

Copyright is owned by the Author of the thesis. Permission is given for a copy to be downloaded by an individual for the purpose of research and private study only. The thesis may not be reproduced elsewhere without the permission of the Author.

**An evaluation of QoL-Steps:
Idiographic assessment of quality of life
for patients in palliative care.**

Andrew Jardine

1999

**An evaluation of QoL-Steps:
Idiographic assessment of quality of life
for patients in palliative care.**

**A thesis presented in partial fulfilment
of the requirements for the degree of
Master of Arts
in
Psychology
at Massey University, Palmerston North,
New Zealand**

Andrew Jardine

1999

Abstract

The primary objective of this study was to evaluate an assessment tool that would enable patients in palliative care to communicate their individual quality of life (QoL) concerns. An examination of existing QoL assessment instruments suggested that most were based upon assumptions more appropriate for research on groups of patients. Such assessment can be classified as standard needs measures. While useful for comparing patients at the aggregate level, standard needs approaches to assessing QoL may not be useful in clinical situations. Instead, an idiographic approach to the assessment of QoL was adopted and it is the development of a particular instrument, called QoL-Steps, which forms the basis for this study.

QoL-Steps used a graphical procedure that enabled patients to nominate their important personal aspects of quality of life, rank these aspects in order of importance, and rate the current and ideal levels of each aspect in two different time periods. The data from a sample of 42 out-patients of a hospice programme, highlighted the variability that would be expected from an idiographic approach to the assessment of individual patients.

Results from QoL-Steps suggest that the instrument is a viable tool. QoL-Steps provided a wide range of variability for patients, in terms of content, difference scores, rankings and patterns of change. Importantly, many patients saw QoL-Steps as a means of communicating their unique needs within an individual context.

Acknowledgements

My first thanks go to Arohanui Hospice, and especially the Director of the Hospice, Dr Simon Allan for his assistance and input to this project. Thank you so much to the 42 patients I spoke with in the course of this study. Meeting so many positive people, who were willing to give their time generously in the hope that they could contribute to a project that would benefit others, was a rewarding process in itself. So many patients I spoke with provided such open and honest expressions of their personal and intimate feelings, which in many cases, brought up emotionally painful and sensitive areas of their private lives. I feel honoured to have been allowed into the lives and confidences of so many people.

Of course, my sincere thanks also go to Dr John Spicer, who has been an inspiring supervisor, always able to offer insightful and positive suggestions, and provide necessary encouragement and guidance throughout the research process.

Finally, I would like to thank my family, Samuel and Benjamin and a special thanks to my wife, Jenny who has been and continues to be of great support as both a partner and friend.

Table of Contents

| | Page |
|---|-------------|
| Abstract | ii |
| Acknowledgements | iii |
| Table of Contents | iv |
| List of Tables | vii |
| List of Figures | ix |
| Chapter One: Introduction | 1 |
| Quality of life | 2 |
| Palliative care | 4 |
| The assessment of quality of life in a health setting | 6 |
| The QoL-assessment continuum within a palliative care setting | 8 |
| Nomothetic assessment: the standard needs approach to quality of life | 10 |
| The idiographic approach to quality of life | 12 |
| Comparative criteria: the QoL-assessment continuum | 14 |
| Relevant domains | 15 |
| Indices and group statistics | 20 |
| Weighting of quality of life domains | 21 |
| The need for a reference point within the assessment instrument | 24 |
| The assessment of change | 29 |
| Response shift: assessing change | 30 |

| | Page |
|---|-------------|
| Chapter Two: Method | 38 |
| Procedure | 39 |
| Initial interview | 40 |
| Modifications to the rating scale | 44 |
| Second interview | 45 |
| Modifications to the time interval | 47 |
| Sample | 47 |
| Recruitment | 47 |
| Participants | 48 |
| Ethical considerations | 49 |
| Analytic strategy | 50 |
| Chapter 3: Results | 51 |
| Variety of content and range of aspects | 52 |
| Chapter 4: Weighting of quality of life issues | 69 |
| Current, ideal and difference scores | 72 |
| Changes in current, ideal and difference scores | 77 |
| Alpha and beta change | 80 |
| Gamma change | 85 |
| Chapter 5: Case results | 88 |
| The gap profile – difference scores (Patient A) | 89 |
| Changing aspects – reconceptualisation (Patient A) | 94 |
| The gap profile – difference scores (Patient B) | 96 |
| Changing aspects – reconceptualisation (Patient C) | 99 |

| | Page |
|--|-------------|
| Chapter 6: Discussion | 102 |
| The range of aspects | 103 |
| Indices and group statistics | 106 |
| Weighting of quality of life domains | 107 |
| The need for a reference point | 108 |
| Assessment of change | 110 |
| Alpha and beta change scores | 111 |
| Gamma change | 112 |
| QoL-Steps as an instrument for communication | 114 |
| Future directions | 115 |
| References | 119 |
| Appendices | 126 |
| Appendix A: Checklist of quality of life domains | 127 |
| Appendix B: Information letter to patients | 128 |
| Appendix C: Consent form | 131 |

List of Tables

| | | Page |
|----------|--|------|
| Table 1 | Quality of life scores measured over time | 21 |
| Table 2 | Aspects of concern for patient A | 23 |
| Table 3 | Aspects of concern for patient B | 24 |
| Table 4 | A comparison of change definitions | 32 |
| Table 5 | Patterns of alpha and beta change | 35 |
| Table 6 | QoL-Steps data example | 46 |
| Table 7 | Sample details | 49 |
| Table 8 | Physical wellbeing - symptoms | 55 |
| Table 9 | Physical wellbeing – treatment side-effects | 56 |
| Table 10 | Physical wellbeing – physical health | 56 |
| Table 11 | Daily activities and functions – domestic tasks | 58 |
| Table 12 | Daily activities and functions – work activities | 59 |
| Table 13 | Daily activities and functions – social activities | 60 |
| Table 14 | Daily activities and functions – sports and leisure activities | 61 |
| Table 15 | Psychological wellbeing – emotional health | 62 |
| Table 16 | Psychological wellbeing – concentration and remembering | 63 |
| Table 17 | Family issues – sources of support | 64 |
| Table 18 | Family issues – relationship issues | 64 |
| Table 19 | Family issues – financial issues | 65 |
| Table 20 | Spiritual issues – issues relating to death | 65 |
| Table 21 | Spiritual issues – personal feelings | 65 |
| Table 22 | Future hopes/goals/concerns | 67 |
| Table 23 | Most important QoL issue for each patient | 70 |
| Table 24 | Alpha and beta change | 81 |

| | Page |
|---|-------------|
| Table 25 Important aspects for patient A at T1 | 89 |
| Table 26 Assessments for patient A at T1 | 90 |
| Table 27 Assessments for Patient A at T2 | 91 |
| Table 28 Assessments for Patient A at T3 | 92 |
| Table 29 Important aspects for Patient A at T1 and T2 | 94 |
| Table 30 Important aspects for Patient A at T3 | 95 |
| Table 31 Important aspects for Patient B at T1 | 96 |
| Table 32 Assessment s for Patient B at T1 | 97 |
| Table 33 Assessments for Patient B at T2 | 98 |
| Table 34 Important aspects for Patient C at T1 | 99 |
| Table 35 Important aspects for Patient C at T2 | 100 |

List of Figures

| | | Page |
|-----------|--|-------------|
| Figure 1 | The QoL-assessment continuum | 9 |
| Figure 2 | Version 1 of the steps | 39 |
| Figure 3 | Number of important aspects given | 53 |
| Figure 4 | Frequency distribution for current position (n= 446) | 73 |
| Figure 5 | Frequency distribution for ideal position (n=446) | 74 |
| Figure 6 | Frequency distribution for ideal position (n=323) | 75 |
| Figure 7 | Frequency distribution for ideal position (n=123) | 76 |
| Figure 8 | Frequency distribution for gap (n=446) | 77 |
| Figure 9 | Frequency distribution for magnitude of change for current position (n=186) | 78 |
| Figure 10 | Frequency distribution for magnitude of change for ideal position (n=186) | 79 |
| Figure 11 | Frequency distribution for magnitude of change for difference score (n=186) | 80 |