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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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A thesis submitted in partial fulfilment of the  
requirements for the degree of

Master of Arts in Nursing

Massey University

2001

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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.

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.

Bob, my husband, chief critic, editor, and support person, endured my frequent absences, pre-occupation and poor housekeeping with commendable composure. He made an invaluable contribution to the quality of this work.

Dr Fiona Alpass, my quantitative supervisor, bore with me throughout the developmental and quantitative aspects of the research and contributed her theoretical and practical expertise as well as her patience. Martin Woods, my main supervisor, was unfailingly patient, supportive and the source of many thoughtful ideas. His personal and professional wisdom were greatly valued.

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

Many others contributed helpful suggestions, on-going interest, and supportive prayer. I thank them all. Finally I acknowledge those who gave of their precious time and energy and love: the participating patients and nurses who command my respect, affection and gratitude for how they continue to give of themselves to others, regardless of the personal cost. The appreciation of this, alone, made the study worthwhile.