoms, function and transcendence (see Table 12).

**Table 12.**  
**Correlations Between Nurses' and Patients' Ratings for QOL Subscales and Overall QOL Time 1 (N=36).**

	Pearson Correlation	Significance
Symptom	.210	ns
Function	.230	ns
Interpersonal	.433	**
Well-being	.351	*
Transcendent	.098	ns
Overall QOL	.480	**

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

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

### 2.2 Correlation at Time 2

Nurses' and patients' ratings of four subscales and overall QOL were correlated at Time 2. There was no correlation between the patient and nurse assessment of symptoms. The correlations in interpersonal, well-being and overall QOL increased in magnitude from those demonstrated at Time 1 (see Table 13).

**Table 13.**  
**Correlations Between Nurses and Patients Ratings of QOL Subscales and Overall QOL Time 2 (N=33<sup>2</sup> ).**

	Pearson Correlation	Significance
Symptom	.131	ns
Function	.433	**
Interpersonal	.616	**
Well-being	.394	*
Transcendent	.474	**
Overall QOL	.603	**

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

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

### 2.3 Correlation of Nurses Time 2 with Patients Time 1

To see if nurses' ratings at Time 2 might be influenced by patient ratings Time 1, further statistical analysis was completed. Nurses' ratings of patients' symptoms, well-being and transcendence Time 2, correlated more highly with patients' ratings of these subscales at Time 1 than with patients' ratings at Time 2 (see Table 14).

**Table 14.**  
**Correlations Between Nurses' Ratings of QOL Subscales and Overall QOL Time 2 with Patients' Time 1 (N=33).**

	Pearson Correlation	Significance
Symptom T2 with Patient T2	.131	ns
Symptom T2 with Patient T1	.377	*
Function T2 with Patient T2	.433	**
Function T2 with Patient T1	.290	ns
Interpersonal T2 with Patient T2	.616	**
Interpersonal T2 with Patient T1	.457	**
Well-being T2 with Patient T2	.394	*
Well-being T2 with Patient T1	.483	**
Transcendent T2 with Patient T2	.474	**
Transcendent T2 with Patient T1	.587	**

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

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

<sup>2</sup> Nursing assessments were unable to be completed for three patients Time 2

### **Patient status at data completion**

One week after the data completion of the patient study (1 May 2000), eight patients of the control group and 14 patients from the intervention group were still alive, i.e. 75% and 60% of patients, respectively, had died. It is important, of course, to note the time differential between the two groups; six months had elapsed since final data collection from the control group so a higher death rate from this group would be anticipated. Unlike other research findings, data in this study revealed no evidence of declining QOL as patients approached death.

## **Summary**

This study on the effect of using a QOL questionnaire to plan patient care experienced difficulty in recruiting and retaining participants because of the focus of palliative care on the terminally ill. These difficulties have been encountered by other researchers working in this field. Seventy-two patients and ten nurses participated.

Hypothesis one, that **'change scores between Time 1 and Time 2 for the five QOL subscales and overall QOL will be greater in the intervention than in the control group'** was not supported. No statistically significant differences between the control and intervention groups' QOL change scores were found. There were significant differences in QOL change scores within the groups. The control group achieved an increase in QOL in the area of symptom while the intervention group sustained improved QOL in the subscales symptom and function, and overall QOL.

Hypothesis two, that **'correlations between nurse and patient assessment of the five QOL subscales and overall QOL will improve between Time 1 and Time 2'** was supported. Patient and nurse ratings at Time 1 correlated in the subscales interpersonal, well-being and overall QOL. At Time 2 these correlations were of greater magnitude and significant correlations were also found in function and transcendence, i.e. symptom was the only subscale without significant correlation. However, in the subscales symptom, well-being and transcendence, nurses' ratings at Time 2 correlated more highly with the patients' ratings at Time 1 than patients' ratings at Time 2.

Qualitative data to expand and deepen the understanding of the quantitative results and consider the third aim of improving nurse's reflective practice is presented in chapter 5.



# Chapter Five

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## QUALITATIVE RESULTS

### Introduction

This chapter outlines the data gathered from: formal and informal patient and nurse interviews, comments added to the QOL questionnaire by participants, a focus group of nurses held five months after the study, and field observations made by the researcher. Both patient and nurse interviews followed a semi-structured format with the interviewer free to follow any pertinent aspect raised by the participants, but sufficiently disciplined to ensure the relevant areas were covered. The material obtained from all these sources was interpreted using content analysis. In the interests of clarity, patient data and nurse data will be presented separately. In the section on patient data, taped and transcribed material from the twelve patient interviews will be presented first, followed by secondary patient data. Because all ten nurses participated in interviews formal, informal and observational data is combined in this section as is material from the focus group. Pseudonyms are used to preserve patient and nurse confidentiality, and to enable the reader both to identify the participants and build up a picture of their personal experience. Quantitative and qualitative outcomes from both groups will be analysed and discussed in chapter six .

### Patient data

All twelve patients approached after completing their second QOL questionnaire, agreed to a taped, transcribed interview. Six of these formal interviews were conducted within each research group (control and intervention). Interviews took place at the patient's bedside and lasted between 15 and 30 minutes. Where patients were sharing a room they were asked if they wished to be interviewed elsewhere. Because of the space between beds, privacy was not an issue and all patients chose to remain where they were. Field notes on non-verbal communication, insights obtained by the researcher and any other relevant observations were made on completion of the interview. Of the twelve interviewed patients, three died within a week of the interview, a further five 12 days - 6 weeks later, while four were still alive on completion of the data collection phase of the study (time span since interview to the end of data collection, one week to seven months).

Informal interviews also contributed to the secondary data pool. Of the 57% of patients who required assistance in completing the questionnaire, the majority used the questionnaire as a prompt for conveying further information to the researcher. Often this

occurred as they gave reasons for answering the questionnaire in a certain way. On completion of the questionnaire, additional information was occasionally elicited by the researcher asking if there were any other elements, significant to the participant's QOL, that had not been covered. The time taken in assisting participants to complete the questionnaire varied between 10 minutes and an hour, reflecting how much thought was required to answer the questionnaire and the amount of additional information the patient wished to share.

Twenty-two of the thirty-one participants who completed the questionnaire unaided added written comments. These comments are included in the data analysis. The researcher also made observational field notes throughout the study. Interview material, written comments and observational records were matched for data presentation (Carspecken, 1996).

### **Accuracy of QOL results**

The twelve interviewed patients were shown their Time 1 and Time 2 QOL questionnaire results and, after explanation or clarification, asked if they agreed with the results shown. Nine patients agreed that these results were an accurate representation of their QOL while three patients agreed with some subscale results, but not all. Where a difference was identified, the researcher sought to establish the reason for the discrepancy, working through the particular subscales of the questionnaire with the participant. Three different reasons for the perceived discrepancy emerged: deficiencies in how the questions were asked in the questionnaire; changes in the participant's attitude; and variability in the patient's condition. Deficiencies in the questionnaire will be specifically addressed in the following section while patient changes in attitude and condition are covered in the general discussion on 'changes in QOL'.

### **Deficiencies in the Missoula-VITAS QOL Index**

In addition to those patients interviewed, many of the other 60 patients participating in the research identified deficiencies in the QOL questionnaire used. Comments made by all patients are integrated into the following discussion. The main difficulties noted were:

- \* construction of the questionnaire responses
- \* framing of certain questions
- \* opposing statements in continuums
- \* linking of concepts within a question

A compacted reproduction of the MVQOLI is provided to enable the reader to readily identify the questions involved (see Table 15).

**Table 15.**  
**A compacted version of the MVQOLI**

---

1. How would you rate your overall quality of life?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worst Possible	Poor	Fair	Good	Best Possible

**Symptom**

2. I feel sick all the time.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree strongly	Agree	Neutral	Disagree	Disagree strongly

3. I am satisfied with current control of my symptoms

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree strongly	Agree	Neutral	Disagree	Disagree strongly

4. Despite physical discomfort,  
in general I can enjoy my days.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		OR	Physical discomfort overshadows any opportunity for enjoyment.	

**Function**

5. I am still able to do many  
of the things I like to do.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		OR	I am no longer able to do many of the things I like to do.	

6.I accept the fact that I can not do  
many of the things that I used to do.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
		OR	I am disappointed that I can not do many of the things that I used to do.	

7. My contentment with life depends upon being active and being independent in my personal care.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree strongly	Agree	Neutral	Disagree	Disagree strongly

**Interpersonal**

8. I have recently been able to say important things to the people close to me.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree strongly	Agree	Neutral	Disagree	Disagree strongly

9. At present, I spend as much time as I want to with family and friends.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree strongly	Agree	Neutral	Disagree	Disagree strongly

10. It is important to me to have close personal relationships.

☐ Agree strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree strongly

**Well-being**

11. My affairs are in order;  
I could die today with a clear mind.

**OR**

My affairs are not in order; I am  
worried that many things are unresolved.

☐      ☐      ☐      ☐      ☐

12. I am more satisfied with myself as a person now than I was before my illness.

☐ Agree strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree strongly

13. It is important to me to be at peace with myself.

☐ Agree strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree strongly

**Transcendent**

14. I have a better sense of meaning  
in my life now than I have had in  
the past.

**OR**

I have less of a sense of meaning  
in my life now than I have had in  
the past.

☐ Agree strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree strongly

15. Life has become more precious  
to me; every day is a gift

**OR**

Life has lost all value for me;  
every day is a burden.

☐ Agree strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree strongly

16. It is important to me that my life has meaning.

☐ Agree strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree strongly

---

N.B. Question 1 was not used in any analysis. Total scores were calculated by summing the five weighted dimensional scores, dividing the sum by 10, and adding 15 to yield a positive score between 0 and 30 (Byock & Merriman, 1998).

### **Construction of the questionnaire responses**

The change from a Likert scale (e.g. No 3) for one statement, to choosing along a continuum between opposing statements (e.g. No 4), was confusing to many patients. The researcher identified this as a potential problem with every participant, demonstrating how to respond, but many patients still found it difficult. *"Why didn't they stick to the same pattern with the questions?"* (Paul). *"I had difficulty in understanding the continuum after using the 1 - 5 scale"* (Joseph, Jonathan, Beth). *"Double negative answers possible. I find this confusing"* (Pat).

### **Framing of certain questions**

Some questions in the subscales interpersonal, well-being, and transcendence were framed in a way that implied developmental growth had occurred through experiencing a terminal illness (e.g. No 8, 12, 14). Many patients found this irritating, especially if they would have responded positively prior to their illness.

- \* *Life has not become more meaningful because it was meaningful before* (Peter).
- \* *Every day was always a gift. I'm not more satisfied with myself as a person because I thought I was pretty good before. It sort of asked them [the questions] in the wrong way for me to be able to answer them in a meaningful way* (Susan).
- \* *Questions 12 and 14 not appropriate and marked neutral because positive had applied prior to illness* (Beryl).

While three patients noted

- \* *I have always been able to say important things to the people close to me.*

Where illness was not seen as the catalyst for personal growth, patients marked their response as neutral. Consequently, their QOL rating from the questionnaire was lower in the subscales affected, and therefore inaccurate from the patient's perspective.

A few patients regarded questions on the meaning of life and satisfaction with oneself as a person *"too nebulous"*, *"airy fairy"* and *"What does that mean?"*, while others commented that they had difficulty in answering them without specifying why they were *"not that easy to do"*.

### **Opposing statements in continuums**

Where participants were asked to choose a statement from either end of a continuum, several participants wanted to choose both, claiming the statements were not opposites, e.g. No 6: *"I wanted to say yes to 'I accept and I'm disappointed'"* (Anne, Beth).



### **Linking of concepts**

Two concepts presented within one question were sometimes regarded as mutually exclusive by certain patients, e.g. No 11: *"I wouldn't mind if I died today, but my affairs are not in order"* (Susan) and, conversely, *"My affairs are in order, but I do mind dying today!"* (Sam). Two participants also felt there was a difference between being active and being independent in personal care although these were combined in the questionnaire (No 7).

### **QOL dimensions not included in the questionnaire**

On being questioned, few patients identified other factors important to their QOL that were not included in the questionnaire. Two comments made were that there was *"Not much attention to physical comfort"* (Nancy) and *"Religion is a driving force in my life. Not directly addressed in the questionnaire"* (Mark). One gentleman, with a twinkle in his eye, also offered *"I'd like a pint"* in response to the question. [The hospice has a drinks trolley which dispenses a variety of liquid refreshment (including alcohol) before lunch and tea each day.] Another patient (who lived on her own) did not quite know how it could have been captured in the questionnaire but felt social interaction within the hospice had influenced her QOL, viz:

*I didn't know I was going to become so outgoing, coming here, joining people who are ... in the same boat in some ways. It does a lot for you and, um, you can do something for them; not a lot but you can do something to help them. I feel that I've had a stay here which has been beneficial to me, beneficial to the people I've met* (Nell).

### **Changes in QOL**

Where there were changes in the QOL rating between Time 1 and Time 2 (either positive, negative or in importance), the twelve interviewed patients were asked to identify the factors they saw as causing the change. The outcomes are discussed in groupings of the subscales - symptom and function; and, interpersonal, wellbeing and transcendent. These groupings reflect the tendency of patients to see them as discrete sections within the whole.

### **Improvement in symptom and function**

Symptom and function are defined by Byock and Merriman (1998, p.234) as:

Symptom = the level of physical discomfort and distress experienced with progressive illness; and

Function = perceived ability to perform accustomed functions and activities of daily living and the emotional response, experienced in relation to the person's expectations.

Five of the twelve patients identified improved QOL in either symptom, function or both. As Cella (1995) notes, improvement in symptom control is generally highly valued by patients. Often there is an associated improvement in general functioning and wellbeing leading to improved QOL. Feeling a lot better and starting to eat were seen as important factors in improving his QOL by Matthew, both attributable to an improvement in his symptom control. The association between improved symptom control and improved function was repeated by Elizabeth who reported that “*TLC [tender, loving care], less pain, catching up on sleep*” enabled her to function better and created “*a new positive attitude*”. More generally, Margaret attributed the improvement in her symptoms to “*the care I was getting*” as did Nell who, on commenting on improvements in symptom and function said:

*Well I was feeling better... not well, but better ... damn sight better. It's a wonderful place to be ... very important. I've been getting the care that's ... I needed* (Fig.3).

The significant improvement in Nell’s overall QOL is clearly demonstrated in her questionnaire scores.

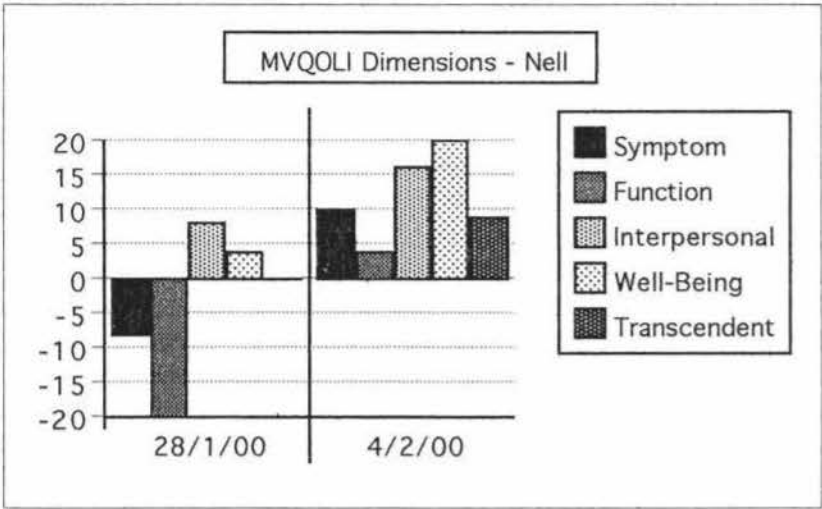


Fig. 3. MVQOLI results for Nell, Time 1 and Time 2.

Note: Where no score is evident in the graph, a score of 0, i.e. neither positive nor negative, is indicated.

The emphasis on care as being the determinant in improvement was echoed by Betty: “*I think it's absolutely a wonderful place. You couldn't get better care*”. Four of the five patients who commented positively on care were from the intervention group.

The subjectivity (uniqueness) of patients’ responses, recognised as crucial in accurately measuring QOL, is shown, however, in Jessica’s response. Her symptoms were significantly improved at Time 2 because her nausea was controlled but the subscales function and wellbeing changed to a negative value in her QOL (Fig 4). The reasons for this outcome will be addressed in the section on negative changes in QOL.

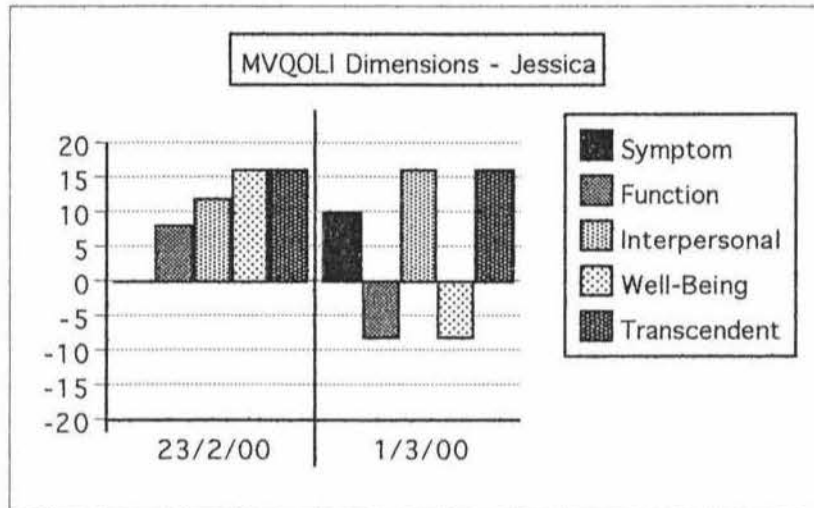


Fig. 4. MVQOLI results for Jessica, Time 1 and Time 2

### Improvement in interpersonal, well-being and transcendence

These dimensions are defined by Byock and Merriman (1998, p.234) as follows:

Interpersonal = degree of investment in personal relationships and the perceived quality of ones relations/interactions with family and friends.

Wellbeing = self-assessment of the individuals internal condition. A subjective sense of wellness or unease, content or lack of contentment (the intra-personal).

Transcendent = experienced degree of connection with an enduring construct, and of meaning and purpose of one's life (the transpersonal).

Three of the 12 patients interviewed achieved increased QOL or a positive increase in importance in the area of interpersonal, three an increase in wellbeing and six an increase in transcendence. Another patient still rated well-being as negative but it had become less important in determining her overall QOL. The improvements were found in both the control and intervention group. In discussing improvements in these subscales between Time 1 and Time 2, three threads emerged. Often the effects crossed the subscales, i.e. affected more than one subscale, so that it was inappropriate to isolate the reasons for improvement in each separate area. The threads identified were: developmental growth; attitude (hope and faith); and variability of QOL.

### Developmental growth

The definition of developmental growth used by Byock and Merriman (1998 p.234) is: "... the experience of wellness and personal growth arising from the completion of developmental work and the mastery of developmental landmarks". This definition reflects the authors' belief that in terminal illness while physical domains in QOL may

decline, compensatory gains can be made in the well-being, interpersonal and transcendence domains. (For a more comprehensive discussion of developmental work the reader is referred back to chapter two, p.14.)

While some patients found the association of illness and developmental growth inappropriate, other patients were clear that the experience of having a terminal illness had brought about positive change. John, whose well-being had improved, noted that, *“relationships, people, have become more important to me and I now accept myself and my limitations instead of fighting them.”* (see Fig 5). Hinton (1999) found that such a change in outlook and priorities assisted in patients’ awareness and acceptance of dying.

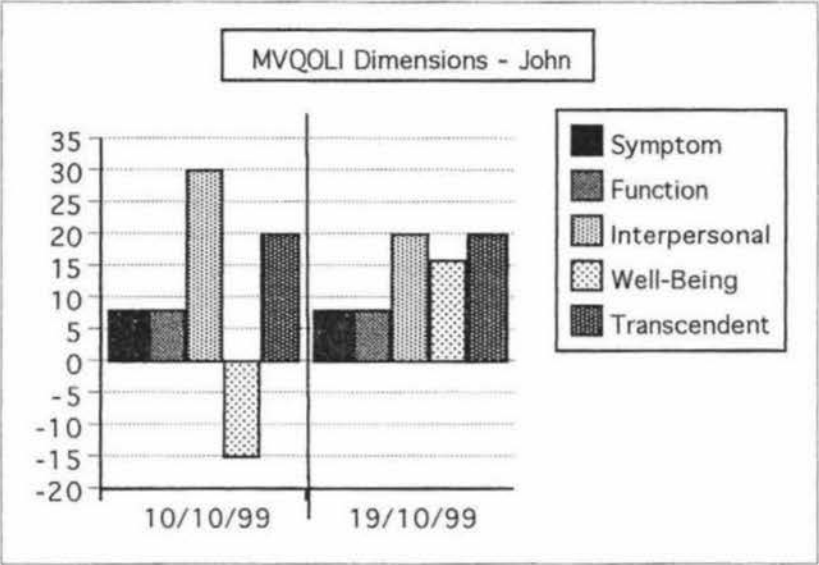


Fig.5. MVQOLI results for John, Time 1 and Time 2

A similar experience of self acceptance and acceptance of the future was identified by Bert whose transcendent score increased in importance, *“acceptance of myself, of knowing what’s wrong with me, what will eventually happen and so on.”*

Nancy commented, *“I know I have used my disease to grow”,* and, *“It’s very important [to reprioritise], I suppose we’re lucky to have the chance”* when reflecting on her improved interpersonal and transcendent scores. (She died four days later). Evidence of a change in priorities and acceptance of the future was also revealed by Nell who commented extensively on why she saw the improvement and increased importance in interpersonal, well-being and transcendence occurring:

*Money becomes even less meaningful at this stage. ... My family has benefited completely from this [terminal diagnosis] because we’ve been talk, talk, talk, talk.... I was able to tell them ... you know, cope, discuss the future arrangements and such like.... Everybody’s been absolutely splendid ... even the grandchildren. I’ve felt much more of a grandmother than I’ve ever done.*

(She died 12 days later).

Nell's important need to feel appreciated by family, to be able to express her feelings to her family and to say goodbye to the people closest to her, has been identified as highly significant for other terminally ill patients (Greisinger, Lorimor, Aday, Winn & Baile, 1997).

Sometimes a change in context was the catalyst for increased self-acceptance, well-being and finding meaning in life. Margaret was overwhelmed by the cards, flowers and gifts she received after admission to the hospice.

*I've got a scrapbook and I'm putting all these cards I've got, every one, in a scrap book. I can't believe I have so many friends. I'd no idea. You've got no idea what your friends mean to you, you know. It certainly is [a better awareness of how other people regard you].* "I feel good about myself" (see Fig. 6).

(She died seven days later).

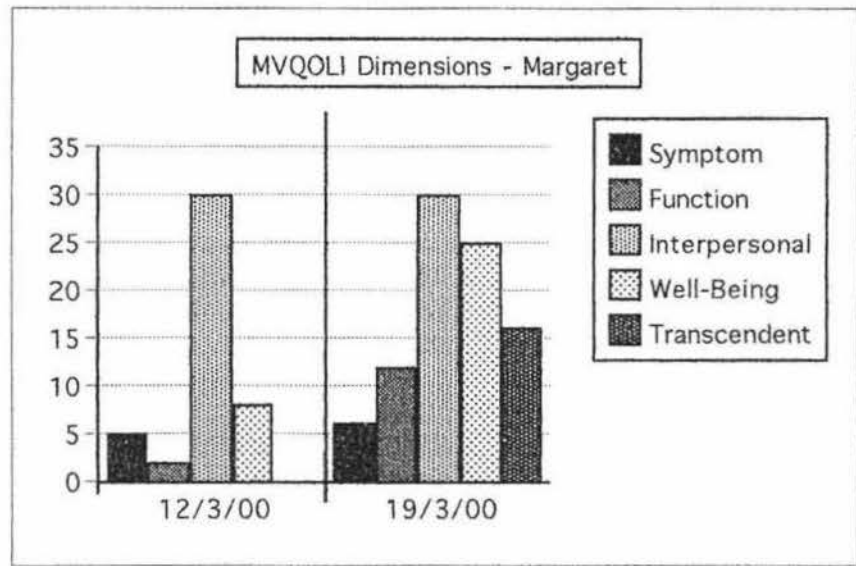


Fig. 6. MVQOLI results for Margaret, Time 1 and Time 2

The Hospice itself and the attitude of the staff were also seen as significant factors in improving QOL by both Margaret and Nell. Margaret commented thoughtfully:

*I think it's just the way they generally look after you and give you the confidence to look after yourself and be what you are. They never down-grade you, never.*

The significance of the approach taken by staff was also noted by Elizabeth. In meditating on the increased meaning in life for her, she said slowly "you're good for me ... it's a nice place to be. It's uplifted me rather than down-graded me." The importance of a therapeutic context in providing quality care was also identified by patients and nurses in a United Kingdom study by Redfern and Norman (1999).



## Attitude (hope and faith)

Personal attitude, including hope and faith, were often significant factors in the initial evaluation of QOL for the patients interviewed but they also influenced improvements in interpersonal, well-being and transcendence QOL ratings Time 2. An attitude of hope was sometimes brought about by addressing the patient's fears:

*They assure you there'll be no pain and that's the thing that's worried me the most. If I don't have that it doesn't matter [not getting home before dying]. ...I'm not worried about anything. ...I've adjusted. (Margaret).*

John traced his improvement in interpersonal and well-being to being "settled in mind", while Elizabeth reflected "What's the point in worrying about it? [affairs not in order] "It's just negative thinking isn't it? Only I can improve on what's happening now." The new attitude of ownership and autonomy had reduced the importance of her negative well-being score.

John was determined not to let his symptoms dominate his life so that he would "live until the end." He saw an advantage in "knowing you are going to die and being able to prepare people for it." This was possible because he was

*not worried about death. I have my own picture of what will happen afterwards and if it doesn't it doesn't matter. My faith is important and a source of strength.*

A non-fearful attitude towards death was also evident in Nell:

*Oh, oh a lot of good has come out of this ... and, um, if death, in the long run is the outcome I haven't given up then cos I had a near-death experience before and, um, it looked pretty nice there ... that was very helpful.*

The positive effect of spiritual experiences, including near-death experiences, has been noted in other patients who subsequently became calmer, less materialistic and more able to find meaning in their lives (Heyse-Moore, 1996; Narayanasamy, 1999).

Bert also achieved an improvement in transcendence by being affirmed in his ability to still contribute effectively in resolving his business affairs. Problems in the sale of his house were actually seen as

*fortunate because it's given me something else to think about ... and try and sort out an answer. Thinking is one of the few things you've got left to be able to do. You do it reasonably.*

The positive effect was evident in his increasing animation as he discussed the issue.

When patients were open, sharing the reasons for a negative score sometimes empowered them to address unresolved issues. Nancy, in commenting on her negative wellbeing score, said thoughtfully:

*I think it's probably because I don't really like to admit that I am so sick and it's, um, going to come to an end before I can [little laugh] finish everything off.... I'm seeing the counsellor today so I'll talk some of that through. I saw her last week and thought that was enough but it wasn't.*

Patients were not always able to express what underlay a positive change or an increase in the importance of a particular subscale (a response shift arising from a change in values). Transcendence had become more important to Betty but she couldn't analyse why. Her context had changed with improvements in symptom and function and she was looking forward to the arrival of a close family member. These factors could have contributed to the increased importance of life having meaning for her. Schwartz & Sprangers (1999) note that response shift may have significant pre-cognitive components of which patients are not yet aware.

### **Variability in QOL**

Profound changes in QOL, not just from day to day, but from hour to hour, were part of the patient's experience. This was particularly so for those patients who disagreed with the results of the QOL questionnaire. Changes had occurred not only between answering the questionnaires Time 1 and Time 2 but also in the time between completing the questionnaire and the interview (1-3 days). These changes were both negative and positive. Betty, in disagreeing with the reported improvement in symptom and function, said *"It varies from day-to-day - depends on the day you answer it. Sometimes I think it has [improved] and sometimes I don't think it has."*

The variability was not just limited to physical symptoms and functioning. Although nothing appeared to have changed clinically or contextually, Bert's function and interpersonal scores had become negative between answering the questionnaire Time 1 and Time 2. On being interviewed two days later, he changed his assessment again and explained it thus:

*I've got more time to think about these things.... I think that's just about sunk into me now [I accept the fact that I cannot do many of the things I like to do]. ... the acceptance of myself, of knowing what's wrong with me.... the truth of the whole thing.*

For him the time to think and process events including

*the way people [friends] are treating me now... I think, you know, they know things... I'm not just a sick man in a hospital for a couple of weeks,*

brought about changes in his journey from being unconscious of the seriousness of his condition (T1), to reality and loss of hope (T2) to a more positive acceptance by the time of the interview. The negative function and interpersonal QOL scores at Time 2 (see Fig.7), were thus no longer valid.

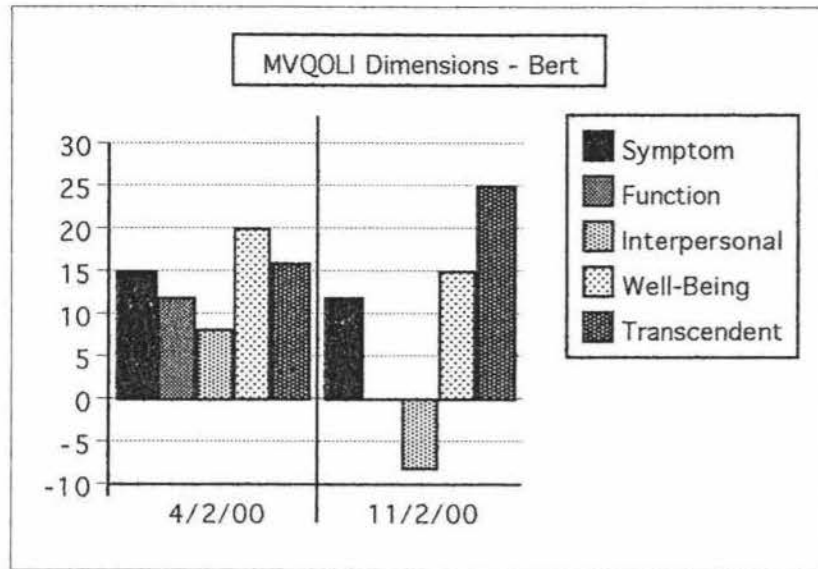


Fig. 7. MVQOLI results for Bert, Time 1 and Time 2

### No change or negative changes in QOL

One patient, in the Hospice for respite care while her daughter was overseas, had an unchanged QOL between the first and second administration of the questionnaire. Her function, well-being and transcendence remained negative. On being gently asked about the results she replied *"I feel I am a burden on my family."* The researcher quietly asked if one of her family needed the care that she did, would she feel they were a burden? She thought for a time then said *"It would be an inconvenience."* After a time of silence she whispered *"I would just like not to be here."* On being asked *"You would like it all over and done with?"* she nodded and smiled. This patient had a devoted family and she was easy to care for. Hinton (1999), in his study on awareness and acceptance of dying, found that some patients who accepted dying found life unpleasant or unrewarding and, therefore, felt that it was time to go. Similarly, Morse, Bottorff & Hutchinson (1995, p.19) note that dying can be a way of achieving comfort as suffering is relinquished.

Another patient (Jessica), in for respite care, had her nausea controlled with a subsequent improvement in her symptom score. However, as mentioned previously, she reported a significant decline in her function and well-being in her QOL assessment Time 2. She explained that this deterioration arose from feeling less able cognitively and a loss of confidence in being able to function as well as she did because *"everything here is done for you. You don't need to cook and organise."* The perceived loss of competence made her less satisfied with herself as a person, i.e. a reduction in well-being.

A move from positive to negative in her transcendence score reflected Valerie's feelings as she contemplated returning home. *"It's the loneliness. The uncertainty of it all. It's all a bit much."* Age as well as disease was a factor here as revealed in her comment, *"When*

*you get to 88 you haven't much energy left for anything. I've come to a dead end. It's all past glory."*

The identified threads above were also evident throughout the research process in patients' written comments, comments made while completing the questionnaires, and field observations made by the researcher. This additional material is now detailed.

## **Developmental growth**

A few patients shared intimate thoughts while being assisted to complete the questionnaire and, occasionally, in written form when doing the questionnaire independently. Some were near the end of their developmental journey:

*acceptance of my illness, treatment and changes to my general wellbeing, with wonderful family support, has give me inspiration to be thankful and understanding to myself and unto the many others who have since touched my life (Paul).*

Others were very aware that the desired end point was some way ahead:

*I feel incompletely evolved from a person who feels and is, to someone who feels more deeply. I feel as though I am part way on a new journey. Grieving for the me that's left behind (Alice).*

Others were equivocating: "Question 14 [I have a better/less sense of meaning in my life] is a hard one. I am not sure yet. 82 is a bit young. Ha ha".

Comments made on the positive effect of being part of the research study included: "Thank you for the opportunity to talk about these things"; "Thanks for the opportunity to take part"; "It's been a good opportunity to share thoughts and goals", (died before completing her second questionnaire). The answered questionnaires were kept to be shared with his wife and children by one enthusiastic participant. Another patient, in being helped to complete the questionnaire, used the opportunity to talk through past hurts (she did not want this addressed in her plan of care), while others expressed their concerns in written form.

*Is it fair to my family to discuss my funeral ? I would like to. Would they think I am being morbid? I would also like to discuss little presents I would like to leave friends.*

This man had noticed his sons "closing off" whenever he tried to discuss these issues. The detrimental effect on patients' QOL when families are unable to talk to the patient about dying and the effect of the patient's death on their own lives, has been noted in other studies (Greisinger et al. 1997).

A very quiet, reticent patient wrote about how worried she was by her husband's reactions - the loss of retirement together, and the loss of self esteem through her altered body image. These written thoughts provided insights into concerns that had not been discussed with her nurse. Other researchers have noted that people are often more willing to disclose information to the unseeing page than to an interviewer. It also showed, however, the desirability for any questionnaire allowing room for additional written comments (not normally available with the MVQOLI but provided for in this study).

### **Attitude (hope and faith)**

Faith was an explicit source of comfort for certain patients: "*I'm looking forward to my future which is with Christ*" (Mary); and "*Just waiting for the Lord to take me*" (Emily) (Emily's function score was negative, all other subscales were positive. Staff noted her peacefulness and uncomplaining attitude. She died six days later). A positive attitude also influenced how patients regarded their QOL:

*I think one should always make the best of things. I have had a wonderful life. I have had my ups and downs like most people, but I still enjoyed life to the full. I still intend to carry on doing so as long as I live* (Peter).

The positive significance of spiritual faith and a sense of completion were two themes identified by Hinton (1999) in his study on the awareness and acceptance of dying of 76 hospice patients .

A young mother, extensively jaundiced and at times semi-comatosed, evaluated her QOL as positive in all areas except function. She regarded "every day as a gift" and lost that gift two days later.

Conversely, a lack of hope negatively affected QOL:

*I feel a little better than I did before but still feel I have nothing much to look forward to. No one needs me. I have no particular aim in life, and I may be going to have to suffer more pain, physical and mental with the onset of the disease. At 68 isn't it time to give up?"*

The lack of being needed and feeling part of something was noted as decreasing hope in a patient study by Herth (1990).

### **Variability of QOL**

As in those patients formally interviewed, other patients noted that their responses varied considerably from day to day:



*Some days I feel good that I have another day [every day is precious] but this [a burden] also has some merit. That's why I have not answered this question. My mind is at a crossroad (Henry).*

Sometimes, responses varied from hour to hour as pain or hope varied (Bill). This minute by minute and day to day variation in patients' emotions and thoughts has been reported by other studies (Greisinger et al. 1997).

Deficiencies in the questionnaire, the variability of QOL, and the importance of patient attitude were also identified as significant factors in QOL assessment and the research process by the nurses.

## **Nurses data**

On the completion of the data collection, each of the ten participating nurses agreed to a taped, transcribed interview on how they found and actually used the research process. In an effort to promote open, critical feedback, nurses were interviewed by the Hospice research co-ordinator and the coded transcripts were then given to the researcher. After consultation with the nurses, however, this anonymity was considered unnecessary and the researcher had access to both tapes and transcripts. Interviews were done out of work hours and lasted between 15-25 minutes.

Five nurses added written comments while completing 18 patient assessment questionnaires. These comments, where relevant, are included in the data analysis. The researcher also had numerous informal discussions with the nurses during the study and made observational field notes. Formal interview material, informal discussion, and observational records were matched and integrated. Nurses were given this chapter (in draft form) to read and invited to identify any inappropriate use of quotes (e.g. taken out of context or incorrectly categorised) or other perceived inaccuracies. The one quote perceived as incorrectly categorised was recategorised.

A focus group which included 8 of the 10 nurses involved in the study was held five months after the data collection was completed. Nurses were asked to comment on any changes in their own practice, the need for or changes in team practice and the need for changes in organisational practice. This meeting was taped and transcribed. Similar material to that of the nurses' interviews was obtained regarding personal practice. Additional material which reflected on changes in team practice and the need for organisational change is presented in the section 'Reflective Practice' in chapter six, to distinguish between immediate and longer-term reflection arising from the research study.

## **Preparation for the research process**

Three of the ten nurses indicated they had initial difficulty in understanding and carrying out the research process. Despite explanations - both oral and written - it was not until the process had actually been implemented that these nurses were able to understand what was involved.

*Initially I found it a bit confusing. Even though the researcher explained it to me and even though I read about it, it took a little bit of doing it before I actually understood what it was all about. And it worked for me. It started to click and work a bit easier and I could assess quite quickly .. the differences (Sarah).*

*When it came to my second [patient]... I had a bit more insight and I spent more time with the patient questioning her and I did a better job the next time... and if I'd done another five I would have improved each time (Juliet).*

A third nurse (Ingrid), nearly three months into the intervention phase of the study, indicated she was still having difficulty in keeping what was required in her head: *"I was still finding my way around the questionnaire and trying to remember to do it."*

## **Difficulties in completing the research process**

All nurses experienced difficulty in completing the two QOL evaluations required for each patient and working with the patient on a joint care plan. Some difficulties such as time constraints were universal while others varied according to the patient and nurse context.

For two nurses, Bronwyn and Cath, the high attrition rate was a particular issue:

*What I found was a particularly high number of my patients didn't finish the second part of the study and that felt quite unsatisfying in lots of ways ... It did feel very unfinished" (Bronwyn).*

*It was frustrating too in that some of the ones you started - you would start the process and it was going well and then they deteriorated and died so you had no sense of completion in that" (Cath).*

Other difficulties experienced by the participating nurses included those already identified by patients: deficiencies in the questionnaire used and the variability of QOL. Additional challenges identified were differences in personality and attitude in both nurse and patient, and the Hospice context at the time. These difficult aspects of the research process will now be presented in greater detail followed by what nurses saw as positive outcomes of the study.

## Deficiencies in the QOL questionnaire

All nurses identified problems in using the questionnaire. These problems echoed those found by patients: the construction of questionnaire responses, the framing of certain questions, opposing statements in continuums, and the linking of concepts.

### Construction of questionnaire responses

Many nurses found the differing construction of the questionnaire responses was confusing: *"the change in marking Likert to going down vertically and choosing the circles directly below the question [was] confusing"* (Cath); *"I found this continuum [of responses] impossible"* (Alison); *"Change in measurement categories [was difficult]"* (Rowena).

### Framing of certain questions

The framing of certain questions to imply developmental growth was also identified by some nurses as inappropriate:

*A couple of patients actually voiced to me that they thought that type of question was unnecessary in their life. Not relevant to their life and other things are more important that they needed to think about and worry about* (Sarah).

*It is important to be at peace with myself .... the word peace is suggestive, sort of a value judgment. Is it a good thing to be at peace with oneself? - some patients do not live or die peacefully. Is that a bad thing?* (Moir).

*Where people have been fighters all their lives sometimes, for some people, to be at peace can be letting themselves down and letting the families down* (Cath).

### Opposing statements in continuum

The opposing statements in the continuum questions were likewise described as difficult for both patient and nurse.

*Questions with two statements were difficult to answer. People didn't always know where to tick and sometimes it was hard to know which statement to agree with. It was hard to interpret. Statements were not always opposite in meaning so responses did not seem to be a continuum.* (Moir).

An example was given where both statements were true *"Two items joined in one statement (No 6) I can accept but still [feel] very disappointed"*. This patient therefore wanted to mark both supposed opposites (acceptance versus disappointment) as true for her.

## Linking of concepts

Again nurses, like patients, criticised the putting together of two concepts which did not necessarily belong together:

*(No 7) Active and independent should not be put together in the same sentence because a person can feel active yet be somewhat dependent for cares and vice versa (Moir).*

*[Active and independent should not be put together in the same sentence] because you can be active but have to be dependent on someone else to be active (Juliet).*

*(No 11) The family were all fine with where things were at and they [the patient] felt that things were OK to die but not that your affairs are specifically in order (Alison).*

Nurses also made more general comments on the difficulties of completing the questionnaire from both the patients and their own perspective:

*Sometimes I felt that I was almost tripping over the wording myself. Actual questions and ratings, I found that really hard (Jo).*

*The wording was difficult I think ... I struggled the most with No 12 : I am more satisfied with myself as a person now than I was before my illness. Illness meaning what? When they were first diagnosed? When they were coming into the Hospice? When the symptoms escalated a bit more? I wasn't sure what that really meant. It was always a bit of guesswork for me", (Bronwyn).*

A particular difficulty with the concept of 'satisfaction' was evident.

*"I am more satisfied with myself. What does this mean? Patients wanted to know what is meant by 'satisfied'. What sort of things about themselves should they be satisfied with? (Moir).*

*I'm more satisfied with myself ... what could that possibly have to do with anything unless you were sort of wanting to get to martyr status.... (Alison).*

*More satisfied with myself as a person now... some of them had thought about it. For some people it had made no difference and with some people it changed things greatly. For some people they didn't want to address it at all. Reflecting on where they had been and what they had done, a lot of the times it was too painful (Cath).*

*Patients found it was quite confusing as well and they had a lot of difficulty in understanding some of the questions and trying to grasp them... some people's intelligence levels and their interpretation ... some people would just find that [interpreting questions] quite easy and other people just wouldn't have a clue what that meant because that is not the way they think (Juliet).*

All nurses criticised question 2, "I feel sick all the time", as being ambiguous. Did it mean nausea, tiredness or feeling unwell? The researcher defined the question as meaning "unwell" with all patients but did not think it was necessary to do so with the nurses.

## Variability of QOL

Nurses identified the variability of patients' QOL as a factor which created difficulties in accurately assessing their QOL. Changes in patient condition also limited nurses' ability to work with the patient on a plan of care. This was particularly so when the patient's and nurse's assessments were made a day apart.

Moirra commented, "*patients' assessments of themselves can change quite quickly depending on how they are feeling on a particular day.*" It was a point repeated by Juliet:

*Their mental status is quite important. They seemed to change their minds from day to day depending on how they may have felt emotionally or physically and from what they may have been processing at the time.*

Bronwyn noted "*huge changes can happen in 12 hours*", while "*A lot of the patients move on so fast*" (Jo), and "*I think it just had a lot to do with how they were at the time of filling in the form*" (Alison).

The context in which the research occurred contributed both positively and negatively to the nurses' experience of the research process. These contexts - hospice, patient and nurse - in connection with the research process will now be considered.

## The Hospice context

### Time

Every nurse identified a lack of time as being critical both in completing their patient assessments (QOL questionnaires) and in working with the patient to develop a joint plan of care. Their corporate views are well encapsulated by comments made by Bronwyn and Juliet:

*The process was quite hard in going back to the patient [to jointly plan care]. I think the study was done over a period of months when we were really busy. Most of us would have wanted to take a bit more time and care with it but didn't often have the time. I probably didn't use the information as much as I could have if I'd had a bit more time. I found that a bit frustrating* (Bronwyn).

*I feel that this was incredibly idealistic kind of stuff, and I think it's wonderful and a really positive thing to do but for me a constraint was time* (Juliet).

### Rosters

Rostering of duties was also seen as contributing to difficulties in working with patients participating in the study: "*Often the roster meant you might not be able to see the patient for a while after the first assessment*" (Moirra). An exacerbating factor in this respect was days off duty:



*"I know the hard thing is sometimes you do this [assessment] and you'd have days off and you'd come back and they would have deteriorated and things would have changed and you missed that opportunity [to go back and work with the patient on their assessment]", (Cath).*

*The lack of continuity if you were off for four days [made it difficult] (Rowena).*

## **Workload**

Changes in the type of patient admitted to the Hospice were identified as the cause of an increasingly heavy and busy workload:

*The patients seem to be coming in so much sicker (Cath).*

*I think all of us at the Hospice would know it's becoming more of an acute palliative care [service] and a lot of our patients come in and do progress through the dying process very quickly ... (Sarah).*

*I feel things have changed... busier in general and that tends to dominate. Busier, more tired, doing more in the same time. Trying to access that information [QOL assessment] on a day-to-day basis when dealing with the daily care routines, it feels like a luxury (Ingrid).*

*We have been so busy over recent weeks one tends to deal with the physical aspects of care and didn't feel we had time to sit down and have in depth discussions about people's other concerns like financial and family issues (Rowena).*

*It [the study] made me more aware of just how busy we were... when you are really pushed for time .. more of the time that you have is put into hands-on care and care of the symptoms or care of hygiene than actually talking about the interpersonal. Other things such as well-being are, not forgotten about, but more of the hands-on things are done (Sarah).*

*I found it [the QOL assessment and joint care planning] difficult to incorporate into the day-to-day care. I was busy and task orientated (Ingrid).*

*[The study] showed us what a huge and quick turnover we have and how unstable our patients are because we'd give it [the QOL assessment] to a patient who'd seem perfectly well (I mean perfectly well in relative terms)) and certainly suitable and three days later the patient was dead. And that happened, and happened and happened. And it just brought home again the rapid turnover and how we have to deal with quite traumatic stuff really (Irene).*

The busy workload was often as disruptive to continuity of patient care as rostering. Jo noted that:

*even if we were the named nurse we weren't actually picking up the same patients ... someone else was looking after them which happened because of the rosters and staffing levels.*

*On several occasions, just because of the way the staffing was, even if you had Joe Bloggs written beside your name... you didn't necessarily get the opportunity to build up a rapport and you were often doing remote research really. I mean you were in the same building for eight and a half hours with the patient every day but you weren't necessarily looking after them for that day (Alison).*

Bronwyn noted on one of her second assessments, “*due to the weekend being very busy I did not care for Charles over this time so I hope I still connected a little.*”

The effect of the Hospice context on the research process was summed up by Rowena.

*Given rosters, time frames and, specifically, heavy workloads made it [the study] very difficult to do. It seemed like ... one more thing to do in a really very hectic day.*

## **The patient context**

### **The MVQOLI questionnaire**

Although deficiencies in the questionnaire have already been discussed, nurses perceived certain patients as having particular difficulty with parts of the research process which sometimes impacted on nurse and patient working together on QOL issues:

*There is a personality factor involved. Some patients can talk about personal or emotional issues while others find it more difficult. It is a bit uncomfortable trying to talk to some patients about intimate things when you do not know them particularly well... One woman seemed to answer the questions because she felt she had to .. just to get it over and done with (Moira).*

*For a lot of people some of these questions are quite invasive and very personal and [for] some people, particularly patients who are strongly introverted or who felt invaded enough in a medical process anyway, they are really difficult questions (Bronwyn).*

*Patients [found some questions] not relevant to their life and other things are more important that they needed to think about and worry about... being with your family, being out of pain, that type of thing. And **they** were the older patients... the older age group that probably wouldn't have liked to speak about things like that anyway. They would have got on with life or got on with things that are more obvious, less like - one patient I think said 'airy, fairy, clap trap!' Sarah).*

This was not every nurse's experience. Rowena did not find that the research process was awkward for her patients and considered patients answered the questions “*to the best of their ability.*” Moira observed “*one young woman was lovely and she was really at ease talking about the questions. It was amazing, particularly as she was young.*”

## Self-reported QOL

Sometimes nurses thought the patients' context interfered with accurate patient QOL self-assessment:

*So, depending like if the patient is actually quite private and doesn't react well to questions or doesn't work in that medium I think we might not have got an accurate sort of answer. And if they are in a place where their survival depends on them believing that they are OK and things are managing OK, despite what I might pick up or other people might pick up, they are choosing not to actually say it or express it (Bronwyn).*

A similar interpretation was expressed by Cath:

*... and I also think sometimes for them, they need to ... maybe it's an out-of-body sort of thing. It's something they're hanging on to, it's **where** they want to be. It may not be the reality of where they are and that's not how I am perceiving it either but it's out there - it's something for them to hang on to and it's not fair to really go into too much depth and take that away from them because that may be all they have.*

Alison described one patient whose QOL assessment did not reflect her clinical state as "mad", while Bronwyn suggested that

*'thinking' patients may well mark some questions neutral because they are not actually in touch with their feelings because they don't know or don't feel safe to experience them.*

This observation was certainly true of one patient who found any 'feeling' type question, e.g Nos 8, 12, 13 and 16 "toonebulous" and generally marked them neutral.

## Attitude

Nurses also positively identified attitudes or the patient's experience as verifying patient QOL scores that were higher than would be clinically indicated:

*I think that with one particular patient they are the sort of people who just accept everything that happens and, sort of, well if it's going to be, it will be, sort of thing (Rowena).*

*The man's function was very, very limited. It was just totally ... [restricted]. He said it was absolutely fantastic, everything was hunky dorey, but it wasn't ... I can understand that this man had lived with that for quite a while (Cath).*

*Despite having horrendous recent surgery this woman (Margaret) comes across as peaceful and in control despite poor prognosis (Bronwyn).*

## Differences in QOL assessment

The significance of the patient's context was often revealed in the discrepancy between the patient's and nurse's first assessment of QOL. This was particularly so in the area of symptom:

*Probably one of the major ones [surprises] was patients seem to cope so well mentally with incredibly dreadful physical symptoms and they seem, to me, to be able to focus in such a positive way and I just found that mind boggling... it's just amazing ... I thought they would be so down with ... and they appeared to be down too, in my mind, but they weren't ... according to this [QOL scores] (Juliet).*

*Some patients who had the most appalling symptoms said their QOL was excellent. Well, from our point of view their QOL was pretty appalling. But, you see, it just leads you to asking the question 'What's **quality** of life?' (Irene).*

*It was interesting to see how the results could be different. What I might think was a terribly difficult way of living might be all right for that particular person. They might come up feeling quite positive about their level of function, for example, while I saw them as barely able to breathe. Especially patients with respiratory problems. It looks difficult for people to breathe yet they find it OK (Ingrid).*

*Sometimes the patient had a different view about being sick all the time. Might have been quite obvious to us that their symptoms were really not controlled, e.g. they might have been vomiting or in pain, but they didn't actually see it as being sick. One particular person I remember was quite the opposite to what we felt so that was interesting ... just that people's views are quite different to ours at times (Sarah).*

The same issue of perceived versus actual QOL was also commented on by Rowena who simply said, "I felt that the patient didn't have a good QOL. They, in fact, felt it was OK."

The discrepancies between nurses' and patients' evaluation of patient's symptoms and function was consistently evident in the questionnaire results with nurses rating QOL much lower in those domains.

## **The nurses' context**

### **Differences in QOL assessment**

How nurses interpreted differences between their and their patients' QOL assessment has been identified in the previous section. The importance of the nurses' context in making such interpretations, while undertaking this research process, is now addressed more specifically.

Some nurses felt totally understanding the patient's perspective was impossible:

*I did try to put myself in the patient's shoes ... but [time difference in completing the assessment] ... and quite apart from that, how people are when they are in their quiet reflection time - it is often different from when they are in their being social sort of time and, you know, I just think that we can't get inside people's heads. We can't do that (Alison).*

*Perhaps my judgment wasn't as good as it should have been but then, one can't really get inside someone else's head (Rowena).*

Others felt the anomaly might lie in the honesty of the patient's assessment or in the patient's understanding of what was required in answering the questionnaire:

*So I found that it [difference in QOL assessment] was very interesting because I often had a strong gut feeling of where a patient might be, but it obviously didn't come up in some of the surveys and I think that [inaccurate patient answers] may be one of the reasons. I mean it may be that I just have 'off' days like everybody else but I think one of the reasons might be that some patients choose not to express that, or choose not to be honest, or aren't in touch with themselves enough to know. Or, quite simply, things might have been bad but they don't seem as bad to them (Bronwyn).*

*What I had picked up verbally... turned out to be different to what they had said when they completed the questionnaire. I don't know whether that was some misinterpretation on paper... of how they read it [the questionnaire] ... What they said to me when sitting comfortably on their bed and just having a chat might be different because they are wanting to get the questions right. I don't know... People only let us know what they want to (Cath).*

Others saw reticence in the patient answering honestly because it was early in the establishment of a patient/nurse relationship:

*Because I am an upfront person I suppose the supposition was that your patients were going to be the same sort of way. You do need to get to know people so I really do believe... the first assessment that you did was often **very** subjective and it was only when you had got to know them more that perhaps you could see that it was a matter of knowing people before they were able to trust you with some of their information and maybe the first time they had said things to you, they really weren't being entirely honest. They were really saying things more that you wanted to hear because it was .. like a casual acquaintance. They didn't know you yet (Alison).*

### **Alternative views**

Conversely,

*I was surprised at so many [assessments] that I actually got very close. I didn't realise how honest a lot of the patients were perhaps. It almost validated a lot of the things I'd sort of absorbed and perhaps didn't write down a lot of the time (Jo).*

*I don't think like that [did you feel patients answered realistically?] I mean I take patients as they are. I accept what they say (Moir).*

Reflecting a different perspective, Irene noted that not only must the patient's perspective be paramount but they also have a wider range of reference when completing the QOL questionnaire:

*I think it's very important for all of us to know that we see a tiny, weenie, weenie little bit of this patient and we tend to think we know it all but we actually know very, very little and it behoves us to be quite cautious. And I think for me, in the whole process, again that fundamental thing that this is a real live person and we have no right to interfere with what they want (Irene).*



## Attitude

Nurses' attitudes to initial patient assessment, within the research process, also influenced their context:

*Sometimes you felt uncomfortable [discussing QOL assessment] .. when you meet a new patient or you are talking about things like that, you judge what you are going to ask them. You judge (assess) them as you get to know them. You ask them intimate questions **as** you get to know them. Between the nurse and patient you build up a trust. Some things you can ask them straight out and feel quite confident about doing it and not make the patient uncomfortable (Sarah).*

*I don't work on the ethos that patients, because they are here, that we ought to own them straight away and they ought to spill their guts out immediately (Alison).*

*'Yes' to some of it [QOL assessment] and then saying but the other side of it is it is really invasive and we have to be mindful of that. It's very upfront... it's great when a patient agrees to do it but you kind of wonder have they given away a bit to do it, y ou know (Bronwyn).*

## Colleageal concerns

Other problems that influenced the nurses context included the perceived attitude of non-participating colleagues, and communication between staff:

*The other problems I found were ownership of patients. Some people who weren't involved in the study being terribly obstructive... I do think that perhaps some people weren't as appreciative of the time that it took than perhaps they might have been or should have been or understood that a continuity was required in order to make this [the study] really work (Alison).*

*There were certain nurses that weren't wanting to have anything to do with the study and they were taking patients and so their patients weren't part of it (Jo).*

## Documentation issues

Three nurses remarked on their need to rely on documentation by other carers to "know what was going on" when they were off duty or caring for other patients. A lack of clear communication in patients' notes and upgrading of care plans was noted: e.g. "respite patients who then became terminal but their care plans still reflect previous abilities" (Jo).

*And even in reading some colleagues' reports which were very, very subjective reports as opposed as to saying **how** people were it was difficult to sort of catch up with how they had been (Alison).*

## Positive outcomes of the research process

All nurses found some positives arising out of participating in the research process. These included the overt positive effect on patients of being in the study; the availability of information about patients that would not normally be accessed or would have taken longer to access; knowledge of the differences in QOL assessment between the nurse and their patient; and the affirming of their assessment skills when such assessments matched.

## Overt positive effects on patients

### Developmental growth

The questionnaire provided a measuring rod for some patients:

*A lot of the patients that I worked with really got a lot out of it I feel. A lot of the patients that I talked to really got a surprise out of the things they felt they had achieved. Didn't realise that they had... (the idea that we talk of sometimes as a journey).. didn't realise the work that they had put in (Jo).*

*I think it possibly helped make the patients a little bit more thoughtful about where things were too. I think that most of the patients I looked after who were involved in this were quite ... thought it was quite sort of special, being involved (Alison).*

For others it provided a legitimate framework to discuss concerns.

*The whole process had quite an amazing effect on Louise. She had been, was, a very reserved lady and none of us had ever been able to get close to her. There had never been a forum where I was able to say to her 'I'm part of this research and I have to put my answers and, you know, I don't know these things about you and I'd love to discuss them with you if you are willing.' And she was willing, and I think that was because I had those questions to ask her that she was able to at last approach some of those things. What I noticed throughout the interview was that this woman who was normally quite flat, with flat affect, showed quite a bit of emotion and cried at times. In the course of that time we were doing the interview we formed an enormous bond that was just really quite remarkable for me, which I had not [done previously] and I actually don't think anyone had done.... And I think it was because of that she was then able to approach 'When am I going to die?' - actually talk about the big scary 'die'. She needed some sort of rational format (Irene).*

Sometimes the questionnaire results enabled patients and staff to recognise a window in the disease process and make "the decision to go home because this is the best time" (Jo).

The results were seen as useful for family dynamics too:

*....the family could then understand where he was coming from instead of trying to interpret it [from what] they were hearing....Dealing with people who are dying, they often find it very difficult to actually use those words with family. Even when they come here, it's not until the later*

*stages when it's obvious that these people are dying that they will start talking about it. So, in that way, it [conversation promoted by the QOL results] was quite good (Cath).*

### **Information obtained through the research process**

Some nurses were aware that there were a “few aspects of the questionnaire that you don't tend to ask about” (Moira):

*I felt that it concentrated quite a lot on the psychological aspect and people's feelings and to be honest we have been so busy over recent weeks that one tends to deal with the physical aspects of care. [There was] value in including interpersonal, social and financial issues in the assessment and to hand it on to - perhaps people who, maybe the counsellors, who can deal with those issues (Rowena).*

Sometimes use of the questionnaire elicited information much earlier in the patient's admission.

*You don't actually get that [information] early in the piece and then you might be on days off and you don't actually strike that relationship [that accesses intimate information] with the patient (Sarah).*

*[There] may be other areas (other than symptoms) where we don't cover as well [as the questionnaire] ... raised issues that may have taken a longer time to get to (Moira).*

*Well-being and transcendence questions ... some of the statements that people were reflecting on ... I felt were things we might not have got on to on a first meeting. Very deep, very deep questions and, unless you had a rapport with somebody, perhaps not the sort of things that would come out in the first instance and even then, **specifically** not what you might know in the end anyhow, except that they were happy with ... they felt everything was fine and the family were all up and about [i.e. fine, and that life was going on] (Alison).*

As is already evident, nurses differed in which questions they thought useful and appropriate. The one question most commonly identified as yielding helpful information was No 11 ‘My affairs are/are not in order...’:

*I found that it helped break the ice with a lot of patients that you would never have felt comfortable [in the initial assessment] talking about dying today, even though we are in the business of dying. It is a very **practical** way of asking (Jo).*

Jo went on to give a specific example of how it had enabled a patient, who was not wanting to talk about dying, to resolve the things about future arrangements that were on her mind. The patient was able to make arrangements for the on-going care of her beloved dogs and resolution of her business affairs without having to formally acknowledge the imminent moment of death. Moira also noted that her patients had responded well to this question:

*My affairs are in order .... was useful. It was a practical question that allowed people to discuss not only things such as their will, funeral etc. but also their relationships (Moira).*

Identification of things not being in order and being able to take appropriate action with a particular patient was seen as helpful by Cath: *"I wouldn't have normally even talked about that, about having their affairs [in order]"*. Juliet and Ingrid also identified that same question as being particularly relevant:

*My affairs are in order (not in order). See, that's a brilliant question to ask because quite often that gets missed. That's something people are thinking about but maybe not verbalising and so that's a brilliant one to ask because then you can..., all sorts of things lead on from that... You find out whether they need to be at home to die or to get home for, even if it's a matter of a few hours, whatever, yeah (Juliet).*

*Are your affairs in order... also transcendent. In fact most of the questions I found [useful] apart from straight old symptom control which is our bread and butter I suppose (Ingrid).*

Revelation of the differences in nurse and patient assessment of QOL was also regarded as helpful by four of the nurses.

*Initially it was just useful to know how your assessment fitted with the patient ... the knowledge of the differences. It was worthwhile to clarify areas and be aware that there could be some therapeutic resources the nurse could use to address areas with a negative response (Moira).*

*I actually found it useful when I got the results of the survey and I could understand how, why they reacted in the way they did, or some of their behaviour (Rowena).*

Bronwyn, in reflecting on the assessment process, said:

*I think in lots of ways it helped keep me focused, particularly on what the patient was wanting and expressing. I always felt like something interesting had happened.*

Juliet commented enthusiastically

*... I think we would have just gained so much out of just seeing what they ticked, and where, and it's just so different from what you actually think.*

These nurses felt more informed by the identification of nurse/patient differences in QOL assessment and therefore empowered to develop a greater understanding of their patients.

## **Reflective practice**

Nurses were specifically asked if the research process had changed their nursing practice. Some examples of a change in approach have already been demonstrated in the preceding sections (e.g. increased awareness of the multidimensional care needed by patients). Additional material is now summarised from each nurse's response.

## Differences in perspective

There was an increased awareness of differences in perspective between nurse and patient:

*It does make you wonder - how differently the nurse's perspective can be from the patients. It made me more aware of how patients feel about certain aspects of their lives (Moira).*

*"It was helpful to get some understanding of where the patient really was at" (Jo).*

*It's just so different from what you actually think and it's quite frightening actually. You opened your eyes as to how complicated the human being is, totally and utterly. And [laughingly] we don't know it all and we never will. And people are just ... just live such different lives, their whole experience of life is so different from others (Juliet).*

*It was a bit of, in some ways, a reality check... One tends to think one knows how someone else feels but at the end of the day ... It gave me insight into how some people feel and how one tends to impose one's value systems and beliefs on to other people and we don't always, - I don't always get it right. Just because I feel a certain way doesn't mean to say that everybody's going to feel like that (Rowena).*

Bronwyn felt that the research process

*...didn't actually affect a lot of my care but the thing that I noticed was what I particularly felt about where a patient might be, may not necessarily be what that patient chooses to express, whether that patient was in that place or not. [Differences in assessment] always made me think 'gosh, what's really happening here?' or 'what's really important?' I always found this a learning thing. [It] affirmed that patients need to be where they are at and it's to know whether some of them actually want to be pushed a bit or whether some of them don't. And it's being really careful about respecting what patients want to share and what they want.*

Cath also discovered a new awareness of differing perceptions:

*I'd find when I walk into a room I'd have a look at everything, and the body language with the patient and families, it's not always what you are seeing and, it's, sometimes your interpretation of what they said... is not right either. It made me more aware that what I was hearing sometimes wasn't really where they were at and that my perception was different... Yeah, just to question things a little bit more in depth really.*

For Irene

*What I found it doing for me was changing my own internal plan of care, so to speak, about this lady.*

Not all nurses experienced a change in practice. Like Bronwyn, Sarah responded:

*No I don't think it changed my practice as such but it made me a little bit more aware of QOL type questions and talking about QOL questions. Particularly with the first questionnaire when the patient was relatively well.*

However, as previously quoted, she did find the questionnaire broadened her



understanding of patients and that “people’s views are quite different to ours at times.”

### Identification of problems

Alison thought the study made her more aware of

*the patient’s perception of themselves and made more concrete my idea that you go to the patient when you are doing your care plan...set the patient’s priorities...go with what the patient saw as their biggest problem.*

The ownership of problems or the need that is being documented was identified as an important issue by Jo.

*The study made me **very** aware of how we [differ in our nursing approach]... not only the assessment, the verbal assessment but the documentation and what we are actually writing down. The ownership of [the need] that we were actually writing down and having, sometimes having arguments with the nurses where you’d write an assessment about your discussion with the patient and everything and you’d come back two or three days later and say ‘well you haven’t written about this [need]. ‘Cause they didn’t see that as a need. And so I was trying to think ‘well this is the patient, this is how the **patient sees**, this is what the patient **sees** as a problem, **sees** as a need and **would** like us to try and help them with.’ And that although I might have it in the assessment that the patient does **not** see this as a problem, does not want us to try and do something, somebody **would** see it as a problem and decide whether it’s got to go down as a care. [I was] trying to be much more patient focussed.*

### Differences between nurses

Discrepancies in assessment and perception between nurses were also identified as a significant issue by Moira and Irene:

*Nurses can assess things differently from each other too. This is evident when it comes to clinical meetings such as handover (Moira).*

*The other thing that it [the study] made me aware of was how we make assumptions and operate on them and pass those assumptions on shift to shift until this is what this person is like (uncooperative and non-compliant versus feisty). And it’s difficult to shift that (own world view) after a while (Irene).*

### Individual insights

Individual clinical insights were gained from the study, when nurses reflected on their own practice.

*I think I probably didn’t go into as much depth as the questions had been... and I think that’s been really helpful to me because I often intuitively get a sense of things that are OK to talk about but this made it a lot more black and white... a lot clearer. I think it will be something that I will have in my skill base now that I can be a bit more specific about.”*

And in terms of patient priorities, *"I think I'm sort of getting better at not trying to fix things and I think some things aren't very fixable (Bronwyn).*

Ingrid, on being asked if parts of the study had made her more aware of how she practised, replied:

*Well it did.... Even though it was fleeting, my reflections, and the constraints of time and tiredness made it difficult, I still think it has raised my awareness over all.... Sort of more about people's personal relationships, about getting their affairs in order and about their feelings of self-worth. Those are things I wouldn't have thought of. Some of the questions have stuck in my mind and will be there for the future.*

Cath commented:

*You are inclined, when you are busy, to get like on automatic pilot and just go through it and do your cares. When you've got the time, when it's quieter to reflect and, without even using the questionnaire now, use some of those things and just discussing with people and seeing if there is something you can do, that you can change.*

Irene found:

*It [the study] made me very aware that I have a lot of trouble bonding with patients at the start. I reflected on that a lot. This [QOL questionnaire] gave me back another tool I can use and perhaps I am the sort of person who needs a tool, otherwise it takes me a **long** time to get into discussion about these things and with some patients I never do it... We need something like this and I went away feeling as if, for the first time in a long time, I had done **that** part of my job well... I'd run into a little bit of a dead end and didn't know how to get out of it really and I felt that this [QOL questionnaire] was very useful. Very useful.*

## Future use

As is already apparent, several nurses intended to use informal QOL assessment as an ongoing part of their individual practice. The appropriateness or feasibility of incorporating formal QOL assessment into admission procedures was also addressed in the nurses interviews. (Previously quoted comments which also relate to this aspect will not be repeated.) All nurses saw some advantage in incorporating QOL concepts into an admission procedure but opinions over the extent to which this should be done and the areas which should be addressed varied considerably. For some nurses a single question was identified as particularly pertinent:

*No 16, It is important to me to feel that my life has meaning. I thought it would be good to have that in our current assessment forms ... I think that is a really important question (Alison).*

Others held different views on what QOL subscales and questions should be included:

*I think parts of it [the questionnaire] could be - symptom, function maybe... more of the well-being too. I'm not sure about the transcendent ones [No 16] because that's the part some patients talked about that it was a load of 'coddely wallop' (Sarah).*

*Some areas that would be useful ... personal, emotional areas, but it would be better to change the way they are asked (Moir).*

Jo and Cath advocated the use of a conceptual framework such as a prompt card or “*head titles, you could use those ... a daily part of the full nursing cares that you’re doing.*” This broader approach would avoid the restrictions of specific questions but would provide sufficient structure to avoid “*not actually finding out some things you perhaps could have*”. Ingrid, too, commented on the need to get a handle on everything within a short space of time, saying:

*I guess I would like to have a framework to assess patients a bit more formally, with a few more cues... and to incorporate some of these things that have been in the survey.*

A more comprehensive endorsing of QOL assessment was evident in Juliet and Irene’s responses: “*I personally think that one of these [a QOL questionnaire, not the MVQOLI] should be part of our system now*”, while Irene went on to imagine its use in clinical practice:

*Well there are some of us who have talked among ourselves about whether we ought to be having a QOL questionnaire that we ask everyone and I’m rapidly coming to an opinion, perhaps not this one exactly in this format, but something like that would be useful. I find just that simple question Are your affairs in order? enormously useful. I mean if we can say ‘Oh look Mr Brown, I would like now, as part of our admission, to approach the QOL questions that we have. I wonder if you would mind answering them?’ And then you just come down the questions and wait for all this stuff to spill out. Watch where the hesitations are, knowing there is a little problem there, watch where they’re opening up, able to answer easily. I just gained an enormous amount from that process.*

The intervention in this comparative study was the use of the patient’s QOL results as the basis for joint patient/nurse planning of care. While QOL assessment and joint patient/nurse planning of care was embraced as a positive experience by most nurses, the reality of clinical care constraints created a tension between theory and practice. This tension is evident in Cath’s concluding thoughts on the future use of QOL assessments:

*... but sometimes, symptom management, patient and family comfort, that’s all you’ve got time for.*

## **Summary**

A wealth of qualitative material was obtained from patient and nurse formal and informal interviews, written comments and field observations. In this chapter the most germane comments about the research process have been directly quoted with other material more succinctly summarised. Analysis of the data identified patient and nurse concerns with the QOL questionnaire used and the variability of QOL in interpreting questionnaire results. The reasons for changes in patients QOL scores were outlined with developmental growth and attitude (hope and faith) emerging as themes. How nurses experienced being part of the research process; the effect of personal, patient and hospice contexts; the effect of the study on reflective practice and possible future use of QOL assessment were then explored. Quantitative and qualitative data will be further analysed, discussed and placed in a broader theoretical context in chapter six.

# Chapter Six

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## DISCUSSION

### Introduction

This chapter seeks to synthesise and integrate the qualitative and quantitative data findings presented in chapters four and five. Initially the QOL theoretical context for the study is re-examined. Thereafter the discussion is organised in separate sections corresponding to the three formal aims of this research. Where relevant, other literature is referred to throughout the chapter. This literature is used to illuminate study results and place them within the setting of current research (Foster, 1997).

The chapter begins by revisiting the context for this study. The concept of QOL and its measurement are considered in the light of the research experience. Particular attention is paid to the strengths and weaknesses of the measurement instrument used in this study (the MVQOLI), and the consequent effects on the research results. In particular, the theory of developmental growth, which underlies the construct of the MVQOLI, is critically evaluated.

Having identified the QOL context, aim one, (to identify if the patient/nurse care planning process, based on QOL assessment, results in improved patient care and consequent improved QOL) is addressed. The study revealed individual patient QOL can be accurately measured by a questionnaire. Using changes in QOL as a measurement of successful nursing interventions however, is more difficult. Difficulties relate to anomalies in patients' QOL results which may be unrelated to hospice care. A response shift concept is applied in an endeavour to theoretically explain these anomalies. The discussion then addresses improvements in patients' QOL. In an endeavour to identify specific nursing interventions that improve patient QOL, the theoretical concept of hope and its relationship to QOL is introduced and applied to the data obtained.

Aim two, (to determine whether the patient/nurse planning process improves nurses' assessment skills in recognising patients' QOL status i.e. increases understanding between nurse/patient) is then considered. Considerable material was obtained from nurses explaining perceived reasons for the differences in patient/nurse QOL assessment. These reasons are critically examined comparing observational with interview material, and applying different theories (time and rapport vs personality; and response shift.) The application of these different theories offers further understanding and explanation of the anomalies in QOL assessment. Findings from the data related to aim two revealed the need for advanced palliative care nursing skills in achieving accurate patient/nurse QOL



assessment. The identification of this need leads on to the discussion of the third aim.

This third research aim was 'to promote reflective practice in nurses by providing feedback on their assessment skills'. Nurses' views on the effect of the research process on their reflective practice were found to be consistent over time. A model of reflective practice is introduced. This model assists in analysing the elements of reflective practice facilitated by receiving feedback on patient/nurse assessment of QOL. Nurses were found to have increased the elements of reflection-on-action and reflection-in-action in their nursing practice. Reflection-for-critical-inquiry among nurses was at an embryonic stage.

The chapter closes with a brief summary of the most significant points raised in this discussion.

## **The QOL context**

Quality of life meant different things to different participants in this study. QOL was therefore found to be subjective and unique to each individual, confirming the equivocal nature of the QOL construct. Most patients found the life-meaning domain of great significance as other palliative care research has found, e.g. a recent study investigating the concerns of 120 terminally ill patients (Greisinger, Lorimor, Aday, Winn & Balie, 1997) found that existential and spiritual concerns were rated extremely or very important to 92-99 percent of the patients concerned. However, a significant number of patients in this research did not share this concern with the meaning of life. While the phrase 'people die as they have lived' is too absolute, patients who have had little interest in the meaning of life and self appraisal in the past, tended to be uncomfortable with questions in the well-being and transcendent dimension, and did not regard such questions as appropriate, even as they approached death. Hilton (1999, p.33), noted that patients accepted death more readily "if it could be contained within pre-existing concepts, beliefs, values or even habitual patterns of reacting". Habitual patterns, both effective and non-effective, were observed as influencing QOL assessment in patients in this study.

In interpreting qualitative data, evidence was also found to support the varying theoretical concepts underlying QOL. Uncertainty and the loss of control negatively affected QOL for some patients while for others the discrepancy between what was hoped for and experienced in reality also reduced QOL. The most significant factors, however, were confirmed as internalised standards, personality traits and the ability to find meaning. Where patients had a positive approach to life and/or a developed spiritual (transcendent) awareness, QOL was rated more highly. Not surprisingly, Gibbons (1999) and Sprangers and Schwartz (1999), suggest that individual perspective and disposition also moderates effective response shift in terminal illness and, hence, QOL. The effect of personality on response shift (with a consequent change in QOL), was also apparent in

this study. An additional theoretical concept which influences QOL was demonstrated. This concept was that of 'hope'. The significance of hope as an important factor in patients' QOL emerged when interventions that improved QOL were considered.

It is important now to consider the instrument that was used in the quantitative design of this study and how both patients and nurses responded to this questionnaire.

## **QOL measurement - MVQOLI**

The Missoula-VITAS Quality of Life Index (MVQOLI), was specifically developed for measuring the QOL of terminally ill patients. The MVQOLI has multi-dimensional domains, and questions which reveal how patients perceive their current status, their satisfaction with that status, and how important the particular dimension being measured is to their QOL. The instrument thus meets the criteria for an acceptable QOL measure in that it provides a subjective response from the patient's perspective (Teno et al. 1999); covers the important concerns of terminally ill patients (Greisinger et al. 1997); allows for both positive and negative responses (Cohen & Mount, 1992); and rates the dimension according to the importance to the patient (Browne, McGee & O'Boyle, 1997). The MVQOLI has the potential to identify patients' uncertainties, discrepancies and ability to find meaning, thus addressing the main theoretical understandings of what influences QOL. It is a valid and reliable instrument for use with terminally ill patients (Byock & Merriman, 1998; Mills, Webb, Stuart, Cooney & Leelarthapin, 1997).

Despite the apparent suitability of the MVQOLI, both nurses and patients in this study found many deficiencies in the questionnaire. These deficiencies were related to the wording and meaning of certain questions, the variable scoring mechanism and the concept of developmental growth which was inherent in many of the questions asked. Questions which were viewed as inappropriate or poorly expressed were particularly found in the interpersonal, well-being and transcendent domains. As found in an Australian study (Mills et al. 1997), some patients found questions in these domains to be confrontational. Certain nurses also expressed disquiet over the tenor of questions asked. These criticisms are now discussed in more detail.

### **Wording and meaning of questions**

This section addresses the concerns raised by patients and nurses about 'opposing' statements in questions, e.g.

- |        |  |  |
|--------|--|--|
| No. 6. | I accept the fact that I can not do<br>many of the things that I used to do. | I am disappointed that I can not do<br>many of the things that I used to do. |
|--------|--|--|

and the linking of what seemed to be dissimilar concepts, e.g.

- |        |   |
|--------|---|
| No.11. | My affairs are in order; I could die today with a clear mind. |
|--------|---|

Byock & Merriman (1998, p.231) consider that one of the strengths of the MVQOLI is that "the subjective wording of the items ... allows respondents to interpret the measured elements according to their own experience." However, many patients found that the wording used did not relate to their own experience. Thus while subjective wording may be an effective way of permitting individual responses, the author's subjectivity can also create a dilemma. For example, Byock & Merriman may consider that acceptance by the respondent implies a lack of disappointment but this was not so for several patients in the study. These patients did not view experiencing acceptance and disappointment simultaneously as incongruent. Similarly, it may seem logical to the authors that having one's affairs in order is a prerequisite for dying with a clear mind but that, again, was not the experience of all participants. This question was further confused by the positive outcome implying an acceptance of immediate death. For some patients this was, understandably, an entirely separate issue from having one's affairs in order.

An additional difficulty concerning the understanding of questions was identified. Although Byock & Merriman (1998) consider that the MVQOLI could be answered by participants of varying educational levels, some patients (as observed by nurses and the researcher) had difficulty in understanding what was required and the concepts involved. Similar patient difficulties with the wording and meaning of MVQOLI items was found by Mills et al. (1997). Thus the wording and meaning of certain questions in the MVQOLI were insufficiently clear and unequivocal for all patients to answer in a way that was satisfying for them. This problem is not, however, unique to the MVQOLI. Similar difficulties with other QOL questionnaires have also been noted (Turner et al. 1998).

### **Variable scoring mechanism**

A number of patients and nurses became confused and frustrated by the construction of questionnaire responses in the MVQOLI. In particular this applied to changing from a Likert scale to a continuum. The researcher spent much time identifying the difficulties with patients who were self-administering the questionnaire. Even this intervention did not always yield accurate responses. One of the nurses, on completion of the study, was still unable to grasp the different evaluation response required when a continuum scale was used. Apparently contradictory answers between the questionnaire and patient reporting in interviews were sometimes the result of difficulties in understanding the scoring system. Turner et al. (1998), noted similar difficulties with the EORTC QOL questionnaire. Cohen and Mount (1992, p.44), suggest that palliative care QOL instruments should be worded in the same direction and response options presented in the same order. Because of the limited resources available to patients they contend that: "in this population, the resulting potential for repetitive modes of response may be the lesser evil compared to the risk of obtaining responses that are antithetical to the patient's intent." Consistent scoring options would have increased the acceptability and accuracy of the MVQOLI for many patients.

## Developmental growth

As discussed in chapter two, Byock and Merriman (1998, p.234), based the MVQOLI on a QOL construct which included an “experience of well-ness and personal growth arising from the completion of developmental work and the mastery of developmental landmarks.” Rather than growth and mastery being implicit in the questionnaire responses however, many questions in the MVQOLI directly confront the participant with a before-and-after-illness self-evaluation. Byock (1999, p.89) claims that a developmental model provides a framework for pro actively helping patients with issues of life completion, life closure, and healthy grieving. While such an approach appears congruent with the values of palliative care, the MVQOLI questionnaire implies that having a terminal illness either encourages people to grow, or fail to grow. Examples of these questions include:

- |         |   |  |
|---------|---|--|
| No. 8.  | I have <b>recently</b> been able to say important things to the people close to me.       |  |
| No. 12. | I am more satisfied with myself as a person <b>now</b> than I was before my illness.      |  |
| No. 14. | I have a better sense of meaning<br>in my life <b>now</b> than I have had in<br>the past. | I have less of a sense of meaning<br>in my life <b>now</b> than I have had in<br>the past. |

Several patients and most nurses were uncomfortable with what could be interpreted as a judgmental approach. As was found in the Australian study (Mills et al. 1997), it was generally those questions above which patients found confrontational.

It is, of course, important to recognise that certain individuals will always find affective and transcendent questions challenging and/or inappropriate. One patient, in viewing the MVQOLI before deciding whether or not to participate in the study said tersely: “I haven’t considered these questions and I don’t know that I want to”. This was a position she adhered to until her death. It is also important to emphasise that such responses are not limited to the MVQOLI. Two patients in the Pratheepawanit et al. (1999) study found the MQOL upsetting, presumably for similar reasons. Richards and Ramirez (1997) also acknowledge that issues raised in QOL assessment might cause patient distress.

While acknowledging that some patients may find elements of QOL evaluation uncomfortable, the MVQOLI appears to increase the likelihood of this happening by focusing on a comparative approach to QOL. It could be argued that the important issue in assessing QOL is the patient’s current QOL, not how it has been obtained. The well-being, interpersonal, and transcendent dimensions, all important to a holistic evaluation of QOL, would be less confrontational if just the present situation is addressed, e.g.

- |         |  |   |
|---------|--|---|
| No. 8.  | I am able to say important things to the people close to me. |   |
| No. 12. | I am satisfied with myself as a person.                      |   |
| No. 14. | I have a sense of meaning<br>in my life.                     | I do not have a sense of meaning<br>in my life. |



The judgmental element is thus removed from these questions which still provide a clear indication of whether the patient is experiencing positive or negative QOL in these domains.

### **Satisfaction with the MVQOLI**

Such criticism of the MVQOLI was not universal. Many patients felt the benefit of answering the questionnaire, welcomed the opportunity to review the personal growth which had occurred, profited by the revelation of areas that needed attention, and enjoyed the opportunity to discuss important issues. Again, the Australian study which evaluated the MVQOLI and other instruments (Mills et al. 1997) also had patients who found the questions pertinent. Those patients, like many in this study, appreciated being asked their views on finding meaning, QOL, and the impact of their illness on these dimensions.

Despite the shared criticisms of the questionnaire itself, nurses too found many advantages in having a multi-dimensional assessment of their patients' QOL specific to palliative care. In particular, they observed that use of a QOL questionnaire provided a more holistic assessment of patients, and that important information became available earlier in the patient's admission than would normally have occurred. The 'opening up' of issues through QOL assessment not only created opportunities for patient/nurse dialogue but also for patient/family and nurse/patient/family interaction. This enhanced communication assisted in developing empathetic understanding and the resolution of many concerns.

Greisinger et al. (1997), suggest that QOL assessments help patients focus on the issues that are important to them, clarify their feelings surrounding these issues and so define for themselves and their caregivers their aims for their remaining life. As noted in chapter two (p.16), Mills et al. (1997) claim the MVQOLI can be similarly growth promoting. Patient and nurse data plus observations in this study support the view that, notwithstanding the legitimate criticisms, the MVQOLI can be a catalyst for communication, value clarification, problem identification, development of aims, recognition of developmental growth, and improved QOL.

### **Conclusion**

Theoretical concepts of QOL as a dynamic, multi-dimensional, individual and variable construct were confirmed by this study. However, the inclusion of existential and emotional dimensions in QOL assessment were found inappropriate by some participants. Uncertainty, loss of control, discrepancy between the ideal and reality, personality, and ability to find meaning were all evident in influencing patients' evaluations of QOL. Although valid, reliable, and useful QOL assessments were obtained the research also confirmed that the perfect instrument for measurement of QOL in the terminally ill, despite the specifically designed MVQOLI, is still to be developed.



Discussion now focuses on the specific aims of the present study and what the data obtained revealed in relation to those aims.

## **Aim One:**

**To identify if the patient/nurse care planning process, based on QOL assessment, results in improved patient care and consequent improved QOL.**

### **Method triangulation**

As outlined in chapter five, the QOL questionnaire results (quantitative data) were verified by nine of the twelve patients on interview (qualitative data). One patient in the control group identified difficulties with the questionnaire itself. She found that the way the questions were framed prompted her to give negative answers which, upon discussion with the researcher, were found to be inaccurate. For the other two patients who perceived differences between the questionnaire assessment and their own assessment, however, the differences arose from changes in their QOL after completing the second assessment. These two patients were in the intervention group. Method triangulation (quantitative and qualitative evaluation of the same variable) could thus be seen to confirm the validity of the QOL questionnaire assessment in reflecting the patients' perception of their QOL. Accepting the validity of QOL questionnaire results as an outcome measure in this study is, however, much more problematical. The reasons for this caution include: variation in the carrying out of the planned intervention; the variability of QOL; anomalies in QOL results; and response shift in patients. Hence, after discussing improvements in QOL, these confounding issues affecting the QOL results will be presented in more detail.

### **Improvements in QOL**

The only positive improvement in QOL within the control group occurred in the dimension of symptom. There was no overall improvement in QOL in this group. This confirmed Byock & Merriman's (1998) finding that symptom control, while necessary, is not sufficient in itself to improve patients' QOL. Positive within-group change in the intervention group was present in the domains of symptom, function and overall QOL. These results are in marked contrast to the findings of an American hospice study where, three weeks after admission, QOL was found to be stable but patients were least satisfied with the physical/functional aspects of QOL (McMillan, 1996). Such findings may indicate differences in culture, e.g. it is possible that American society is predominantly sensate in nature and therefore may place more emphasis on physical domains, or that New Zealand is more advanced in effective palliative care practices for symptom control and functioning. The limitations of the study, however, preclude such sweeping generalisations.

Although there was no statistically significant between-group change, the within-group change in the intervention group represented a clinically significant outcome, i.e. patients' satisfaction with their improved QOL provided social validation of the goals, interventions and outcomes of the QOL evaluation and patient/nurse care planning process. Method triangulation using quantitative (statistical) and qualitative (interviews, observations and written comments) data thus contributed to a deeper, more complex understanding of QOL satisfaction in participants.

It would be feasible to consider that an increased sense of control, achieved through joint care planning, would positively increased patients' QOL. Patient participation in decision making is acknowledged as being important in increasing QOL in terminally ill patients (Bottorff et al. 2000). It was evident, however, from nurse interviews and field observations that not all nurses used patients' QOL questionnaire results to jointly plan care. While some nurses actively used joint care planning to increase patients' participation and autonomy others did not find (or make) the opportunity to do so. Rather the information obtained from seeing patients' QOL results alerted nurses to how patients actually viewed their QOL and, in particular, to domains where QOL was evaluated as negative. Such knowledge then became part of the nurses' understanding of the patient's context potentially enabling more individualised, therapeutic nursing care.

## **Variability of QOL**

Formal and informal qualitative data also revealed the extreme variability of QOL in terminally ill patients and hence, the fleeting reliability of QOL data. This variability was apparent in all domains. Physical symptoms; relationships with others; and the fluctuating nature of denial and acceptance of dying (Copp, 1998; Hilton, 1999), all had the potential to quickly alter QOL, both positively and negatively. Nurses also appreciated the transient nature of QOL evaluation and saw the need for a daily patient self-assessment to determine how the patient's QOL could be maximised each changing duty or day. Such variability in QOL suggests that quantitative assessment of palliative care interventions may not by itself yield accurate outcome results. Alternative forms of evidence to detect clinically significant improvements in QOL arising from an intervention, (such as social validation or consumer reports (Thorne, 1999)) are necessary.

## **Anomalies in QOL results**

As was evident in chapter five, interviews, written comments and observations yielded much richer data regarding patients' QOL than was available through quantitative methods. This more comprehensive, subjective data was especially valuable in identifying the multiplicity of factors which may underlie a change in QOL. Although the Hospice context was acknowledged as a positive factor in improving QOL, many,

perhaps most QOL changes arose from a change in the patient's context. Positive changes were often the result of personal growth, revealing the mastery of developmental tasks identified by Byock and Merriman (1997). Thus a decrease in function was more than compensated for by an increase in well-being and transcendent. Improved communication with family and significant others resulted in improved QOL in the interpersonal and well-being domain.

On the other hand, while an improvement in symptom and function could be anticipated from better management of nausea and vomiting, impaired bowel function, and fatigue and pain, certain patients did not record improved QOL in these domains. Other patients who had clinically improved and whose interpersonal context did not appear to have changed, nevertheless reported a diminished QOL in well-being or transcendent. Thus, during the research process, the researcher became increasingly aware that paradoxical QOL results were emerging. The search for explanations for such contradictory or negative cases is an important facet of observational research (Mays & Pope, 1995 a). In seeking to understand the apparent contradictions that were observed, a response shift construct (a change in peoples' attitudes, values, conceptualisations or priorities (Gibbons, 1999; Norman & Parker, 1996; Schwartz & Sprangers, 1999; Thompson & Hunt, 1996)), as discussed in chapter two, offered a theoretical explanation of what was occurring. The challenge of identifying the causes of atypical QOL results is now considered.

### **Measurement of changes in QOL - the challenges**

This study attempted to statistically measure change in patients' QOL outcomes, created by joint patient/nurse care planning, based on the patients' QOL assessment. Traditional parametric statistics (e.g. pairwise t tests and analysis of variance) as used in this study, examine alpha changes (Thompson & Hunt, 1996), i.e. any change is assumed to be a result of the intervention. However, beta change (a recalibration of the patient's scale for assessing QOL) and gamma change (a reconceptualisation of the concept of QOL) appeared to be simultaneously occurring with many patients.

Where QOL is deficient, experienced palliative care nurses actively seek to promote alpha, and encourage beta and gamma change in their patients. Such an approach attempts to address the theoretical concepts identified as inherent in QOL, i.e. changing the patient's present experience *and* changing hopes and expectations (Cohen, Mount, Strobel & Bui, 1995). Thus, attaining a measure of control through joint care planning (reducing uncertainty) may improve QOL through alpha change. A recalibration of the ideal where the ideal is impossible in reality (discrepancy) increases QOL through beta change. Gamma change occurs when the patient achieves developmental tasks with a consequent reconceptualisation of QOL (finding meaning) leading to improved QOL.

Rather than a measurable outcome of a specific intervention, beta and gamma change arise from a response shift in the person concerned. When such change is achieved through the intervention of joint care planning, the concept of response shift may appear irrelevant since the nursing intervention still appears to be the catalyst for improved QOL. However, response shift, both positive and negative, can occur regardless of nursing interventions. Under these circumstances, positive change in QOL may not be attributed to positive nursing interventions or, where negative change occurs, to a lack of holistic care.

Using the results of a QOL questionnaire as an outcome measure must therefore be approached with considerable caution. Rinck and colleagues (1997) also make this point in reference to measurement of care interventions, stating that QOL is not only a reflection of care given but is also associated with the personal characteristics of the patient.

### **Examples of response shift**

Examples taken from interviews and observational field notes illustrate beta and gamma change which is unlikely to be attributable to the nursing intervention. One patient in the study was admitted to the hospice expecting to die within a short period. Her initial QOL assessment was positive. In the intervening week before the next assessment, appropriate treatment resulted in considerable physical improvement and she was soon to be discharged home. Despite this clinical improvement her second QOL assessment was considerably lower than the first. The expectation of death was replaced by the expectation of an unspecified period of living. Hilton (1999), in a study on the progress of awareness and acceptance of dying in cancer patients, noted that patients became more anxious when death appeared probable rather than certain. It seems likely that, in addition to becoming more anxious, this patient found that what was acceptable symptom control and ability to function when death seemed imminent became less so when she experienced a change in context, i.e. the anticipation of a longer period of life. Thus beta change created a decline in her QOL although nursing interventions had assisted in returning lost function and independence.

When patients answered questions related to previously unconsidered aspects of QOL, their first response was sometimes automatic. This initial positive response was then subject to a period of reflection and reassessment. Consequently, subsequent questionnaire results showed a decline in QOL although their clinical symptoms or function remained unchanged or improved. How they measured their QOL had therefore changed between answering the questions at Time 1 and Time 2. This more considered approach could be regarded as positive in that patients were now possibly recognising and facing developmental tasks yet to be completed. The potential for growth, however, may show as a decline in quantitatively measured QOL, e.g. Dennis, in completing his second QOL questionnaire commented, "I'm not as positive this time", although his pain and vomiting were much improved. Conversely, positive beta change was evident in



Margaret's willing acceptance of dying in the Hospice when she had originally planned to go home. This acceptance of reality reduced discrepancy, and increased her QOL.

Gamma change was observed in a number of patients where a major change occurred in the perspective or frame of reference within which the QOL questions were perceived or classified. This may have been associated with an "honest" facing of the terminal nature of their illness between answering the questionnaire the first and second time. Sometimes this reflected an increased trust from the patient where they could drop the "front" they had chosen to maintain (Jones, 1993). QOL responses were consequently more negative in the second questionnaire. Patients also varied in their "slice of reality" (Thompson, 1996 p.658), reflecting on-going use of denial/acceptance as a valid coping mechanism (Copp, 1998), and/or their state of hope. Adjustment and hoping for a pain-free death created improved QOL for Margaret (despite her deteriorating physical condition), through a reconceptualisation of what QOL comprised. Social comparison prompting gamma change was evident in Nell's case where she found being in a hospice environment with people experiencing similar problems put her own situation in some perspective: *"It's been very good for me."* Other researchers have found similar benefits when patients were able to share experiences with others in the same situation (Ersek & Ferrell, 1994; Gibbons, 1999; Hilton, 1999).

Both positive and negative changes in QOL were therefore occurring without necessarily being related to the patient/nurse joint care planning intervention. However, positive changes in patient QOL assessment did arise from direct patient/nurse interaction. Defining nursing actions which contributed to an increase in QOL provides qualitative confirmation of the quantitative findings and a theoretical perspective from which to improve clinical practice. Thus in identifying these nursing interventions which may have improved patient QOL, it is useful to compare QOL with the construct of hope. The next section considers research concerning the importance of hope to cancer patients and the part hope plays in maintaining QOL. Hope fostering interventions are compared with the actions of nurses in this study as a way of more clearly defining positive QOL interventions. Identification of hope-fostering interventions may then enable nurses to incorporate such approaches in their clinical practice, advancing their palliative care skills and increasing patients' QOL.

### **The significance of hope in QOL**

Some patients specifically mentioned hope when considering positive changes in their QOL. For others it was implied in their response. Other researchers have also found that hope is an important factor in maintaining QOL (Flemming, 1997; Herth, 1990; Hockley, 1993; MacLeod & Carter, 1999; Tait, 2000). Greisinger et al. (1997) found that having a sense of hope was the most highly rated concern of 120 terminally ill cancer patients. Nurses too are very aware of the significance of hope from their own practice, e.g. the 10th International Conference on Cancer Nursing, 1998 had 'Hope and Vision'



as the conference theme. Like QOL, hope is a complex, multidimensional (Herth), dynamic (Kylma & Vehvilainen-Julkunen, 1997) concept that can change and evolve according to the patient's circumstances (Nuland, 1993). This makes definition difficult. Philosophers, psychologists, theologians, doctors and nurses have all offered alternative understandings. Herth (p.1250), in her study on fostering hope in terminally ill people found that hope was defined similarly, irrespective of age, by people who are dying. Among these individuals hope could be synthesised "as an inner power directed toward enrichment of 'being'." Hockley, and Urquhart (1999), suggest that hope also has an external element in that it is an interior sense that there is help on the outside. This external dimension is important in recognising that, although individual personality and attitude are significant, nurses can be actively promoting hope in their patients.

The close association between hope and QOL in the terminally ill becomes increasingly evident when the categories or characteristics of hope and QOL are compared. Although the elements of hope differ according to the researcher or author they can be generally classified as physical or functional; relational or social; affective (emotional); temporal (awareness of past, present & future; spiritual or existential); and contextual (life situation and living conditions) (Kylma & Vehvilainen-Julkunen, 1997; MacLeod & Carter, 1999). Using Byock & Merriman's (1998, p.234) QOL dimensions as developed for the MVQOLI, consistent elements can be seen between the two concepts (see Table 16).

**Table 16.**  
**Comparison of the characteristics of hope and QOL**

Hope <sup>3</sup>	QOL
Physical or Functional	Symptom Function
Relational or Social	Interpersonal - relationships
Temporal or Existential	Transcendent - transpersonal
Affective (emotional)	Well-being - intrapersonal
Contextual	addressed indirectly in the above

Such comparisons become even more closely aligned when the key categories of hope-fostering strategies as found by Herth (1990, p.1254) are compared to the QOL dimensions of the MVQOLI (Byock & Merriman, 1998, p.234) and the highly important concerns of dying cancer patients found by Greisinger et al. (1997 p.149). The alignment of the characteristics of hope-fostering strategies, QOL, and concerns of dying patients are shown in Table 17.

<sup>3</sup> adapted from Kylma & Vehvilainen-Julkunen (1997) and MacLeod & Carter (1999).

**Table 17 .**  
**Comparison of hope, QOL dimensions and patient's concerns<sup>4</sup> .**

Key categories of hope-fostering strategies	QOL dimensions of the MVQOLI	Highly rated concerns of 120 terminally ill cancer patients
<i>Interpersonal/connectedness</i> Presence of a meaningful shared relationship(s) with another person(s)	<i>Interpersonal</i> Degree of investment in personal relationships and the perceived quality of one's relations/interactions with family and friends	<i>Family concerns</i> Knowing that my family appreciates me Saying goodbye to the people closest to me Expressing my feelings to my family Knowing that my family will be all right without me
<i>Lightheartedness</i> Feeling of delight, joy or playfulness that is communicated verbally and non-verbally		<i>Emotional concerns</i> Feeling restless
<i>Personal attributes</i> Attributes of determination, courage and serenity	<i>Well-being</i> self-assessment of the individual's internal condition. A subjective sense of wellness or unease, contentment or lack of contentment	<i>Existential concerns</i> Having a sense of hope Knowing that my life has meaning and purpose Knowing that my life has been productive
<i>Attainable aims</i> Directing efforts at some purpose	<i>Function</i> perceived ability to perform accustomed functions and adl and the emotional response, experienced in relation to the person's expectations	
<i>Spiritual base</i> Presence of active spiritual beliefs and practices	<i>Transcendent</i> experienced degree of connection with an enduring construct, and of meaning and purpose of one's life	<i>Spiritual concerns</i> Finding strength in my beliefs Finding comfort in my faith
<i>Uplifting memories</i> Recalling positive moments/times	<i>Well-being &amp; Transcendent</i>	<i>Existential concerns</i>
<i>Affirmation of worth</i> Having one's individuality accepted, honoured and acknowledged	<i>Well-being</i>	<i>Existential concerns</i>
	<i>Symptom</i> the level of physical discomfort and distress experienced with progressive disease	<i>Physical symptoms</i> Knowing what symptoms I might experience Knowing my prognosis Talking to my doctor truthfully about my prognosis

<sup>4</sup> adapted from Byock & Merriman (1998, p.234); Greisinger et al. (1997, p.149); and Herth (1990, p.149).

As can be seen, the comparison of hope with cancer patients' concerns and the MVQOLI QOL dimensions reveals compelling similarities. If then, hope is so closely aligned with QOL and patient concerns, it seems appropriate to consider that improvement in patient's QOL may arise from nursing interventions that have fostered hope and reduced patient concerns. This assumption is now considered in regard to the research data.

Patients who had experienced an improvement in symptom and/or function attributed their improvement to the care they were getting. As previously noted, a caring relationship between nurse and patient is essential to engender hope. Much has been written on 'caring' in nursing literature. In palliative care it has been defined as providing comfort, i.e. relief of pain and other symptoms but especially acceptance conveyed by touch and attending to the detail of physical care (Penson, 2000); "a dynamic 'turning toward each other' meeting of nurse and patient through which the nurse enters and empathetically shares the patient's situation and suffering" (Fox, quoted in Hockley, 1993, p.183); 'being there' and showing an interest in the patient (Flemming, 1997); and, the provision of support, sharing of information on hope and dying and the encouragement of closeness so a sense of belonging is fostered (Herth, 1990). Four of the five patients interviewed who commented on care as increasing their QOL were in the intervention group. This ratio suggests that joint care planning, the information obtained from the QOL assessment, and/or increased time together had fostered a caring relationship (interpersonal connectedness) between patient and nurse. This caring relationship may have served to engender hope with consequent improvement in patient-reported QOL.

### **Positive context**

The positive context mentioned by patients (the Hospice itself and the attitude of staff), already identified as important in maintaining hope, has also been found central to quality of care (Redfern & Norman, 1999). When staff accept each patient's individuality and are thoughtful and friendly hope is fostered and QOL improves. Patients' comments and observations made during the study testify to nursing interventions that created a positive context. Lightheartedness, described by Herth (1990) as a hope-fostering strategy, was not specifically mentioned by patients. However, the researcher observed many instances of humour and 'play' with patients. Redfern & Norman found that nurse-patient relationships which enhanced quality of care were characterised by affection and humour on the part of the nurse. Hinton (1999), in a study of awareness and acceptance of dying found humour formed an important part of patient acceptance. A study on terminally ill patients' expectations of nurses, also revealed that humour and sensitivity to patients' moods were rated as very important nursing characteristics by patients (Arblaster, Brooks, Hudson & Petty, 1990). Such responsive, lighthearted relationships between patients and nurses were apparent during the study. Within a broader context, people visiting the Hospice for the first time often comment on the smiling demeanour of staff and the spirit of fun that is evident.

### **Other factors affecting hope and QOL**

As the data shows, both patients and nurses were aware of the importance of personal attitudes and attributes. Such awareness on the part of nurses implies an acknowledgment and encouragement of patients' positive approach to life. Where patients' assessments or hopes were unrealistic to health professionals' eyes, nurses were generally able to accept the patient's subjective experience (Flemming, 1997) and avoid destroying hope.

In some instances nurses were also able to use the QOL questionnaire results to improve connectedness between the patient and their family. Creating and, in some cases, facilitating the opportunity to talk about hitherto undisclosed issues fostered sharing relationships, thereby increasing hope and QOL.

### **Spiritual, existential and transcendent issues**

The MVQOLI revealed the significance of these dimensions to many patients. Nurses were able, as necessary, to involve members of the spiritual care team, discussing with them an appropriate approach. Where patients expressed no interest in this area the team were able to encourage reminiscence of past experiences (uplifting memories) and, where appropriate, life review (knowing that a productive and meaningful life had been achieved), thus increasing hope and QOL. Nurses also acknowledged that a response shift in the patient may occur and spiritual issues which had previously been submerged could surface (Hockley, 1993). At times, certain nurses were able to 'be present' for patients who were experiencing spiritual pain thereby promoting healing (Heyse-Moore, 1996). Nurses and the multi-disciplinary team were thus able to assist certain patients in their search for meaning.

### **The use of response shift**

A reconceptualisation of attainable aims was found by Herth (2000) to be important in maintaining hope as patients deteriorated physically. A shift in values can reduce discrepancy between the perceived ideal and reality, thereby increasing QOL. As has been seen, nurses were able to identify patients acceptance of reality through their QOL assessment. While not negating hope ('a hope is not a promise', Penson, 2000, p.94), they were then able to work with the patient to promote a response shift in attainable aims:

Sometimes it's just putting a thought in that person's head and getting them off thinking of negative things and enjoying the small things that they *can* enjoy in their day (Cath).

## Conclusion

In summary, although the patient's QOL assessment was not always used to jointly plan care, the extra time spent with the patient "being there" and showing interest (Fleming, 1997), and the information gained from a holistic assessment enabled nurses to more quickly develop a caring relationship, fostering hope and improving QOL in the intervention group. The research process itself, rather than just joint care planning, appeared to be the catalyst for this positive outcome. Quantitative assessment of individual patient QOL was confirmed by qualitative data. No statistically significant difference in change in QOL was found between the control and intervention group. Completeness of data, however, achieved through qualitative data, confirmed the clinically significant within-group change in the intervention group. Allison, Locker and Feine (1997) suggest that measures of within subject pre and post intervention change are the most appropriate data for comparison of QOL. Testa and Simonson (1996) also point out that meaningful changes in QOL for a single patient are typically much smaller than differences between patients. The necessity to consider clinical and statistical significance in measuring the effectiveness of an intervention on QOL was thus borne out by this study.

It is worth noting that the patients in the control group also benefited from the extra interest and time spend with them by the researcher. Even just completing the questionnaire enabled some patients to move towards a new awareness of 'being' through clarifying their values, reflecting on the meaning of their life and the purpose of life and death: i.e. 'hope fostering activities' (Herth, 1990). As indicated by the quantitative data, however, the brief nature of these interactions and (sometimes) a lack of follow-up yielded less tangible benefits for patients' QOL in the control group.

## Aim Two:

**To determine whether the patient/nurse planning process improves nurses' assessment skills in recognising patients' QOL status, i.e. increases understanding between nurse/patient.**

### Nurses' and patients' ratings of QOL Time 1

Nurses were closest to seeing QOL from the patient's perspective in the domains of interpersonal and well-being. As found in other studies (Cohen et al. 1997; McMillan & Mahon, 1994), they tended to regard symptom and function more negatively than did their patients. Sometimes this perception was a matter of professional experience, i.e. viewed from a knowledge of effective symptom control versus the patient's subjective experience and, sometimes, because the nurse viewed the patient's condition from how they would feel in the same position. Nurses were also unable to accurately assess how



patients viewed the meaning of their life, how precious that life was to them and the importance patients attached to their life having meaning (transcendent). Such questions are very intimate and personal, as nurses intimated, often requiring rapport and trust to be established before patients would be ready and willing to speak of such matters. Indeed, some nurses felt very uncomfortable in addressing transcendent issues with patients before developing a therapeutic relationship.

### **Nurses' and patients' ratings of QOL Time 2**

On the second comparison of QOL between patients and nurses (7-10 days after the first), nurses appreciated their patients' perspective in all domains except symptom. They were particularly congruent in the domains of function, interpersonal, transcendent and overall QOL. These results were impressive evidence of patient/nurse synchrony. It could be asserted that working together on a joint care plan had markedly increased the nurses' ability to "walk in their patients' moccasins", i.e. increased their understanding of their patients. A similar caution, however, to that applied in evaluating patients' changed QOL is necessary. Logic would suggest that closer contact and the opportunity to get to know the patient over a longer time would help increase the likelihood of nurses understanding the patient's perspective regardless of the intervention. In addition to relational propinquity, exposure to the patient's initial evaluation of their QOL would be likely to increase nurse awareness and understanding without joint care planning. The significance of this additional information and contact in increasing understanding of the patient is borne out by the qualitative data provided by nurses.

An analysis of nurses' ratings of patient's QOL time two was carried out with the patients' initial QOL assessment. It was found that nurses' second ratings of symptom, well-being and transcendent actually correlated more highly with patients' ratings at time one than time two. It appeared that nurses had initially adjusted their view of patients' QOL, in accordance with the evidence presented at time one, but were subsequently unable to accurately detect further patient change in these areas for the assessment at time two.

There are several possible explanations for the discrepancy in nurses' assessments of patient symptom, function and transcendent QOL. These factors appear to apply to both the first and second assessments. Discussion of the contextual elements which may have contributed to this lack of understanding is now presented.

### **Anomalies in patient/nurse QOL assessment**

There are a number of interrelated factors which may explain differences between patient and nurse in assessing patients' QOL.

### **Preparation for the research process**

As already identified, three nurses found it took some time to translate the theory of the QOL assessment and intervention (joint care planning) into practice. These nurses' initial assessments of patients may have been adversely affected by the unfamiliarity with the research process. The effort required to remember the nature of the tool being used is likely to have channelled energy and concentration away from patient responses. In retrospect it would have been advantageous for nurses to trial the procedure with non-participating patients prior to stage two of the study. A trial would have been especially helpful to those nurses who were not at the meeting where nurses had the opportunity to complete the instrument. Although holistic assessment of new patients is expected within 24 hours of admission to the hospice, it became obvious that nurses had often limited their assessment to areas they felt comfortable with, i.e. symptom and function. The multi-dimensional nature of the MVQOLI may thus have required new assessment skills to be developed. It could be assumed that had the study continued for a longer period with a large number of patient participants per nurse, the correlation between patient and nurse assessment of QOL is likely to have increased as nurses' assessment skills improved.

### **Deficiencies in the MVQOLI**

Difficulties in understanding the meaning of words, the concepts used, and the scoring mechanism have all been previously identified as issues contributing to discrepancies in questionnaire response. Divergent understandings of what was being asked may have influenced patient/nurse responses rather than a misunderstanding of the patients' position, i.e. the instrument itself created ambiguity. While this was undoubtedly the case on some occasions (e.g. nurses' understanding of the word 'sick'), it may also reflect the temptation to blame the tool rather than the worker. It is obvious that communication issues are likely to have been a factor in patient/nurse QOL divergence. Factors influencing effective communication will be discussed in later sections.

### **Variability of QOL**

Getting to know the patient is an on-going process because of their changing condition (Bottorff et al. 2000). The majority of nurses felt that rapid changes in patients' QOL made it extremely difficult to accurately assess QOL. This was especially so when patient/nurse assessments were done at different times of the day or (rarely) on a different day. Nurses usually left their assessment until the end of the duty whereas most patients completed their assessment in the late morning. From observation, this variation in the time when the assessment was undertaken was certainly an issue with a small proportion of patients. In the researcher's view, however, short-term changes in patients which occurred between patient and nurse assessments were the exception rather than the rule. Some nurses may have found variability of QOL a comforting explanation for differences in assessment.

### **Available Time**

Every nurse identified a lack of time as a significant issue in successfully assessing patients' QOL. Time was obviously important in establishing the rapport and trust needed to share intensely private matters, such as the spiritual dimension in transcendent (Elsdon, 1995). This may explain why transcendent was not well assessed in the initial completion of the questionnaire and why subsequent changes were not always identified. Several authors, (DiTullio & MacDonald, 1999; Elsdon, 1995; Ersek, & Ferrell, 1994; Flemming, 1997; Jones, 1993) emphasise the need for nurses to be fully present with patients by sharing a time of quiet reflection, i.e. time when the nurse is 'with' the patient, not 'doing things to' the patient. Nurses in this study stated they seldom had the time to be 'with' their patients. One nurse (not participating in the study) commented that the hospice had become so busy there was not even time to stay with the patient while they were in the hydraulic bath - often a good time for therapeutic discussion. "Time cramping", such as this, has been identified as a primary source of work stress in hospice workers (DiTullio & MacDonald).

Arblaster et al. (1990) suggest that deep philosophical discussions with terminally ill patients cannot be planned but arise spontaneously. For such patient/nurse communication to occur there must be sufficient time and flexibility to put 'doing' tasks to one side and just be 'with'. Rodenburg and Smales (2000) call this special spiritual moment 'soul space'. They see the creating of safe space between patient and nurse as a necessary prerequisite for sharing at this depth. In commenting on the difficulty in maintaining the original palliative care principles of holistic care, with increasing workloads and financial constraints, Rodenberg and Smales identify communication as the key factor in giving quality care. Time spent communicating is necessary for the establishment of rapport. Rapport leads to safe space for the patient and promotes the development of 'soul space'. It can therefore be argued that lack of time inhibits nurses' ability to communicate, to develop rapport, to participate in deep sharing and, therefore, to know how emotional and spiritual dimensions of QOL are experienced by their patients.

Communication then was seen as a key factor in being able to accurately assess QOL. The inhibiting effect of heavy workloads with consequent time constraints was perceived by nurses as a significant factor in creating anomalies in patient/nurse assessment of QOL. This applied to both the initial and subsequent QOL assessment and joint care planning. Nurses in other palliative care studies have identified pressures of workload as detracting from their ability to include patients in making decisions about their care (Bottorff et al. 2000). Rostering also reduced the continuity of care and, hence, opportunities to build understanding through communication.

### **Patient and nurse context**

The confounding effect of patient personality, attitude and reluctance to address confronting questions were also put forward by nurses as explanations of patient/nurse QOL assessment anomalies. Many nurses expressed their discomfort in addressing the highly personal and private issues involved in QOL assessments with introverted patients, patients who thought such questions inappropriate, or patients who were reticent about personal matters. Nurses often felt that the initial QOL assessment had to be completed before nurses had time to build up the rapport necessary to understand the patient and for the patient to be honest in their answers. Nurses in a palliative care study using the MQOL expressed similar concerns, considering that it would be inappropriate to use the MQOL on hospice admission because good rapport was necessary for patients to answer truthfully (Eischens, Elliott, & Elliott, 1998).

Greisinger et al. (1997), on the other hand, contend that most terminally ill patients have already thought about physical, emotional and spiritual concerns and are not surprised to be asked about them. In the authors' view patients may find such questions difficult to consider but such consideration is appropriate and is beneficial, especially in an interview such as establishing QOL. Ersek and Ferrell (1994) found that spirituality greatly influences cancer patients' ability to find meaning and deal with pain. In a study of suffering in the advanced cancer patient, one of the common shortcomings in effective management was stated to be unaddressed existential distress (Cherny, Coyle & Foley, 1994).

The need to promptly address patients' emotional and existential concerns is clearly established. Patients appear to want these concerns addressed; indeed a criticism of existing health practices is that health professionals do not initiate discussion in these areas. An alternative view of the cause of discomfort in discussing what nurses see as private and personal matters is therefore presented to challenge nurses' assumptions of patient reticence. The impact of time will also be considered from a different perspective along with the effect of physical deterioration.

### **Alternative perspectives**

#### **Personality**

In a study of 78 cancer nurses, Wilkinson, Dissanyake, Roberts and Aldridge (1998) found that nurses' personalities determined how they communicated with patients. Nurses who were more emotionally stable, less anxious, and less prone to guilt undertook more in depth assessments of patients' psychological state and awareness of their condition. Wilkinson (1992) also established that, in order to communicate well with cancer patients, nurses need confidence achieved through professional knowledge, an understanding of their own and others' attitudes to cancer and death, and communication training with supervision. Further evidence of the importance of the



nurses' context is found in a study by Ashworth, Longmate and Morrison (1992). This study identified the features essential to patient participation in care. The authors argue that participation is an interpersonal rather than an organisational concern. For collaboration between patient and nurse to occur it is important that both have: a shared set of assumptions; insight into each other's emotions and understanding of the situation; a sense of being valued, and an absence of feeling threatened. The collaboration required between patient and nurse in accurately assessing QOL requires a similar context. This context may indeed take time to achieve with certain patients, but it could be argued that the personal characteristics of the nurse, including their professional and interpersonal skills, are likely to be as significant as time and the patients' context in achieving accurate assessment of patients' QOL.

### **Time**

In her article on research in the cancer communication field, Thorne (1999, p.373) suggests that how time is spent is of more relevance than "the pervasive concern that professionals have about controlling time". The author notes that if you ask patients to tell you what they think and listen without interruption (rather than directing the patient), research shows the extra time needed in the interaction is about 90 seconds. Thus rather than explicitly needing more time, nurses in palliative care may also need to reflect on how they actually use the time available. As an example of this within the research process, a nurse remarked thoughtfully that they had "made time" to complete the study requirements. There was, however, a personal cost in terms of energy and work pressure in 'making' this time.

### **Differences in symptom and function QOL assessment**

Where patients had a positive attitude and/or had achieved a response shift in reconceptualising their QOL, they rated symptom and function more highly than nurses in this study. Nurses were better able to assess patients' positions on these dimensions in the second assessment but still failed to achieve significant correlation on symptom evaluation. As noted previously, health professionals and carers have consistently been found to be more negative than patients in assessing QOL in this area. In a phenomenological study which looked at patients who had experienced major illness, surgery or trauma, More, Bottorff and Hutchinson (1995, p.18) uncovered themes which reflected "the experience of the lived body associated with discomfort". They suggest that some patients are able to move beyond discomfort by learning "to live in the world in a new way without being dominated by one's body". Terminally ill patients who have achieved such a change (response shift) will thereby have the potential to assess symptom and function from a different paradigm to that of nurses.



## **Conclusion**

Nurses in this study were successful in understanding their patients' perspective of QOL in the domains of well-being, interpersonal and overall QOL on the initial QOL assessment. In the second assessment they improved their ability to understand their patients in every domain although this improvement was not statistically significant for symptom. For well-being and transcendent, however, nurses' scores were closer to patient scores in these dimensions at Time one than to patient scores at Time two. Nurses' inability to accurately assess all dimensions of patients' QOL has been attributed to deficiencies in the QOL instrument used, the variability of QOL, lack of time, and the patients' context. While these factors have undoubtedly had some bearing on QOL assessment, it is suggested that nurses' communication skills and personalities also impinge on their ability to understand QOL issues from their patients' perspective. Reflection on practical experience, leading to wisdom (phronesis) is pivotal in developing the advanced palliative care nursing skills necessary for accurate QOL assessment. The discussion therefore now moves on to the third aim of the study.

## **Aim Three:**

**To promote reflective practice in nurses by providing feedback on their assessment skills.**

### **Reflective practice**

#### **Introduction**

As discussed in chapter two, there has been increasing awareness that reflective practice, long encouraged in teaching and education (van Manen, 1995), is also critical in nursing. Its importance lies not only in professional development (developing advanced palliative care skills) but also in enabling nurses to identify to funding authorities why they make a difference, and as a prerequisite for communal action leading to organisational change. All of these outcomes are important in palliative care where funding is a constant challenge, increasing workloads impinge on the ability of nurses to provide the level of holistic care seen as inherent in the hospice philosophy, and increasingly complex consumer needs demand a highly trained, skilled, caring workforce.

Hospice staff require "a rare mix of interpersonal skills, compassion, and professional acumen" (DiTullio & MacDonald, 1999, p.641). Both skills and acumen can be developed through reflective practice. Increasing financial pressure on health services is eroding the quality of nurse/patient relationships (DiTullio & MacDonald) as nurses are expected to do more in less time. Nurses need evidence to prove that trained, experienced staff make financial sense to achieving positive health outcomes. Reflective practice can help nurses to describe what they alone can do. Nurses glean much of their satisfaction from attending to quality of life issues (Fitch, 1998). Thus financial constraints which

reduce staffing levels not only compromise patient care, they may also increase stress levels in nurses. Nurses can use collective reflective practice to identify factors which detract from their ability to give holistic care and seek organisational change.

Having briefly outlined some of the issues relating to reflective practice, the data presented in chapter five and arising from the focus group are now examined to see what, if any, reflective practice occurred with nurses in this study. The consistency of findings between the interviews with nurses immediately after the research and the individual and communal findings of the focus group, some five months later, is significant. Nurses not only retained the learning from the study but had further reflected on their own and the Hospice team practice. Comments from the focus group, additional to those presented in chapter five, are incorporated in the text.

Differences in QOL assessment, as revealed by questionnaire results and the research process per se, can thus be seen as an opportunity to engage in the persistent self-exploration and questioning necessary for professional development (Chapman, 1998). It is then necessary to consider the skills that are required to engage in such reflection. Two research studies have sought to develop a model to aid understanding of the reflective process. A reflective model based on the ideas of these researchers is now presented.

### **The reflective model**

A modified model of reflective processes, initially developed by Atkins and Murphy (1993, p.1191) and incorporating the findings of Teekman (2000), is used to examine the reflective abilities of nurses in this research. The model identifies three sequential stages in the reflective process. Stage one involves the nurse recognising a situation that causes her at least a moments hesitation or questioning or intuitive unease. As the nurse later revisits this unease or awareness, the original situation must be able to be clearly recalled for useful reflection to occur. This accurate recollection is then subjected to critical analysis by the nurse in stage two of the process. Such critical analysis requires the nurse to analyse what went on from a personal and professional perspective. Previous experience and knowledge are applied to the situation and, where necessary, a lack of knowledge is acknowledged. The awareness of knowledge deficit or difficulty in seeing a new pattern are necessary precedents to seeking new knowledge. This new knowledge may be achieved through discussion with colleagues or appropriate professional reading. The meaning and understanding of new knowledge is then subject to evaluation and synthesis (integration into what the nurse already knows) in stage three of the process. This then leads to a new perspective which is translated into new behaviours. An explanation of the model is presented in Figure 8.

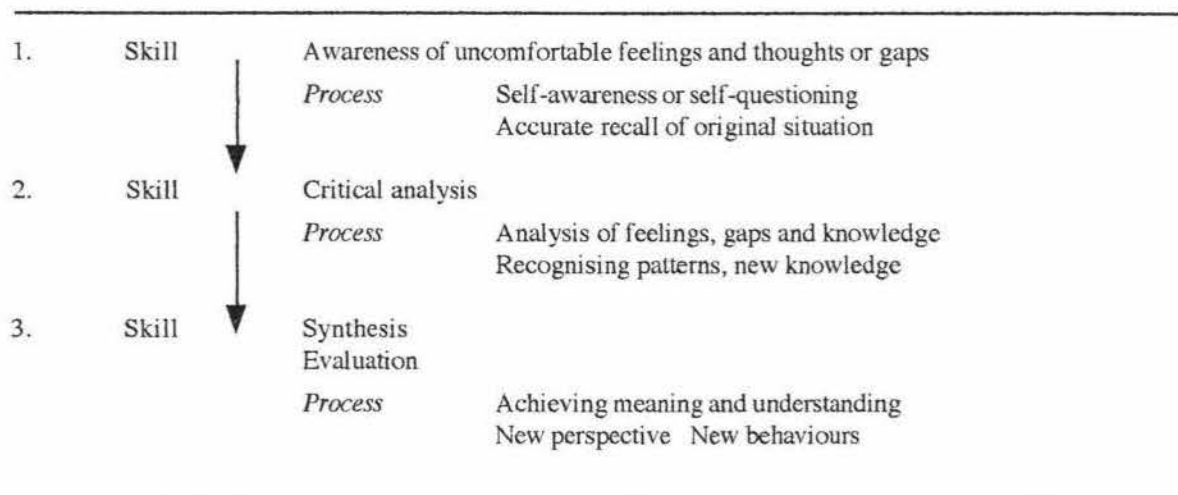


Fig 8. Skills and Process Required for Reflections

The model is now applied to the data from chapters four and five related to reflective practice.

### Inner discomfort or an awareness of uncomfortable feelings and thoughts

All nurses received feedback from QOL assessments where their view of the patient's QOL was not that of the patient. The way nurses described their reactions to this situation included: *it does make you wonder; quite frightening actually; a reality check; gosh, what's happening here* (shocked); and, again, *frightening*. Not all nurses experienced uncomfortable feelings when discrepancies occurred. These nurses often used *interesting* as a response to the results. The research process itself (which included talking with other nurse participants, discussing QOL issues at 'hand over' meetings and, sometimes, discussions with the researcher) also had the potential to create uncomfortable situations or awareness, seen as the beginning of the reflective process.

### Self awareness

The analysis of feelings arising from challenges in the research process depended upon both the personality of the nurse and their belief in the assumptions underlying reflective practice. From observation it was obvious to the researcher that certain nurses were more interested and able to confront self (Johns, 1996) than others. Those nurses who readily agreed to participate in the research had already identified the research process as a way of receiving feedback about their own performance and a way to learn and improve. Others had agreed to join in as a way of supporting the researcher and were perhaps, less motivated and less open-minded (Atkins & Murphy, 1993) about changing their practice. One nurse was heard to comment "*I don't know what we are doing this research for when all it does is show us we are wrong*". Sometimes nurses' needs to discuss situations indicated discomfort that was not consciously acknowledged by the nurse

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<sup>5</sup> adapted from Atkins & Murphy (1993, p.1191); Teekman (2000).

concerned.

### **Gaps**

Rather than self awareness of discomfort, Teekman (2000) uses the concept of 'gaps' which challenge nurses to make sense of a situation thereby facilitating reflective practice. Nurses can become aware of 'gaps' or unexplained phenomena within their practice. For example, differences in QOL can be caused by gaps between the patients' and nurses' perceived reality and between assessment and interpretation of assessment findings. Gaps also exist at an interpersonal level between nurse and patient, and between the nurse and other members of the palliative care team. Nurses who did not appear affectively aware of discomfort arising from divergent patient/nurse QOL assessments were certainly rationally aware of gaps. It may be that a non-emotive response is just as effective in gestating reflective practice in these nurses as the awareness of uncomfortable feelings is in others, i.e. the nurses who saw gaps used an objective rather than a subjective approach.

### **Accurate recall of the original situation**

In situations where nurses were self-aware, either of discomfort or gaps, they appeared able to recollect the essential elements of a discrepancy in the QOL situation. Sometimes this took the form of a written comment on the questionnaire: *"Done just before discharge. Fred wasn't happy re management on incontinence."* or *"Eliza is tricky! Eliza sees herself as being able to carry on her life as before... She does not see how dependent she is on her daughter who is finding the going difficult."* Although these comments applied to the patient's context, it was apparent to these nurses that the situation described had implications for patient QOL, and the nurse's professional responsibilities in relation to that QOL. It was clear they found this situation challenging.

Often the discussion of particular situations took place informally between staff, between nurses and the researcher, and at 'hand over' meetings. There was an on-going debate over patients' ability to answer the questionnaire "honestly". This particularly occurred when the nurses' assessment was based on 'reality' rather than 'hope' and applied to nurses who were unable to accept the patients' own kind of hope (Hockley, 1993).

### **Critical analysis of feelings, knowledge and gaps**

Nurses generally showed evidence of being able to analyse situations and identify their knowledge and assumptions in relation to those situations. Sometimes this analysis was of the patient's context and this was used as an explanation of the gap that had emerged in the QOL assessment:

*It was quite interesting because the patient was, I think, covering up for a lot of how he was actually feeling. As he settled into the Hospice and*

*we won his confidence he opened up to exactly how things were for him....*

This patient had negative changes in his QOL between the first and second assessment. The nurse thus interpreted this change in QOL as an initial lack of trust with a consequent concealment of how he actually saw his QOL while, in her assessment, she had reflected the 'true' QOL he was experiencing. The researcher observed that this patient had actually clinically deteriorated between the first and second assessment and it was this decline that was revealed in the second assessment. Nurses' analyses could therefore have been challenged, with consequential growth in objective analysis, if guided reflection had been part of the study.

Differences in patient/nurse assessment of well-being were analysed by a nurse as arising from:

*The patient had been perfectly happy here but obviously from what you are seeing here and how they were being here they were still not as well as they had been some months before and [they are] really grieving for that.<sup>6</sup>*

On occasions nurses were also able to challenge their own assumptions which had created the gap in the QOL assessment:

*What I might see as a terribly difficult way of living might be alright for that particular person. They might come up feeling quite positive about their level of function, for example, while I saw them as barely able to breathe.*

Others recognised that because they tended to "project one's own feelings on to the patient" they rated patients' QOL as lower than the patient did.

Sometimes the questions in the questionnaire itself created discomfort, for example the concept of contentment and being at peace with oneself. Some nurses found the ideas of what is considered a 'good death' and the need for developmental growth created conflict within themselves. This conflict promoted exploration of their own beliefs and how they reacted when patients chose differently. It also raised what they considered were ethical questions: "if patients are not 'content' do we have the right to "move" them as specialists in palliative care?"

On the other hand, nurses identified that when patients were content they were

*...in a different space. They didn't think they were sick. People who were at peace had a good QOL as shown in QOL assessment. These patients have got it sussed. Most of the time we're alongside but they've done it [achieved QOL].*

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<sup>6</sup> A good example of discrepancy between the ideal and the reality with no compensatory reconceptualisation (response shift).



This reflection is confirmed by Hinton (1999), who found that patients who showed a greater acceptance of dying had a higher QOL .

Critical analysis, which revealed how patient's care plans are often based on nurse assumptions, was also prompted by discrepancies in QOL assessment:

*It opened up a new world for me. Planning care is based on nurses' assumptions and could be way out. This is frightening.*

The organisational context in which nursing practice occurs is seen as crucial to promoting reflective practice (Johns, 1996; Ostermand & Kotthamp, 1993). The research process also drew nurses' attention to the environment in which they practised. The issues of time and workload with the implications for establishing caring relationships, have already been discussed. In addition, time, workload and rapid patient turnover also have implications for the amount of energy nurses have available to expend in reflective practice and this was also revealed by the study: "*It makes you think but I'm too tired to do much with it.*" The researcher noticed, however, that as nurses became more experienced with using and reflecting on QOL assessment, energy started to be created by the interest in assessment results and the individual feedback received.

### **New perspective**

Exploring alternatives to existing patterns of response can lead on to the synthesis and creation of a new perspective.

There were many examples of nurses developing a new perspective which led to a change in practice. These examples included behavioural changes that arose from integration of new knowledge with previous knowledge (synthesis). The new knowledge arose from the QOL research results, discussion with colleagues (including the researcher) and reading the cumulative qualitative data. Observations or discussions with colleagues are acknowledged as an important source of relevant information in reflective practice (Osterman & Kottkamp, 1993).

An example of behavioural change was seen in two nurses who had previously not perceived psychological, social and spiritual care as being part of their role:

*It has raised my awareness overall... sort of more about people's personal relationships, about getting their affairs in order and about their feelings of self-worth. Those are things I wouldn't have thought of.*

and

*more aware of other [than physical cares] things that need attention.*

Another nurse translated her new perspective into behavioural change in that:

*It [the research] taught me, with new patients, to remember back to the [QOL] questions. To try to establish a special time, build rapport and ask some of those questions. It broadened and deepened [my awareness of] the need to continually focus on that kind of thing. It's easy to just get on with cares and never go back for a special time.*

As shown above, several nurses continued to use general QOL questions in assessing patients, especially 'Are your affairs in order?' The following example is illustrative of the way in which this perspective was incorporated into a new pattern of practice:

*Are your affairs in order? It's really in my head now for discussing with patients - wills and stuff. I'm not afraid to mention that now. It stayed with me. It can be [negative for QOL] if it's not done.*

Certain nurses had reflected on the differences in patient/nurse interpretation, which led them to check out the different understanding of words by different people. Appreciation of different patient/nurse priorities and realities also applied to drawing up care plans: "There were differences between what they needed and what I thought they needed"; and, "[I learned] don't get into what I thought should happen". This realisation of differing interpretations encouraged care plans to be drawn up focussing on the patient's priorities.

It can be seen that most nurses in this study were able to reflect-on-action (reflective-thinking-for-evaluation). These changes (new perspectives leading to behavioural change) now entered their practice as reflection-in-action. Some nurses were aware that they had changed but were unable to clearly express these changes. Schon (quoted in Atkins & Murphy, 1993) states that 'reflection-in-action is a process we can deliver without being able to say what we are doing'.

Teekman (2000) and Osterman & Kottkamp (1993), however, both see a further dimension of reflective thinking that can lead to critical inquiry and generate change, a somewhat similar proposition to that of critical social theory (Campbell & Bunting, 1991; Friere, 1970).

### **Reflection-for-critical-inquiry**

Teekman (2000, p.1127) identifies this third level of reflective thinking as reflection-for-critical-inquiry:

Reflective thinking as critical inquiry goes beyond questions of technical proficiency to thought reflection as to how contexts influence health and nursing. Critical inquiry is concerned with examining when certain choices of practice are made, the influence of hegemonic conditions within the health delivery system as well as concerns for ethical and moral issues related to justice and equality.

In a similar approach, Osterman & Kottkamp (1993), assert that personal behavioural change always intersects with the culture in which the individual exists. They suggest that unrecognised, habitual behaviours arise from deep acculturation. When behavioural change occurs, this entails a change in the relationship between culture and behaviour. Behavioural change arising from reflective practice (self-awareness, critical analysis, synthesis of new knowledge resulting in a behavioural change (new perspective)) may thus no longer conform to the old culture. The authors propose that reflective practice also means working for cultural (organisational or sectorial) changes that will support the new behaviours.

Teekman (2000) found no examples of reflection-for-critical-inquiry in the data for his study. Nurses in the present study were specifically asked to identify changes they thought were needed, as a result of reflecting on the research, both in the team situation and the organisational context. Although all nurses identified deficits in the existing cultural environment, responses on the need for change or how this could be achieved varied widely. The issues of rostering, inadequate communication and collegial concerns were raised, but evidence of further critical analysis was not always present. Some nurses, however, suggested that changes had already occurred in team practice as a result of the research, i.e. resulting from reflective practice. One of these was a change in the nursing team culture:

*Since the study, (the people who have been in it), we have talked differently together and that's been wonderful. It's still there,*  
and *Some patients we don't do as a team, but some others we are still doing it - spiritual and social - talking together, sharing ideas, doing it in more depth now than before.*

There was a new awareness of acting as patient advocates (justice and equality) within the multidisciplinary team:

*I think there have been changes - the nursing team is pushing for spiritual care for a particular patient. Pushing for communication on that - other members of the [multi-disciplinary] team, pushing them to come back to the nursing team with all that input into her. We want to know the **whole** picture, not just medical, but that the patient is OK spiritually. I think, for me, some of those questions - we are trying to work through, even though she can't answer them. I'd like to see that for more patients as the need arises.*

The change in professional behaviour and team culture, created by being part of the research process, was highlighted by one of the nurses as the focus group debated the on-going use of a specific QOL questionnaire:

*How can we - people who weren't in the study and don't have that background - how can we bring them on board unless we use a questionnaire? How do they come upon information like that? It might be OK for us who have worked with it [to just use prompts to obtain QOL information].*

This query revealed the new knowledge and change in practice that the research process had brought about in participating nurses. The difference that now existed between their own and non-participating nurses current practice (culture) was clearly evident to this nurse.

### **Organisational change**

Discussion of the need for organisational change centred around reducing the amount of duplication in report writing; care plans: how these should be used and based on patient priorities; increased staffing levels; and, in particular, the need for more registered nurses to improve the quality of documentation and care. A discussion on the hygiene expectations of patients' families and certain hospice colleagues ensued. When these priorities were followed, it led to physical care being emphasised rather than the nurse spending that time 'with' the patient. Such debate begins to address some cultural issues within the organisation and, more generally, society. However, the reflection-for-critical-inquiry was at a very embryonic level demonstrating the need for guided reflection (Johns, 1996), in a nurturing environment of openness and trust (Osterman & Kottkamp, 1993). Teekman (2000) also notes that there are essential requirements if reflective practice is to be practised in the workplace. These preconditions include support staff who are trained and skilled in reflective processes, availability of time to reflect, and a 'safe' place for staff to discuss the outcomes and potential dilemmas of reflective thinking.

### **Conclusion**

The effect of this research study on promoting reflective practice in nurses by providing feedback on their assessment skills, is encapsulated in the following quote by one of the participants:

*If we don't get it right (as shown by the research) we've got to go back to looking at why we don't get it right. If we don't get it right what happens to the patient? We can spend a lot of time continually not getting it right. We've got to go back to looking at **why** we don't get it right and I think that's been a huge benefit of the research to me, in our own personal practice and to the patients as well.*

Nearly all of the nurses in this study became self-aware of discomfort or gaps within their practice. Evidence of critical analysis of feelings and knowledge was observed. This analysis led to new knowledge being generated through observation and discussion, resulting in new perspectives. The nurses were willing to grow and change their practice through reflection-for-action and reflection-on-action. Some of these changes have led to an element of cultural change within the nursing and multi-disciplinary team but reflection-for-critical-inquiry was still at a developmental stage. Reflective practice could be further developed and deepened by providing the opportunity (time and space) to

reflect with an experienced guide (skilled in palliative care and reflective practice). This would require organisational change and is outside the parameters of this study.

## Summary

Quantitative and qualitative data, presented in earlier chapters, were analysed and discussed in relation to the overall understanding of the QOL concept and the particular aims of this study. The instrument used to obtain quantitative data was critically examined. It was shown that quantitative QOL measurement, of itself, while an accurate reflection of how patients' view their QOL is not an effective outcome measure of the effect of a nursing intervention. In addition, although patient/nurse understanding was considerably improved during the research process, the causative factors creating this improvement were also diverse, clouding definitive conclusions. Anomalies in patient/nurse QOL assessment were examined from the nurses' perspective, and alternative explanations, drawn from observation and literature, were offered. Reflective practice in nurse participants was demonstrated at a personal and team level leading to new perspectives on QOL assessment, and changes in nursing practice.

The conclusions drawn from the research, the limitations of the research process and recommendations for the future are presented in the final chapter. A theme of 'revelation', arising from the experiences of patients, nurses, and the researcher is proposed as a unifying concept. Based on the results of the study, a working model of advanced nursing practice in palliative care captures the most significant findings and suggests a way forward in promoting the QOL of terminally ill patients.



# Chapter Seven

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## CONCLUSION AND RECOMMENDATIONS

### Introduction

This study was driven by the goal of improving quality of life (QOL) in terminally ill patients. In order to research factors influencing this goal three tasks were necessary.

The first task was to achieve an understanding of what research studies in this area had already revealed. Such studies identified the complex nature of the QOL concept, and the resulting difficulties in the measurement of QOL. An extensive literature review on QOL research material from nursing and other social sciences was therefore undertaken to: identify gaps in QOL research in palliative care, arrive at the most compelling description of the QOL concept, and determine how to appropriately measure this QOL construct in the terminally ill.

The second task was to discover how patients viewed their QOL, how effective nurses were at assessing their patients' QOL and providing appropriate care, and whether this assessment and care could be improved to increase patients' QOL. This complex task required different research methodologies including quantitative and qualitative methods used in a comparative design. Initially the QOL enjoyed by patients receiving normal hospice care was measured to provide a baseline. A second group of patients then received a new nursing intervention. This intervention involved joint patient/nurse care planning based on QOL assessment. Evaluation of the effects on QOL of a nursing intervention was then possible. As part of the second task, nurses were also assessed on their ability to identify the QOL experienced by these patients. This assessment provided nurses with feedback on their ability to understand the patient's perspective of their QOL.

Only when nurses can take their "learning" from one patient's QOL assessment and begin to apply it to other patients in their care, will improved QOL for all terminally ill patients start to become a reality. Therefore, the final task was to determine if nurses develop *phronesis* (practical wisdom) and advanced nursing skills, which contribute to improved patient QOL, through reflecting on their practice. The effect of the research process on nurses' reflective practice was examined through individual nursing interviews, observations, and a collective focus group.

This concluding chapter now examines how effectively these three tasks were achieved; the learning that occurred through experiences of revelation during the study, including

the limitations and strengths of the research methodology used; and finally, advances recommendations arising from the research process including a model for advanced nursing practice in palliative care.

## **QOL concept, measurement, and research**

Understanding the dynamic, subjective and multidimensional nature of QOL is a philosophical and scientific challenge. Recent thinking and research on QOL was discussed in the literature review in chapter two. This review revealed an increasing consensus that QOL, like pain, is what the patient says it is and exists when the patient says it does. Thus, the variable and individual nature of QOL contributes to difficulty in definition and measurement of the concept. There is, however, evidence that the inclusion of the dimensions of physical, psychological, social and spiritual well-being in a QOL assessment enables greater appreciation and understanding of what influences each patients' perception of their QOL (Fowler, Coppola & Teno, 1999).

Once having established the most appropriate QOL domains to be considered, the researcher then faces the task of identifying the level of importance these different facets have in contributing to patients' QOL. Researchers of the ideographic persuasion consider that individually chosen domains and rating systems yield the most accurate and useful patient QOL assessment. This approach requires considerable time and experience from both staff and patients, which is hard to achieve in a busy palliative care setting. However, using a QOL instrument, although more efficient in terms of time and energy, may fail to provide detailed information that can be utilised by staff to promote QOL. It was suggested that an alternative approach which reduces the amount of time needed but still allows for individual patient exposition could yield the most satisfactory outcome. This was found to be so. The study identified that the use of a QOL instrument, specifically designed for terminally ill patients, provided a helpful foundation from which patient and nurse could explore and develop a deeper understanding of the patients' QOL and how it could be improved.

There has been no published research which specifically addresses how to improve terminally ill patients' QOL in a hospice setting. This study found that using information obtained from patient QOL assessments enabled nurses and patients to have a deeper appreciation of issues important to the patient, provided the basis for joint patient/nurse care planning, and promoted reflective practice in the nurse, thus contributing to the development of advanced nursing practice. All three of these outcomes contributed to improved QOL within the intervention group.

There have been calls for a new research paradigm in palliative care. Triangulation is a recent research approach that combines different methodologies to achieve a more

complete understanding of the phenomenon being examined. The use of triangulation in this study, in particular the combining of quantitative and qualitative methods (method triangulation), was particularly effective in revealing clear evidence of clinically significant improvement in patient QOL, when statistical significance was less compelling. Other forms of triangulation contributed to the quality of the research.

## **Unifying theme: revelation**

Careful analysis of all sources of qualitative data related to the second and third tasks of this study (using patient/nurse assessment of QOL to improve patient QOL, and nurses' reflective practice) revealed patterns of behaviours which were illustrative of the personal experiences of the patients, the nurses and the researcher. These patterns coalesced around a significant unifying theme. The theme is that of *revelation*. Before identifying the evidence that supports this theme, it is appropriate to consider the way in which 'theme' is applied in distilling the study's data and what is meant by 'revelation'.

DeSantis and Ugarriza (2000) criticise the current use of 'themes' in qualitative nursing research as ambiguous, imprecise and of little use in formulating strategies to assist clients. The authors call for a much more rigorous definition of the unified, holistic meaning that is conveyed by using the term 'theme'. They suggest that themes should make explicit the implicit meaning of data; be defining points and indicators of important issues; and represent important aspects of and issues in the lives of people. Only when 'theme' is used in this way, the authors contend, can effective health care interventions arise from research. In the researcher's view the theme of revelation, as applied in this study, meets the criteria outlined by De Santis and Ugarriza.

'Revelation' is defined in the Oxford Compact English Dictionary (2000) as the revealing of something previously unknown; a surprising or remarkable thing; or, the disclosure of knowledge to humans by divine or supernatural means. The use of the word in this study is limited to the first two meanings although certain patients indicated they had also experienced the third dimension.

## **Revelation experienced by patients**

Merely completing the QOL questionnaire itself created new insights for many patients. The multi-dimensional aspect of their lives was revealed in a more comprehensive, often surprising, way. Sometimes this revelation prompted positive life review, with a resulting increase in QOL as they faced the end of that life. Nuland (1993, p.242) makes the observation, related to such a review, that "the greatest dignity to be found in death is

the dignity of the life that preceded it". The consequent revelation to the patient of their emotional, social and spiritual state, however, was not always welcome or acceptable. These patients declined to complete the questionnaire, found the questions irrelevant or became uncomfortable with evaluating their life in this way. Where the latter response applied, subsequent evaluation often showed diminished QOL as patients faced a previously unrevealed reality.

When revelation was acceptable to the patient, this process was often continued by analysing or sharing the reasons for their QOL responses with either the researcher or their nurse. Revealing such deep and intimate information helped to quickly create a caring, therapeutic relationship between patient and nurse. This relationship was important for working together on hope-fostering strategies that addressed negative aspects of QOL, especially those aspects that were of greatest priority to the patient. Such shared revelation helped improve the QOL experienced by the intervention group in this study.

Sometimes the QOL questionnaire revealed information that was unknown to the patient's family. Effective communication, usually facilitated by the nurse, then helped to resolve misunderstandings or to address matters that had not previously been raised. This increased patient/family shared understanding also helped to improve the patient's QOL.

The culture created by patients sharing a terminal diagnosis within a hospice setting often provided a context for revelation. Sometimes this new knowledge was facilitated by contact and social comparison with other patients and sometimes by the reaction of family and friends to the patient's situation. Being part of this new culture created opportunities for redefining and reconceptualising QOL. When this response shift was positive, there was an increase in the QOL enjoyed by the patient.

## **Revelation experienced by nurses**

### **Differences in QOL assessment**

All nurses in this study experienced an element of surprise during the research process. For most nurses it was how different their view of QOL was from that of the patient. For one nurse it was how honest the patients were and how close she was in her assessment of her patients' QOL. Some nurses found the discrepancy between patient/nurse QOL assessment a revelation of enormous proportions. Other nurses, like patients, found reasons external to themselves to explain uncomfortable findings. Regardless of individual rationalisation, all nurses found the new knowledge obtained from QOL evaluation to be of value in understanding and working with their patients. This increased rapport was effective in improving patients' QOL.

## **Revelation of culture**

The study also spotlighted shadowy components of the cultural context in which nurses were working. These cultural elements were thrown into sharper relief as nurses sought to provide the patient-centred care required by the study. The constraints of time, lack of continuity of care, and rostering problems emerged as significant detractors from providing such care. High turnover of patients (especially when caused by death), collegial concerns (especially divergence over the ownership of patients' needs), and communication issues between team members were all revealed as important forces acting upon the Hospice culture. As yet, revelation of this culture has not brought about action for organisational change beyond that which has occurred within the nursing team.

## **Revelation through reflective practice**

The revelation nurses experienced, both personally and professionally, prompted them to engage in reflective practice. An increasing awareness of deficits in their practice skills, knowledge and understanding, promoted the seeking of new knowledge including hope-fostering strategies. There was evidence of this new understanding being translated into phronesis and advanced palliative care nursing practice. This advanced personal and professional practice ensures terminally ill patients, admitted subsequently to the research, continue to receive care based on an appreciation of QOL issues by the nurses who participated in the study. Such patient-based QOL care should continue to motivate and influence their clinical practice thus assisting in improving the QOL of Hospice patients. The formal introduction of changes in clinical practice, arising from this study, is dependent upon the researcher presenting the results to the Hospice management and further work with nursing staff to determine the best way of bringing about sustainable change. These issues for the future are discussed in the recommendations section.

## **Revelation experienced by the researcher**

Most research yields some surprising phenomena and unexpected results to those undertaking the research. This study was no exception. The brief outlining of the researcher's significant moments of revelation is done in chronological order within each section. This approach enables the reader to identify how the research evolved over the time of the study.



## **Revelation pertaining to Nurses**

### **Participation**

The first revelation was of the willingness of fellow nurses to personally and professionally commit themselves to the QOL study. Other nurse researchers have spoken of the difficulty in accessing patient participants when nurses are 'door keepers'. The nurses participating in this study always acted as patient advocates when they felt answering a QOL questionnaire was inappropriate for a particular patient but they also proactively identified patients whom they considered suitable. When the researcher needed to assist the patient with completing the questionnaire, this process was always accommodated regardless of the disruption to the nurse's planned schedule. Such co-operation facilitated the progress of the research.

### **Perseverance**

The nurses themselves, as was evident in chapter five, were already compromised by time constraints, heavy workloads and limited energy. For some nurses much explanation, reinforcement, individual attention and repetition of instructions was needed to become proficient in applying themselves to the requirements of the research. In addition to the considerable personal energy and commitment that was required to understand the research process, on top of their normal patient workload, nurses also had to find time to do their own patient QOL assessments and work with the patient in new ways. Once the research process was understood, all nurses persisted with the agreed process even when physically and emotionally taxed.

### **Self-appraisal**

The extra challenge of facing critical evidence of patient/nurse QOL assessment disparities was also demanding of nurses, both personally and professionally. Nurses in this study revealed their commitment to excellence in palliative care nursing in honestly examining their skills, knowledge and clinical behaviour by reflecting on their practice.

### **Personality**

The influence of individual nurse's personality on how they approached QOL evaluation was a further revelation to the researcher. Differences were to be expected, especially as these had already been experienced while working together as colleagues. The effect of these personality differences as revealed in the research was, nevertheless, surprising. In particular, three examples stand out. One was the nurse who did not see herself as the initial assessor of psycho/social and spiritual issues, who could facilitate the introduction of other members of the multi-disciplinary team as appropriate. She had never seen such issues as part of her care responsibilities. The second was the nurse who steadfastly saw her QOL assessments as being 'correct' while patients who differed were seen as mistaken, not honest, lacking in insight or too private or introverted to reveal themselves

adequately. This nurse was observed to be very committed to her patients and extremely conscientious in meeting what *she* saw as her patients' needs. During the research process she indicated that a shift in her practice had occurred in that she would now go to the patient and check their priorities for the care plan. The third revelation was that of the well developed phronesis (practical wisdom) of certain nurses. This personal and professional wisdom was wonderfully revealed during the study. Revelation of nurse diversity prompted the researcher to search for relevant research material on the effect of personality differences on patient care. There was little material available. One useful study on how nurses communicate with patients was integrated into chapter six.

## **Revelation pertaining to Patients**

### **Recruitment and retainment**

Although, as previously identified, other palliative care studies had experienced difficulty in recruiting and retaining patient participants, the reality of this difficulty was a revelation to this researcher. In one month during the study only four patients were able to complete both QOL questionnaires. The extended time required and seven day a week commitment for little data return was not foreseen.

### **Openness**

On a more positive note, the willingness of very ill patients to participate and reveal intimate thoughts and feelings was also a surprise. Using a questionnaire as a type of formal structure for legitimising such discussion was unexpectedly effective. The researcher experienced at first hand how quickly a rapport could thus be established, enabling the patient to reveal the intimate and important issues which affected their QOL.

### **QOL results**

Early in the study it became evident that inexplicable changes, particularly negative changes, were occurring between the first and second QOL questionnaire results of certain patients. The clinical symptom and function improvements that were being observed were not being revealed in improved QOL. The tentative theoretical explanations being attempted by the researcher were suddenly illuminated by the discovery of the response shift concept (see chapter two, pp.28-31). This discovery provided a very welcome revelation that offered new insights into such apparent and unexpected discrepancies.

### **Acknowledgement of staff**

Informal and formal interviews were also sources of revelation. It was surprising to the researcher that when asked about improvements in their QOL which drew forth comments about hospice care, no specific health professionals or individuals were ever mentioned by patients. This contrasted markedly with cards and letters from patients' families who, almost invariably, identified specific staff members when conveying their gratitude for the care received. The reticence in naming staff may have arisen from patients trying to be objective in the context of a research study or may reveal the importance of the total team in meeting patients' QOL needs.

### **Researcher's satisfaction**

At a personal level it was a revelation to the researcher, who normally works in this area, how very satisfying it was to have time to just sit down and listen to patients with no other agenda to complete. The relaxed, patient-centred interaction was possible at a much deeper level than that normally experienced while trying to provide care for a number of patients. These experiences confirmed the necessity for a low nurse/patient workload if the holistic, patient-centred, best possible QOL philosophy of palliative care is to be practised and maintained in reality. The experiences also revealed the value of a formal QOL assessment which gives the patient 'permission' to discuss matters they may feel fall outside a normal patient/nurse relationship. Patients, after all, are often more familiar with a functional hospital environment than they are with the holistic palliative care philosophy.

### **Limitations and strengths in the study**

The researcher also inevitably became aware that there were several limitations in this study. Some of these limitations have already been identified. They include reduced patient numbers, replacing nurse participants, uneven distribution of patients to nurses, differences in applying the research intervention, and problems with the questionnaire used. These limitations are now outlined more formally before considering the strengths and limitations of the triangulation approach used.

#### **Patient and nurse sample limitations**

Difficulties in the recruitment and retention of patient participants, common to research in palliative care, reduced the number of patient participants from 100 to 72. This lesser number slightly reduced the statistical power of the study. The reduction in patient numbers also reduced the number of patients available for allocation to nurses. Instead of the planned ten patients (five in each of the control and intervention groups) nurses varied between having five-ten patient participants overall. Rostering, limited duties, and the

loss of many patients between the first and second QOL assessments, all contributed to the difficulty in achieving equitable patient distribution across nurses.

Early in the research there was also a loss of registered nurse participants. Three nurses were lost to the study because of promotion, transferring to another city, and parental leave. These nurses were replaced (during stage one of the study) by two experienced enrolled nurses and a registered nurse who had previously been reticent about taking part. Because nurse participants were fully briefed before the second part of the study (stage two) was undertaken, such replacements were anticipated to have minimal effect. Despite efforts to comprehensively outline what was required, however, the ten nurses differed in their commitment to and understanding of the research process.

### **Procedural limitations**

During the second stage of the research (intervention), nurses were observed to be differing in their interpretation of what was expected on them. In particular, two nurses (from the original cohort) were not using the patients' QOL assessment results as the basis of a care planning discussion. The researcher sought to address observed anomalies, but initially the research process was not uniform for each patient and nurse. The nurses' ability to fulfil their research role was also compromised by lack of time, energy, and heavy workloads.

### **Measurement limitations**

The study revealed deficiencies in the QOL questionnaire used to obtain quantitative data. As discussed in chapter five, differing interpretations of the questions asked, the confusing scoring mechanism and the appropriateness of the developmental growth focus which underpinned the questionnaire used, created ambiguity in responding to and interpreting certain QOL results.

### **Design limitations**

Qualitative data gathered during the study revealed that the sole use of quantitative data to measure the effect of an intervention is not appropriate. In particular, it was not possible to statistically differentiate between the variables creating changes in patients' QOL or those increasing the understanding between nurse and patient. Thus the outcomes of aims one and two could not be evaluated by quantitatively measuring changes in patients' QOL or the lessening discrepancy between patient/nurse assessment of QOL. Qualitative data, however, enabled an understanding and explanation of what underlay such changes.

Notwithstanding the above limitations, the study yielded much useful and illuminating data on QOL in the terminally ill and how this can be improved. In particular this collection of comprehensive data was facilitated by using a triangulated approach.

## **Triangulation**

A more complete revelation of the research results was possible through the varying methodologies used in the research process. There were challenges, however, in balancing the strengths and limitations of a triangulated approach, particularly in the area of method triangulation. These challenges are outlined in more detail.

### **Method triangulation**

Patient quantitative and qualitative data were collected separately, i.e. the interview took place after completion of the second questionnaire. This avoided contamination of the variable being measured (the effect of joint care planning on patients' QOL) and yet allowed an in depth understanding of the factors effecting any QOL change. It was then possible to confirm the value of the intervention through social validation, and describe and interpret the patients' experiences.

Although the same separate approach was used for nursing participants (nurses were interviewed on the conclusion of quantitative data gathering), the use of the same questionnaire for subsequent patients meant nurses took the "learning" from previous patient experience to the next patient. This led to an accumulation of experience in using the research process and understanding of QOL issues. Although the study was too small to statistically identify improvements in patient/nurse QOL assessment over time, qualitative data supports this interpretation. Thus the effectiveness of the intervention in improving patients' QOL may well have differed between the beginning and latter stages of the study as nurses developed their assessment and implementation skills. This "learning" was facilitated by discussion with colleagues and the researcher on the reasons for anomalies in QOL assessment and appropriate interventions to promote QOL. An element of social action research was therefore evident, modifying the intervention variable rather than controlling it as is considered necessary in purely quantitative research. However, the interaction between the researcher and participant nurses promoted discovery of shared meaning and new knowledge, thus capturing the on-going research experience of the nurse. The combined methods thus yielded a more complete picture of how improvement in nurse/patient understanding was being accomplished.

Maintaining the control group as an uncontaminated baseline against which to measure any improvement in the intervention group was also difficult. As in other studies (Cohen & Mount, 1992; Greisinger, Lorimor, Aday, Winn & Baile, 1997; Turner, Payne, Jarrette & Hiller, 1998), the effect of completing the questionnaire, with the assistance of the researcher, actually became a therapeutic intervention in itself for many patients in the control group. Sometimes the questionnaire itself was a catalyst for change, at other times it provided a vehicle for the discussion of issues important to the patient. Occasionally, when patients showed evident distress there was a moral imperative for the researcher to instigate follow-up by a member of the multi-disciplinary team, e.g. nurse,



physiotherapist, spiritual care, or occupational therapist (Beaver, Luker, & Woods, 1999). This type of intervention has also been found necessary in other studies (Greisinger et al.). Thus the positive change in control group QOL scores, arising from such interventions, may have reduced the disparity between the QOL of the control and intervention group. This positive change in control group scores would have reduced the statistical impact on QOL of joint care planning in the intervention group.

Overall, the combined quantitative and qualitative methods used succeeded in providing both a convergent assessment of QOL (validating the accuracy of the MVQOLI in within-subject assessment of QOL) and a more complete picture of differing assumptions in what causes QOL changes (describing and interpreting patient and nurses' experience).

### **Data and analytical triangulation**

The use of data and analytical triangulation validated the qualitative material obtained, thus increasing the quality of this study. Interview and observational material were checked for consistency as was the reliability of the information given over time. Nurses were able to check and confirm the validity of their data and the framework within which the data was analysed and presented.

### **Theoretical triangulation**

Theory and method triangulation was used not to prove or disprove competing theories but to reveal the complexities of QOL evaluation, factors affecting nurses' ability to accurately assess patients' QOL, and how reflective practice can be encouraged to promote prudence and advanced palliative care nursing skills.

These findings can be summarised as follows:

- \* QOL is a complex, unique concept which means different things to different patients.
- \* QOL assessments provide a snapshot of patients' QOL at a particular point in time.
- \* QOL assessments provide useful information to both patient and nurse.
- \* Quantitatively measured QOL changes are not, when used alone, an appropriate outcome measure of an intervention.
- \* QOL assessments need both a quantitative and qualitative dimension to be fully understood.
- \* Nurses and patients differ in their assessments of patients' QOL.
- \* Nurses' ability to accurately assess patients' QOL can be compromised through time and contact constraints, the level of personal and professional wisdom, and the personality of both nurse and patient.

- \* Changes in QOL can occur in various ways, the most significant agent in changing patients' QOL is response shift, i.e. a change in how QOL is measured or a reconceptualisation by the patient of what constitutes QOL.
- \* Understanding between patient and nurse can be increased by sharing patients' QOL assessments. This shared understanding leads to new nursing strategies which help to improve patients' QOL.
- \* Feedback on patients' QOL, and the ability of the nurse to assess this QOL, promotes reflective practice in nurses at a personal and team level.
- \* Nurses demonstrated changes in behaviour (improved palliative care nursing skills) as a result of reflective practice.

## **Conclusion**

QOL measurement is a useful way of enabling both patient and nurse to understand the patient's current state of 'being'. For varying reasons nurses are not always able to ascertain the patient's perspective without patient-reported QOL data. When such data are used as the basis of therapeutic dialogues, nursing interventions which reflect patient priorities can lead to improved QOL. In addition, access to the patients' view of their world can promote reflective practice in nurses and assist them in developing assessment and intervention skills which result in improved palliative care nursing. However, although a valuable instrument for improving individual care, QOL measurement is not a suitable outcome measure for auditing hospice care or interventions because all the domains measured and factors influencing patients' QOL are not necessarily under the control of the hospice (Teno, Byock & Field, 1999).

What effective actions to help improve terminally ill patients' QOL can be suggested as a result of the above findings? These may be summarised as: creating receptivity in the nurse for personal and professional growth; development of QOL awareness and nursing assessment skills; routine patient QOL measurement to be used as the basis of care planning priorities; and, promotion of reflective practice that leads to behaviour changes in nurses which reflect advanced palliative care nursing. A necessary precondition for promoting QOL through such changes is an organisational context which encourages personal and professional growth, provides skilled teaching in QOL issues and reflective practice, and where staffing levels allow time for effective palliative care. Such an organisational context could be developed by adopting the range of recommended interventions presented in the following section.

## **Recommendations**

### **Creating receptivity for personal and professional growth**

The philosophy and practice of palliative care is based on an holistic understanding of life, acceptance of the individual's interpretation of meaning, and the goal of providing the best possible QOL. When these attitudes and goals are evident between colleagues and within organisations, nurses are able and willing to evaluate their own practice and take self-responsibility for on-going personal and professional development. Acceptance, affirmation and a willingness to do things differently are as necessary for practitioners of palliative care as they are for the patients they care for. The philosophy of palliative care thus needs to be practised throughout the multi-disciplinary hospice team for on-going receptivity to evaluation and development of practice to occur.

### **Development of QOL awareness and assessment skills**

Nurses' awareness of and sensitivity to the practical implications of QOL issues could be heightened by including teaching on the QOL concept and QOL assessment in orientation programmes for new staff and subsequent education modules. The emphasis on physical elements, easier to assess and address, would then be replaced by an awareness of the need to be 'with' the patient in order to understand the meaning of the psychological, social, and spiritual issues which are likely to be of more importance to the QOL of the patient (James & Macleod, 1993). The theoretical understanding of QOL and QOL assessment could then be demonstrated in clinical practice during orientation, by observing a skilled palliative care nurse interviewing a new admission. Such role modelling would provide an example of how QOL assessment can be achieved early in the patient's stay and incorporated into the patient's care plan.

### **Routine patient QOL assessment**

As has already been established, the information gathered from formal evaluation (questionnaire) of a patient's QOL can make a considerable contribution to effective care and the patient's satisfaction with that care. In some cases patients also find answering a QOL questionnaire less threatening than discussing QOL issues with staff, particularly early in their admission. It is therefore recommended that a QOL questionnaire be made available, on admission, to every suitable hospice patient. Answering such a questionnaire would be voluntary. The patient would understand that their QOL results would be used as a basis for discussion with the multi-disciplinary team to maximise the patient's QOL while under the care of the hospice. Where patients did not wish to or were unable to complete a questionnaire, an alternative assessment could be completed by the admitting nurse. This process mean that, while a self-assessment of the patient's QOL would not always be available, it would ensure that all dimensions of their life were actively considered as part of their care plan, and the patient's priorities were reflected (as far as possible) in care interventions.

### **Promotion of reflective practice**

Actively promoting reflective practice will increase nurses' skill in the social, psychological and spiritual areas, so important in providing total care for the terminally ill patient. Although the importance of reflective practice is acknowledged and the art promoted in palliative care education modules, there is a danger that reflective practice is merely kept for assignments. It can then be seen as an optional theoretical endeavour rather than a way of developing phronesis (an integral part of advanced palliative care nursing practice), and practice development. Reflective practice thus needs to be seen as a normal component of the clinical day. As discussed in chapters two and six, such an approach entails a conscious commitment to developing reflective practices on the clinical floor. In particular, it requires a trained and skilled staff member (mentor) and a safe place to discuss the complexities and dilemmas of reflective thinking and application of the resultant insights.

Individual awareness of unease or 'gaps' in a clinical situation has been identified as the first step in the reflective process. Feedback on differences in QOL assessment can promote awareness of such gaps. It is suggested that nurses routinely formulate their own picture of their patients' QOL, as part of their daily patient assessment, and implicitly compare this perspective with that of the patient. Revealed differences (or similarities) can then be subjected to critical analysis during the duty and explicitly discussed with the mentor and/or other colleagues at hand over meetings. Discovering meaning and understanding could then lead to a new perspective and new behaviours not only in the nurse concerned but also in other team members. Both personal and professional development can then occur.

Practice development within the wider hospice setting can also be promoted by using open reflective practice. Shared reflective practice can enable nurses to scrutinise not only their own caring but also to review challenging or difficult aspects of practice, service delivery, or specific care problems that are occurring in their hospice environment (Corner, 1999). Through identifying common experience a collective voice could be created to address issues which detract from meeting patient needs. This gathering of evidence and collective expression of concern is likely to be a prerequisite for team and organisational change.

A model of advanced nursing practice in on-going terminally ill patient care illustrates the significant elements outlined in the above recommendations (see Fig.9). The first requirement is for an organisational context which encourages personal and professional growth, provides skilled teaching in reflective practice and maintains staffing levels which allow for the quality time necessary to deliver holistic care. Within this context palliative care nurses must then be receptive to personal and professional growth and already have begun to develop practical wisdom from life and nursing experiences. Nurse phronesis is thus a prerequisite for the delivery of effective palliative care nursing. The model then portrays the need for a combination of subjective and objective data which are reflected on

by the nurse. Data and reflection then lead to patient centred care plans based on patient QOL needs and priorities. Consulting relevant journal articles and open reflective discussions with a mentor and/or colleagues help analysis and the adoption of new interventions or behaviours that enhance hospice patient care. Such information gathering, analysis and reflection are not merely carried out on patient admission but are part of on-going patient assessment and professional practice. In short, the reflective process involves continuous re-assessment and interactive review of the patient's QOL. The care given thus reflects the changing needs of the patient not merely from day to day but, if necessary, from hour to hour.

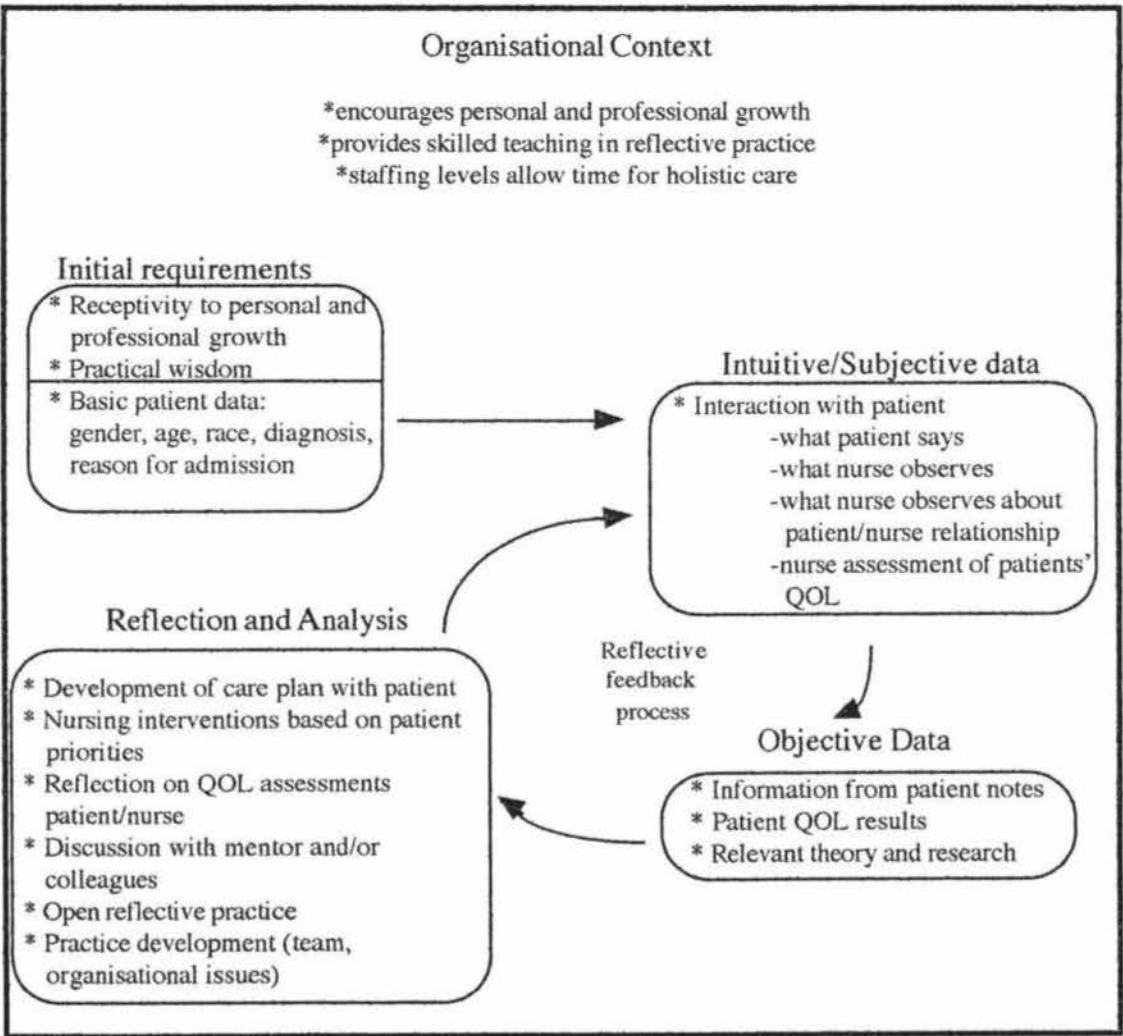


Fig. 9. Advanced Palliative Care Nursing Practice

**Organisational context**

The importance of a supportive, proactive environment which reflects the palliative care philosophy in attitudes to staff as well as patients has already been noted. The study revealed a Hospice context which, in their opinion, detracted from the nurses' ability to



provide the multi-dimensional care expected in advanced palliative care nursing. The most significant negative factor identified was a lack of quality time. Such lack of time not only restricts 'being with' patients, it also limits open reflective practice, essential to the development of personal and professional palliative care skills. Hand over meetings are limited to discussion on practical essentials instead of being a forum for reflective practice that will enhance the care given to terminally ill patients.

The pressures on nurses to do more in less time are universal and apply equally to palliative care services. These pressures are a reflection of the health services environment within which hospices operate. Indeed, the increasing absorption of palliative care into the general medical services is a compelling example of such pressure. Providing the extra staff to both reduce workloads and promote reflective practice will add to the financial difficulties already being experienced by the hospice movement. Addressing the funding and accountability arrangements of hospices is beyond the scope of this study. The data gathered, however, confirm the increasing threat to the pioneering philosophy of palliative care. These dangers are threefold: increasing financial constraints relative to patient demand; educating specialist staff who are then time-compromised in their ability to deliver advanced palliative care; and, failure to provide an environment which seeks to continually improve patient care through reflective practice. All these issues potentially compromise palliative care's goal of the best possible QOL for patients and their families. Palliative care nurses need to develop a collective voice, based on evidence, to express their concerns. This will then aid organisations in presenting a more compelling case for the level of funding consistent with the goals of palliative care.

### **Future research**

Further studies are required to find a reliable, practical, and meaningful outcome measure that can be used to audit the effect of interventions on terminally ill patients' QOL. Such an instrument could enable comparative studies of different interventions on care, promote challenge of the status quo, and provide justification for health care spending.

Studies which examine the effect of nurses' personality on their ability to assess patient QOL and deliver patient-centred care, would also contribute to an understanding of advanced nursing practice in palliative care.

### **Research in the study Hospice**

Although nurses participating in this study demonstrated increased reflective practice and the application of new knowledge (related to QOL) in their on-going patient care, such behavioural change will need reinforcing if it is to persist and be further developed. An action research project flowing on from the present study and involving all nursing staff

could address how the results of the study can be incorporated into improved patient care. In particular, such a project would need to cover how QOL assessment can best be achieved; what organisational change is needed to enhance patient care; and, how reflective practice can be perpetuated and further developed through a culture of receptivity and active support.

## **Concluding statement**

The concept of QOL is inherent in all palliative care. To improve our care we need to understand what each patient's perception of QOL is. When we achieve this insight, we are able to give "total freedom to others to make their own way into meaning." (Cicely Saunders quoted in Kasternbaum, 1998). Insight will call for sensitivity to differing individual orientations and life experiences. Patients for whom social, emotional and spiritual issues are significant as they journey to death, can then be given the opportunity to share their needs and receive an appropriate response. For those whose life has had little introspection and regard such issues as irrelevant, nurses can confine 'holistic care' to what is meaningful for these patients.

Most nurses do not inherently recognise their patients' perception of their QOL. This lack of patient/nurse congruence is unlikely to be recognised without some definitive measure which provides the patient with an opportunity to reveal their thoughts and feelings. Such a measure has the potential to heighten both the patient's and nurse's awareness of the patient's strengths, challenges, and priorities in a timely, cost-effective manner. This increased patient awareness will then provide the basis for appropriate interventions which can improve patients' QOL.

Nurses can increase their skill in assessing patients' QOL and achieving appropriate responses. For nurses to develop these advanced palliative care skills they need assistance in developing and continuing reflective practice, an environment which supports personal and professional development, and time to spend 'being with' patients. It is important for specialist palliative care to retain its distinctive philosophy and values. Education and equipping of staff is crucial in maintaining and improving standards, providing care that is patient and cost effective, and demonstrating that hospice care achieves the best possible QOL for patients. Teaching about QOL issues, providing clinical support for reflective practice, and achieving staffing levels appropriate to the level and diversity of patient demands, will help provide a professional and organisational environment conducive to enhancing nurses' abilities to give practical expression to the philosophy of palliative care.

This study succeeded in demonstrating that QOL means different things to different people. It showed that when patients and nurses are exposed to QOL measurement, increased understanding can lead to clinically significant improvements in patients' QOL and the nurses' ability to assess this QOL. This alignment of care with the needs of the patient is facilitated and sustained by continuous professional development through reflective practice.

The study used a variety of research approaches to better understand the complex issues addressed. These theoretical frameworks and methods have been clearly described. Quantitative and qualitative data were presented separately from the discussion to enable the reader to assess the relationship between the evidence and the interpretation. The unifying theme that emerged from patient and nurse data was that of 'revelation'. It is important that such revelation continues to be encouraged. Continuous revelation can be achieved by on-going research, "the more the better, *with the patient*" (Nell, a participating patient, 2000). To be effective, however, the insights from such research need to be incorporated into both patient and nurse routines, formally on admission and informally each day thereafter. Only then will we succeed in improving terminally ill patients' QOL through practising advanced nursing care.

Palliative care is under threat of assimilation into mainstream medical practice as fiscal constraints are imposed by the current health services environment. If optimal QOL for the terminally ill is to continue as the goal of palliative care, the hospice movement needs to demonstrate its unique capacity to deliver this goal. Improved QOL is dependent upon an educated, reflective, skilled workforce. To secure the positive outcomes which the pioneering philosophy of the palliative care movement sought to achieve, it must be a workforce who demonstrate the philosophy in their interactions with their patients, patients' families, and each other. When these conditions are met, the collective voice of hospice workers and those who benefit from hospice care can validate the philosophy of palliative care and call for the financial support necessary to underpin this care.

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## APPENDIX A

MVQOLI - 25 item version

Patient: \_\_\_\_\_

### MISSOULA-VITAS QUALITY OF LIFE INDEX™ VERSION-25S

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#### INSTRUCTIONS:

Indicate the extent to which you agree or disagree with the following statements by filling in one of the circles below the question. For items with two statements, indicate agreements with one or the other or if they are equally true, choose "Neutral". If you make a mistake or change your mind, place an X through the wrong answer and mark the circle indicating your correct answer. Your mark should look like this -- ●.

#### GLOBAL

How would you rate your overall quality of life?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worst Possible	Poor	Fair	Good	Best Possible

#### SYMPTOM

1. My symptoms are adequately controlled.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree Strongly	Agree	Neutral	Disagree	Disagree Strongly

2. I feel sick all the time.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree Strongly	Agree	Neutral	Disagree	Disagree Strongly

3. I accept my symptoms as a fact of life.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree Strongly	Agree	Neutral	Disagree	Disagree Strongly

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4. I am satisfied with the current control of my symptoms.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

5. Despite physical discomfort, in general I can enjoy my days.

☐  
Agree  
Strongly

☐  
Agree

OR  
☐  
Neutral

Physical discomfort overshadows any opportunity for enjoyment.

☐  
Agree

☐  
Agree  
Strongly

## FUNCTION

6. I am still able to attend to most of my personal needs by myself.

☐  
Agree  
Strongly

☐  
Agree

OR  
☐  
Neutral

I am dependent on others for personal care.

☐  
Agree

☐  
Agree  
Strongly

7. I am still able to do many of the things I like to do.

☐  
Agree  
Strongly

☐  
Agree

OR  
☐  
Neutral

I am no longer able to do many of the things I like to do.

☐  
Agree

☐  
Agree  
Strongly

8. I am satisfied with my ability to take care of my basic needs.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

9. I accept the fact that I can not do many of the things that I used to do. OR I am disappointed that I can not do many of the things that I used to do.
- ☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Agree      ☐ Agree Strongly

10. My contentment with life depends upon being active and being independent in my personal care.
- ☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree Strongly

## **INTERPERSONAL**

11. I have recently been able to say important things to the people close to me.
- ☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree Strongly

12. I feel closer to others in my life now than I did before my illness. OR I feel increasingly distant from others in my life.
- ☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Agree      ☐ Agree Strongly

13. In general, these days I am satisfied with relationships with family and friends.
- ☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree Strongly



14. At present, I spend as much time as I want to with family and friends.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

15. It is important to me to have close personal relationships.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

### **WELL-BEING**

16. My affairs are in order;  
I could die today with  
a clear mind.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

OR

My affairs are not in order;  
I am worried that many  
things are unresolved.

☐  
Agree

☐  
Agree  
Strongly

17. I feel generally at peace  
and prepared to leave  
this life.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

OR

I am unsettled and  
unprepared to leave this  
life.

☐  
Agree

☐  
Agree  
Strongly

18. I am more satisfied with myself as a person now than I was before my illness.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

19. The longer I am ill,  
the more I worry about  
things "getting out  
of control".

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

The longer I am ill, the more  
comfortable I am with the  
idea of "letting go".

☐  
Agree

☐  
Agree  
Strongly

20. It is important to me to be at peace with myself.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

## TRANSCENDENT

21. I have a greater sense  
of connection to all  
things now than I did  
before my illness.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

OR

I feel more disconnected  
from all things now than  
I did before my illness.

☐  
Agree

☐  
Agree  
Strongly

22. I have a better sense  
of meaning in my life  
now than I have had  
in the past.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

OR

I have less of a sense of  
meaning in my life now  
than I have had in the past.

☐  
Agree

☐  
Agree  
Strongly

23. As the end of my life approaches, I am comfortable with the thought of my own death. OR As the end of my life approaches, I am uneasy with the thought of my own death.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Agree

☐  
Agree  
Strongly

24. Life has become more precious to me; every day is a gift. OR Life has lost all value for me; every day is a burden.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Agree

☐  
Agree  
Strongly

25. It is important to me to feel that my life has meaning.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

Did you complete this questionnaire by yourself?

☐ YES

☐ NO

## **Appendix B**

### **Information Sheet (Nurses)**

#### **The use of Quality of Life Assessments by nurses and terminally ill patients in planning care**

##### **Introduction**

Between June and December 1999 the researcher is taking leave to undertake a Quality of Life research study at Mary Potter Hospice. Using the Missoula-VITAS quality of life index (MVQOLI), this study seeks to determine the usefulness of a QOL assessment in planning patient care and compare the ratings of quality of life (QOL) of terminally ill patients made by patients and their nurses. The MVQOLI assessment will identify areas of patient distress, satisfaction and strength and distinguish differences between your patient's and your own perceptions of their QOL. Using the patient's assessment, you and your patient will then work together to devise a care plan and strategies that will address the areas of difficulty. Any change in the patient's QOL and your ability to assess this will be measured in a QOL retest, 7-10 days after the interventions are initiated.

You will have two days (or longer if needed) to decide if you wish to take part.

##### **About the study**

- Aims:**
1. To identify if the patient/nurse care planning process, based on QOL assessment, results in improved patient care and consequent improved QOL.
  2. To determine whether the patient/nurse planning process improves nurses' assessment skills in recognising patient's quality of life status, i.e. understanding between nurse-patient.

##### **Participants:**

**Nurses:** Over the period June to December 1999, Mary Potter Hospice registered nurses, who have worked in the hospice field for at least a year, will be invited to participate. Nurses within this category, who care for the patient for at least 2 days prior to the initial QOL assessment, will be eligible for inclusion in the study.

**Patients:** All patients admitted to Mary Potter Hospice over a six month period will be eligible to participate unless they:

1. are unable to understand and communicate in English;
2. are confused or disorientated;
3. are experiencing psychological symptoms that, in the opinion of the hospice staff, might be exacerbated by completing the index;
4. are experiencing symptom therapy that may limit their ability to provide informed consent;
5. are near death.

It is hoped 10 nurses and approximately 100 patients will be willing to participate, i.e. 10 patients per nurse over the 6 month period.

This is a two-stage study. In stage 1 the first five patients for each nurse will comprise a non-intervention group where the MVQOLI is administered to the patient only and is not used as the basis for joint construction of the care plan, (approximately 3 months). In stage 2 each nurse will work with a further five patients using the MVQOLI as the basis for joint development of the care plan and to compare patient/nurse assessments. i.e.

#### Stage 1 (non-intervention group)

1. Administration of the MVQOLI to the patient only, 2-3 and 7-10 days after admission.
2. Interviews, using a semi structured format, with a sample of patients (1 from each nurse's group of 5) to explore why they have experienced any change in their QOL over their period of care.

Following completion of stage 1, a training session on how to use the MVQOLI, including how to identify significant patient/nurse assessment differences, will be given to the participating nurses.

#### Stage 2

1. Administration of the MVQOLI to patients and nurses 2-3 days after patient admission.
2. Nurse receives own and patient's QOL assessment to identify differences in perception.
3. Nurse uses patient's QOL assessment to draw up a care plan, jointly with each patient.
4. Reassessment of MVQOLI for both patients and nurses 7-10 days after first assessment.
6. Interviews, using a semi structured format, with a sample of patients (1 from each nurse's group of 5) to explore why they have experienced any change in their QOL over their period of care.

### **Benefits and risks**

The benefits to you of being in the study are that you may develop a clearer understanding of your patient's physical, psychological and social needs through viewing their QOL assessment. Areas of dissatisfaction, distress and personal strength should be revealed to facilitate the drawing up of an appropriate care plan. It is hoped that this will enhance nurses' ability to give patient-focused palliative care that meets patient's perceived needs. This process should both enhance their QOL and your job satisfaction. The confidential opportunity to impartially evaluate your patient assessment skills and evaluate intervention outcomes is intended to promote reflective practice in a way which can lead to shared professional wisdom.

By arrangement any additional work time that is needed for the study may be added on to your time sheet and will be paid for by Mary Potter Hospice.

A possible risk to nurses participating is that they may be challenged psychologically if their perceived skill in patient assessment is not confirmed by congruent patient/nurse QOL scores. Your normal supervision will enable you to discuss any personal or professional issues that arise with an independent counsellor outside the hospice.

You may also find some patients easier to assess than others because of their personality or background. It is anticipated that by working with 5 patient participants during the intervention (stage 2) study period, you will have sufficient numbers to obtain a balanced assessment of your ability to evaluate patients' QOL.



## **Participation**

- \* Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part this will not affect your employment.**
- \* If you do agree to take part you are free to withdraw from the study at any time without having to give a reason and this will in no way affect your employment.**


## **Confidentiality**

No material which could personally identify you will be used in any reports of this study. All questionnaire results and electronic files will be protected by password or kept in locked cupboards. On completion of the study and academic requirements all data will be wiped or destroyed.

You can ask for informal feedback on the study from the researcher at any time. There will be regular updates at staff meetings. The research results will be presented to the Clinical Committee at Mary Potter Hospice and to the entire hospice team. Two journal articles will be written in conjunction with the main supervisor. The thesis and journal articles will be available to staff in the Mary Potter Hospice library.

Where possible, a brief synopsis of results will be available to interested patients and/or their families.

This study has received ethical approval from the Wellington Ethics Committee and the Directorate of Mary Potter Hospice.

Researcher:	Nita Hill,	Registered Nurse, Master of Arts (Nursing) student, School of Health Sciences, Massey University
	Home Address:	
Supervisors:	Martin Woods,	School of Health Sciences, Massey University Phone: (06) 350 4325
	Fiona Alpass,	School of Health Sciences, Massey University Phone: (06) 350 4325

**Please feel free to contact the researcher if you have any questions about this study**

## **APPENDIX C**

### **Nurses Consent Form**

**1. Project Title:**

### **The use of Quality of Life Assessments by nurses and terminally ill patients in planning care**

**2. Researcher:**

Nita Hill, Registered Nurse, Masters student Massey University

**3. Aims of the study:**

1. To identify if the patient/nurse care planning process, based on QOL assessment, results in improved patient care and consequent improved QOL as assessed by the patient.
2. To determine whether the patient/nurse planning process improves nurses assessment skills in recognising patient's quality of life status i.e. understanding between nurse-patient.

**4. Participants' Consent**

I have read and I understand the information sheet dated May 1999 for volunteers taking part in the study designed to improve patients' quality of life. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my employment.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have any side effects to the study.

I know who to contact if I have any questions about the study.

**5. Statement to be signed in the presence of the researcher and witness:**

I have read the consent form and have had opportunity for discussion with Nita Hill.

I know that I may withdraw from the study at any time and I understand that this withdrawal will not adversely affect my employment.

I understand that this study has been approved by the Central Health Wellington Ethics Committee and if I have any concerns about the study, I may contact Sharron Cole, Chairperson, Ethics Committee Wellington Hospital, Telephone 385 5999 ext 5185

I hereby consent to voluntarily complete two Quality of Life Assessment questionnaires, 7-10 days apart, for each of my stage 2 patients and discuss the patient's initial results with them as a basis for their nursing care plan.

**Signature:**.....(nurse)  
**Date**.....

**Signature:**.....(witness)  
**Date**.....

**Witness name**.....(please print)

I have discussed with .....the aims and procedures involved in this study.

**Signature:**.....(researcher)  
**Date**.....

Researcher: Nita Hill      Ph: 

Research supervisors: Martin Woods  
Ph: (06) 350 4325  
Fiona Alpass  
Ph: (06) 350 4325

Note: A copy of the consent form to be retained by participant.

## **APPENDIX D**

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### **Patients' Information Sheet**

#### **Using a Quality of Life Questionnaire to help plan nursing care**

##### **Introduction**

You are invited to take part in a study that seeks to discover your quality of life (QOL). The study is intended to see if using QOL assessment for patients like you will help improve hospice care services. You have time to consider the study and, if you want to, discuss your participation with family or friends before deciding to take part. The researcher will ask you for your decision tomorrow but you may take longer to decide if you wish.

##### **About the study**

Over the period June 1999 to April 2000 patients in Mary Potter Hospice, who are thought to be well enough, are being invited to join in the study.

One to three days after you have come into the hospice you will be asked to fill in a 16 item questionnaire about your quality of life. This will probably take about 15-20 minutes. The researcher will read out the questions and fill them in for you if you wish. Once your answers are analysed your nurse will discuss the results with you and use them to help plan your care.

Seven to ten days after you first fill in the questionnaire you will be asked fill in the questionnaire again. The researcher may spend some time with you to talk about any changes that have occurred (about 15-30 minutes). With your consent, this interview will be tape recorded.

##### **Benefits and risks**

The benefits to you of being in the study may be that you, or you and your nurse, will be able to see clearly what things are going well for you and what things could be improved.

The risk of being part of the study is that you may find some of the questions ask you to consider parts of your life that you have not previously thought about. This might be painful or distressing. The nurse will help you to cope with this, if you wish, or with your approval, ask the spiritual team or counsellors to visit you.

##### **Participants' rights**

- \* Your participation is entirely voluntary (your choice). You do not have to take part in this study, and if you choose not to take part you will receive the usual care.**

- \* **If you do agree to take part you are free to withdraw from the study at any time without having to give a reason and this will in no way affect the care extended to you by Mary Potter Hospice.**
- \* **You do not have to answer all the questions in the questionnaires and you may stop the interviews at any time.**


### **Confidentiality**

No material which could personally identify you will be used in any reports of this study. All questionnaire results, electronic files, tapes and transcripts will be protected by password or kept in locked cupboards. The researcher will transcribe all tapes. On completion of the study and academic requirements all material will be returned to you, wiped or destroyed. Other nurses who care for you will have access to your results as part of your care plan.

### **Results**

You can ask for informal feedback on the study from your nurse or the researcher at any time. After the study has been written up a brief summary of the study's findings will be available to you or your family by contacting the researcher at Mary Potter Hospice.

This study has received ethical approval from the Wellington Ethics Committee and the Directorate of Mary Potter Hospice.

Researcher:	Nita Hill,	Registered Nurse, Master of Arts (Nursing) student, School of Health Sciences, Massey University
	Address:	
Supervisors:	Martin Woods,	School of Health Sciences, Massey University Phone: (06) 350 4325
	Fiona Alpass,	School of Health Sciences, Massey University Phone: (06) 350 4325

**Please feel free to contact the researcher if you have any questions about this study**



## **APPENDIX E**

### **Patients Consent Form**

1. Project Title:

### **Using a Quality of Life questionnaire to help plan nursing care**

2. Researcher:  
**Nita Hill**, Registered Nurse, Masters student Massey University

3. Aim of the study:

To develop a process to enable nurses to clearly understand the needs of terminally ill patients, leading to the development of careplans aimed at improving patients' quality of life.

4. Participants' Consent:

I have read and I understand the information sheet dated May 1999 for volunteers taking part in the study designed to assess patients' quality of life. I have had the opportunity to discuss this study. I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect the care extended to me by Mary Potter Hospice.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study. I agree that nurses who care for me will have access to my plan of care.

I have had time to consider whether to take part.

I know who to contact if I have any side effects to the study.

I know who to contact if I have any questions about the study.

If I am interviewed by the researcher, I consent to my interviews with the researcher being audio-taped. I understand that I can ask to have the audiotape stopped at any time.

YES/NO

5. Statement to be signed in the presence of the researcher and witness:

I have read the consent form and have had opportunity for discussion with Nita Hill

I know that I may withdraw from the study at any time and I understand that this withdrawal will not adversely affect the care extended to me by Mary Potter Hospice.

I understand that this study has been approved by the Central Health Wellington Ethics Committee and if I have any concerns about the study, I may contact Sharron Cole, Chairperson, Ethics Committee Wellington Hospital, Telephone 385 5999 ext 5185.

I hereby consent to voluntarily complete two Quality of Life Assessment questionnaires, 7-10 days apart at Mary Potter Hospice and, if selected, discuss the results with my nurse as a basis for my nursing care plan. If selected, I am also willing to discuss reasons for any changes in my second Quality of Life Assessment in an interview with the researcher, Nita Hill.

Signature:.....(patient)

Date.....

Signature:.....(witness)      Date.....

Witness name.....(please print)

I have discussed with .....the aims and procedures involved in this study.

Signature:.....(researcher)

Date.....

Researcher: Nita Hill      Ph: 

Research supervisor: Martin Woods  
Ph: (06) 350 4325

Fiona Alpass  
Ph: (06) 350 4325

Note: A copy of the consent form to be retained by participant and a copy placed in the medical file.

## APPENDIX F

**MVQOLI - 15 Item Version** Patient: \_\_\_\_\_

### MISSOULA-VITAS® QUALITY OF LIFE INDEX V - 15

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#### INSTRUCTIONS:

Indicate the extent to which you agree or disagree with the following statements by marking in one of the circles below the question. For items with two statements, indicate agreements with one or the other or if they are equally true, choose "Neutral". If you make a mistake or change your mind, place an X through the wrong answer and mark the circle indicating your correct answer.

Today's Date: \_\_\_\_\_

#### GLOBAL

How would you rate your overall quality of life?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Worst	Poor	Fair	Good	Best
Possible				Possible

#### SYMPTOM

1. I feel sick all the time.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

2. I am satisfied with current control of my symptoms.

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Agree	Agree	Neutral	Disagree	Disagree
Strongly				Strongly

3. Despite physical discomfort, in general I can enjoy my days.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

OR Physical discomfort overshadows any opportunity for enjoyment.

☐  
Agree

☐  
Agree  
Strongly

## **FUNCTION**

4. I am still able to do many of the things I like to do.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

OR

I am no longer able to do many of the things I like to do.

☐  
Agree

☐  
Agree  
Strongly

5. I accept the fact that I can not do many of the things that I used to do.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

OR

I am disappointed that I can not do many of the things that I used to do.

☐  
Agree

☐  
Agree  
Strongly

6. My contentment with life depends upon being active and being independent in my personal care.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

## INTERPERSONAL

7. I have recently been able to say important things to the people close to me.

☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree Strongly

8. At present, I spend as much time as I want to with family and friends.

☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree Strongly

9. It is important to me to have close personal relationships.

☐ Agree Strongly      ☐ Agree      ☐ Neutral      ☐ Disagree      ☐ Disagree Strongly

## WELL-BEING

10. My affairs are in order; I could die today with a clear mind.

☐ Agree Strongly

☐ Agree

☐ Neutral

☐ Agree

☐ Agree Strongly

OR

My affairs are not in order; I am worried that many things are unresolved.

11. I am more satisfied with myself as a person now than I was before my illness.

☐ Agree Strongly

☐ Agree

☐ Neutral

☐ Disagree

☐ Disagree Strongly



12. It is important to me to be at peace with myself.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

### **TRANSCENDENT**

13. I have a better sense of meaning in my life now than I have had in the past.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Agree

☐  
Agree  
Strongly

**OR**

I have less of a sense of meaning in my life now than I have had in the past.

14. Life has become more precious to me; every day is a gift.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Agree

☐  
Agree  
Strongly

**OR**

Life has lost all value for me; every day is a burden.

15. It is important to me to feel that my life has meaning.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

## **APPENDIX G**

**MVQOLI - as used in this study**

# **MISSOULA-VITAS QUALITY OF LIFE INDEX™**

**V - 16**

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### **INSTRUCTIONS:**

Indicate the extent to which you agree or disagree with the following statements by marking a dot in one of the circles below the question. If you make a mistake or change your mind, place an X through the wrong answer and mark the circle indicating your correct answer.

Today's Date: \_\_\_\_\_

1. How would you rate your overall quality of life?

☐  
Worst  
Possible

☐  
Poor

☐  
Fair

☐  
Good

☐  
Best  
Possible

SYMPTOM

2. I feel sick all the time.

- ☐ Agree Strongly
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Disagree Strongly

3. I am satisfied with current control of my symptoms.

- ☐ Agree Strongly
- ☐ Agree
- ☐ Neutral
- ☐ Disagree
- ☐ Disagree Strongly

4. Despite physical discomfort, in general I can enjoy my days.

☐

OR

Physical discomfort overshadows any opportunity for enjoyment.

☐

☐

☐

☐

## FUNCTION

5. I am still able to  
do many of the things  
I like to do.

OR

- I am no longer able to  
do many of the things  
I like to do.

☐ ☐ ☐ ☐ ☐

6. I accept the fact that  
I can not do many of the  
things that I used to do.

OR

- I am disappointed that  
I can not do many of  
the things that I used  
to do.

☐ ☐ ☐ ☐ ☐

7. My contentment with life depends upon being active and being  
independent in my personal care.

☐ ☐ ☐ ☐ ☐  
Agree Strongly Agree Neutral Disagree Disagree Strongly

## INTERPERSONAL

8. I have recently been able to say important things to the people close to me.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

9. At present, I spend as much time as I want to with family and friends.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

10. It is important to me to have close personal relationships.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly



WELL-BEING

11. My affairs are in order;  
I could die today with  
a clear mind.
- OR
- My affairs are not in order;  
I am worried that many  
things are unresolved.

☐

☐

☐

☐

☐

12. I am more satisfied with myself as a person now than I was before my illness.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

13. It is important to me to be at peace with myself.

☐  
Agree  
Strongly

☐  
Agree

☐  
Neutral

☐  
Disagree

☐  
Disagree  
Strongly

**TRANSCENDENT**

14. I have a better sense  
of meaning in my life  
now than I have had in  
the past.

**OR**

I have less of a sense  
of meaning in my life  
now than I have had in  
the past.

☐                      ☐                      ☐                      ☐                      ☐

15. Life has become more  
precious to me; every  
day is a gift.

**OR**

Life has lost all value  
for me; every day is  
a burden.

☐                      ☐                      ☐                      ☐                      ☐

16. It is important to me to feel that my life has meaning.

☐                      ☐                      ☐                      ☐                      ☐  
Agree                      Agree                      Neutral                      Disagree                      Disagree  
Strongly                                                                                     Strongly

Comments (optional)

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## **APPENDIX H**

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### **Nurses' Initial Letter**

20 October 1999

Dear Team and especially

Thank you enormously for your co-operation and support throughout Stage one of our research into "Quality of life in the terminally ill". Your proactive approach has been a wonderful help and your interest marvellous for my morale. Bless you!

Stage one (researching a control group) has been a rather longer process than I had anticipated, just over four months. Because of this, my supervisors have reduced the number of patients in each research group from fifty to thirty. This means we will be able to move on to Stage two on the 1st of November. Hoorah!

You will remember (I hope) that Stage two is the more exciting part. In particular:

- \* You will now have the opportunity to work with the patient, using their questionnaire results, to devise a care plan that will have the potential to increase their quality of life.
- \* By completing a MVQOLI questionnaire on your understanding of the patients' perspective, you will also have the opportunity to check out your assessment skills.
- \* A further completion of the questionnaire some 7 - 10 days after the first will enable you to:
  - assess the effectiveness of the interventions
  - reassess your understanding of the patients' QOL perspective.

It is hoped that these interventions will give you additional insights into how effective/non effective nursing interventions are in improving palliative care. They may also help promote reflective practice.

I will be going over the questionnaire and the use of the results with you next week, probably at the nurses' meeting and individually. There will be time for questions and I would appreciate any suggestions on how we can best work together during this experimental stage. In a very real sense it is actually OUR research, not mine!

I am excited to be doing something that can make a difference and I hope you are too. Please feel free to speak up about anything you don't like or you think could be improved.

Yours in research!

Nita.

## APPENDIX I

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### Nurses' Second Letter

14 February 2000

Dear

We have already completed three and a half months of Stage Two of the Quality of Life research study. Unfortunately, as you are probably aware, there has been a dearth of suitable and willing participants. We have also lost nine patients between questionnaires one and two through deterioration, death or, conversely, early discharge. Only eighteen patients i.e. half of the number required, have been able to answer both questionnaires. Very sad. Thank you for your patience, especially those who have made the effort to complete the first questionnaire only to lose the patient.

At the present rate of recruitment it may take until May to get the 36 patients required. I appreciate that this is much more drawn out than you had anticipated but the actual number of patients per nurse i.e. five, will not change. I hope this is OK with you.

I would like to remind you of the purpose of the study:

#### **Aims:**

1. To identify if the patient/nurse care planning process, based on QOL assessment, results in improved patient care and consequent improved QOL.
2. To determine whether the patient/nurse planning process improves nurses' assessment skills in recognising patient's quality of life status, i.e. understanding between nurse-patient.

and the benefits and risks:

The benefits to you of being in the study are that you may develop a clearer understanding of your patient's physical, psychological and social needs through viewing their QOL assessment. Areas of dissatisfaction, distress and personal strength should be revealed to facilitate the drawing up of an appropriate care plan. It is hoped that this will enhance nurses' ability to give patient-focused palliative care that meets patient's perceived needs. This process should both enhance their QOL and your job satisfaction.

**The confidential opportunity to impartially evaluate your patient assessment skills and evaluate intervention outcomes is intended to promote reflective practice in a way which can lead to shared professional wisdom.**

By arrangement any additional work time that is needed for the study may be added on to your time sheet and will be paid for by Mary Potter Hospice.

**A possible risk to nurses participating is that they may be challenged psychologically if their perceived skill in patient assessment is not confirmed by congruent patient/nurse QOL scores. Your normal supervision will enable you to discuss any personal or professional issues that arise with an independent counsellor outside the hospice.**



You may also find some patients easier to assess than others because of their personality or background. It is anticipated that by working with 5 patient participants during the intervention (stage 2) study period, you will have sufficient numbers to obtain a balanced assessment of your ability to evaluate patients' QOL.

If you are unclear or dissatisfied or unhappy about any part of the study, could you please advise me? I'd really appreciate that. No offence taken! I do hope that you are finding some personal benefits in reflecting on your practice (not always a comfortable thing to do) and in gaining deeper insights into your patient's world view.

## **APPENDIX J**

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### **Respite Patients' Letter**

July 1999

Dear

I am a registered nurse who normally works at Mary Potter Hospice. At present I am undertaking a Masters degree at Massey University. As part of my Masters degree I am trying to discover ways of improving patient care in the Mary Potter Hospice. To contribute to this research, patients are being asked to answer a short questionnaire on their quality of life. The patients answer the questionnaire on admission to the hospice and then again, seven days later.

You are booked to come into the hospice, shortly, for intermittent care. I would be grateful if you could read the enclosed information sheet and decide if you would be prepared to be a participant in the research, i.e. answer the quality of life questionnaire. By sending you the information before you come in, I hope you will have plenty of time to decide whether or not you want to participate.

I will be in the hospice when you are admitted. If you would like to participate, could you please let the nurse admitting you know. I will then come and discuss it with you and, if you agree, give you the questionnaire to answer. It is fine to decide "no". This will in no way affect the care given to you at Mary Potter.

Thank you for taking the time to read this letter. I hope your stay at Mary Potter will be enjoyable.

Yours faithfully,

Nita Hill

## APPENDIX K

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### Nurses' Semi-structured Interview Questions

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1. How have you found using the QOL approach to plan patient care for patients who were part of the study?  
(prompting questions) *Did being in the study change your approach to patient care?*  
*How do you think it changed?*
  2. What did you understand was involved in using the QOL approach to plan care with your patients?
  3. How did you go about planning care with your patients who were part of the study?  
(prompting question) *Were there any problems in carrying out the approach as it was intended by the researcher?*
  4. Did being part of the study make you more aware of how you practice?  
(prompting question) *Could you tell me more about that?*
-

## **APPENDIX L**

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### **Patients' Semi-structured Interview Questions**

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#### **With the selected patients on completion of the 2nd MVQOLI assessment**

1. "Do you agree with this assessment of your quality of life?"
2. If no, "what seems to be different from how you see things?"
3. If the assessment differs from the initial MVQOL completed  
"What do you think accounts for the changes in your ..... ?"  
(category/categories which have changed)

#### **If the patient is sufficiently well**

4. "How effective do you think the questionnaire was in finding out about your quality of life?"
  5. "Do you think some different questions would have been more helpful?"
  6. If so, "have you any suggestions about what questions would be more helpful?"
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## APPENDIX M

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### Nurses Third Letter

14 September 2000

Dear

The thesis writing goes on! Sorry if you feel/think that it seems to be taking inordinately long. It's a shared view.

The attached chapter is a first draft of the qualitative results. ie. all that lovely, lovely material you shared with Helen in your interview and with me informally. Although you have read and verified your transcripts, your material is now integrated with that of the other participating nurses. I have gone through your material (tape and transcript) numerous times and come up with the categories and themes that are evident in the chapter. What it means, of course, is that your quotes are now separated into different areas which I hope are logical and convey your message.

**It is really important to the validity of the research that you agree with how your quotes have been used.** i.e. has defining them and placing them in a certain category actually changed the meaning of what you were saying? I would be really grateful if you could find the time to look through the chapter and check this out. I'd also appreciate any other comments or thoughts or insights! I know it's a lot to ask you to read 29 pages but you could just check out your own material if it seems overwhelming. Please feel free to write all over the document and return it to me by **Tuesday 26 September**, or earlier.

I have used the pseudonym 'Alison' to preserve your confidentiality. If you would like to change the name used please let me know. Provided no-one else wants that name too, I can easily change the text.

I would also like to provide a "thank you" lunch combined with a focus group, probably in the first week in October. A variation on chocolate fish! Belinda has agreed that you would be paid for an hour to attend the focus group meeting. The agenda for the meeting would be to get your feedback on what you want to happen with the research results i.e. what changes would you like to see at MPH both in context and clinical practice. My Massey supervisor would probably attend and we would have an independent facilitator. Would Gaye Robertson be appropriate? It would be at MPH so those on duty can attend. Confidentiality will still be preserved and I would write a short paper, after the focus group, to pass on to management your suggestions arising from the research. If there is a day that week that particularly suits you or doesn't suit you please let me know asap. Phone [REDACTED]

Again many thanks for being prepared to indulge me in this research process. I really hope it will have clinical significance for us as palliative care nurses and enhance the care we provide at Mary Potter.

Arohanui,

Nita