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LIVING TOWARD DEATH:

the enduring work of terminally ill people

A thesis presented in fulfilment of the requirements for the degree of
Doctor of Philosophy

at Massey University, Albany,

New Zealand

Elizabeth Niven

2001

MASSEY UNIVERSITY



1061681390

Errata

Living toward death: the enduring work of terminally ill people Doctoral thesis of Elizabeth Niven, Massey University, 2001

p 42 Kylma & Vehvilainen-Julkunen (1997) in their meta-analysis of the concept of hope, note that one aspect identified in the articles is the distinction between generalised and particularised hope.

p 85 'nurse' in para 2 line 3 should be 'nurses'.

p 109 para 2 line 1 should read 'Facticity is used by Heidegger . . .'

p110 para 1 line 1 should read 'These ideas suggest . . .'

p127 para 1 line 1 (beneath quote) should read 'Jan portrays herself as someone who is coping well with the dreaded cancer diagnosis and treatment.'

p 130 (in quote) line 4 should read *'They have got so much to deal with when they are dying.'*

p 140 footnote 27 should read Kapanol as sustained release medication.

p 154 final para line 3 delete 'a'

p 157 para 2 line 4 should read '. . . and is answered in chronos'.

p 164 final para line 7 delete 'that'

p 187 final para line 4 should read '. . . as he considers . . .'

p 188 para 1 line 3 alters becomes alter.

P 211 para 2 line 11 Health professionals becomes 'Health professionals' assessment . . .'

p 211 para 2 line 13 delete 'all'.

p 221 para 3 line 7 'is there' should be 'there is'.

p 223 para 2 line 3 insert 'by' between 'used – professionals'.

p 223 para 2 line 5 delete 'who'.

p 226 para 1 line 18 delete 'them'.

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TO WHOM IT MAY CONCERN

This is to state that the research carried out for the Doctoral thesis entitled "LIVING TOWARD DEATH: the enduring work of terminally ill people" was done by Elizabeth Niven in the School of Health Sciences, Massey University, Albany, New Zealand. The thesis material has not been used for any other degree.

Supervisor

Jim Kelly

Date

9. 5. 01

Abstract

This study explores the lived experience of terminally ill people using the personal narratives of patient, kin and nurse. Six sets of patient-kin-nurse form the sample, with data gained via individual interviews. The study is guided by the values of phenomenological philosophy while narrative theory assists data analysis. Interpretation of the data is informed by Anthony Giddens' social constructs relating to modernity and self-identity.

The diagnosis of a terminal illness usually forces major changes in the lives of patients, and often provides time for reflection. Although the experience must be individual it is also part of a common human experience that may be enriched by the knowledge of others who have lived through similar ordeals. Yet the constantly evolving nature of the social and health context suggests that the experience of terminal illness is never static and that fresh understandings of living with a life-threatening illness are always necessary.

The thesis is that living toward death can be seen as the enduring work of the patient. The patient, in response to experience and events of illness, develops a readiness for change via a process of constantly reconstructing his selfhood. Readiness for change allows him to maintain hope during uncertainty, knowing that change is certain and that he has overcome previous challenges. In this way a sense of enduring self is created that is functional for him and his kin as death comes closer. The interrelational nature of living toward death is presented in the notions of negotiating support and handing over, and these aspects also contribute to the patient's evolving selfhood.

The sense of enduring self developed by the patient may contrast with the kin and nurse expectations when they are working towards closure, challenging practitioners to renew their focus on the patient's position and putting aside already acquired assumptions of dying experiences. Similarly the patient's need to negotiate for support and care appears to question the caring actions of kin and nurse, and demands that existing understandings of caring relationships are re-examined. The study shows that the patient's sense of enduring self that develops during his terminal illness has the potential to transcend his death, and that where this happens, both patient and kin approach his death with readiness.

Acknowledgements

This work is dedicated to the participants -- patients, kin, and nurses -- who have shared their journeys with me by agreeing to take part in the study. It is also dedicated to three people whose journey's end I shared as daughter, neighbour and friend – to my father, John Niven (1918 - 1988); to my neighbour, Alma Logan (1916 - 1996); and to my friend, Dorothy Limbrick (1939 - 1999). All these people taught me what it is like to live toward death in grace and serenity.

Ethical approval for this study was gained from the Massey University Human Ethics Committee and from the North Health Ethics Committee.

I acknowledge the support of the Fieldhouse Trust and the Mary Lambie scholarships, without which this study would not have been possible. A grant from the Faculty of Health Science & Technology, UNITEC, provided writing time at the end of the project, and this is acknowledged with gratitude.

I thank my supervisors, Dr Judith Christensen, Dr Philip Culbertson and Dr Julie Boddy for guidance, support and faith. Judith's early work helped clarify the bounds of the study; Philip's encouragement and gentle critique helped develop the scholarly quality of the work; and Julie's firm guidance at the end ensured that the thesis was completed in a discipline specific quality.

I thank my family, particularly my mother, Natalie Niven, who has always encouraged me to continue. The calm assumption of my children, Robert and Katie Sturch, that the work would be completed was confidence building. Various family have supported in their own specific and special ways, and I am grateful for these contributions.

Colleagues and friends have been part of this journey. I have valued the debate and encouragement of our doctoral study group both as group and as individuals. My colleagues at work have kept an interest and belief in the study, and this has been helpful. I thank my colleagues involved in palliative care whose work is the basis for the study, and whose belief in the value of the project was always a stimulus to continue.

Warren Limbrick has offered friendship and critique throughout the project, even at a time when he had to live a journey similar to that of the kin participants. His faith has kept me true to the course.

Always, I give thanks to God for life, for faith, for work.

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