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**A Death of One's Own:
Understanding Dying Well For Patients
Receiving Palliative Care**

A thesis presented in partial fulfilment of the requirements
for the degree of Doctor of Philosophy in Psychology at
Massey University, Palmerston North

Angela Jane McNaught
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It is the thought of doing the best you can today, and making today really count, and being really positive, and then letting it go and doing the same thing again tomorrow.

K.M.

Abstract

This thesis investigates individual differences in understandings of dying well from the perspective of patients receiving palliative care. Dying well has traditionally been researched from the health professional's perspective, and this has produced a relatively uniform understanding. The present research addresses gaps in the literature specifically with respect to addressing the palliative care patients' perspective, and the investigation of individual differences in understandings of dying well.

Q-methodology was used in the present research to develop accounts of dying well. In this approach a number of statements about a construct are sorted onto a response hierarchy, with the resulting data subjected to a weighted average procedure and factor analysed in a by-participant factor analysis. In the present research, interviews were conducted with patients and hospice nurses to develop a series of themes, or statements, about the notion of dying well. Following a number of guidelines, these themes were then reduced to a manageable set of statements for pilot testing on further patients and health professionals. The final set of 40 statements (Q-set) was established for the task of Q-sorting. Forty patients were recruited from Arohanui Hospice, Palmerston North, to carry out the Q-sort. This task involved placing the statements on a quasi-normally distributed response hierarchy from *most important* to *least important*. The resulting Q-sorts were then factor analysed in a by-participant factor analysis, which grouped participants, rather than statements, together on the basis of their correlations. A weighted average procedure was undertaken to produce exemplar Q-sorts for each factor, and these exemplars represent an amalgamation of the similarities between participants. The exemplars were then interpreted in combination with interviews carried out during the Q-sort process.

Four factors, or accounts, of dying well for patients receiving palliative care resulted from this analysis. These were labelled as: religious-oriented, independent-oriented, idealised, and

family-oriented accounts. The placement of the statements in the religious account reflected the relative importance placed upon God and religious faith. In addition, statements reflecting personal control were rated least important. This was in contrast to the next account, independent-oriented, where statements reflecting control and independence were rated as most important. The third account, idealised, indicated a death denying position, and an idealised notion of the dying experience. Family-oriented, the final account, emphasised the importance of family above all else, including superseding the needs of the individual.

Focussing specifically on patients' perspectives has addressed an apparent gap in the literature, and identified an alternative perspective on the notion of dying well. Uncovering four different accounts suggests that there are individual differences in understandings of dying well for patients receiving palliative care. The nature of these differences implies that there is neither total idiosyncrasy nor total uniformity in patients' understandings. This thesis concludes with a discussion of limitations of the present research, possible future directions for research, and a discussion of the potential clinical implications of the findings.

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[Dying]

It's finding a different way to live in the world, that's what it is, and if you can do that, it's not so bad.

S.G.