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A shared revelation

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

by

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Abstract

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

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.
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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.

The entire staff of Mary Potter Hospice, from the Director of Palliative Care to the crucial cleaners, gave the research tremendous support. Dr Rod Macleod (Director of Palliative Care) was enthusiastic in granting approval for the study and took an on-going interest in the results. Other staff were always willing to be of assistance. I am particularly indebted to Dr Helen Carter, Research Co-ordinator at the Hospice, who was generous with her time and talent including interviewing the participating nurses at the end of the study. Dr Annabel Dunn was an ever-positive encourager, so important when data was slow in coming in! Gaye Robertson, Education Director, facilitated the focus group and helpfully passed on any articles that looked relevant. The Hospice administration also agreed to pay for any overtime that was needed for the participating nurses to complete the research process, and financed the photocopying of the QOL questionnaires used. This was much appreciated.

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Chapter One

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 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.

1 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.