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

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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.

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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.

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Chapter 1

Introduction

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 evaluation of a particular instrument, called QoL-Steps, which forms the basis of this study.

The key objectives for QoL-Steps was that it would:

1. Enable patients to express in their own terms important aspects of individual and personal QoL.
2. Enable patients to rank these aspects in an order of personal importance.
3. Allow patients to make two assessments for each important aspect they nominated: the first being the patients personal evaluation of where they currently believed themselves to be with respect to an aspect, and the second, to suggest where they would ideally like to be with respect to that aspect.
4. Reflect the gap between reality and expectations for the patient, derived from the difference between the patient's current and ideal positions.
5. Allow for the assessment of change by monitoring the same patient over time.

Importantly, idiographic assessment allows patients to select QoL aspects that are of personal concern, which in turn, form the content of the measure. The assessment of changing needs of individual patients, albeit over a relatively short period of time, was also a key objective of the research.

The research was conducted in cooperation with the Arohanui Hospice, Palmerston North. Interviews were with 42 patients of the Hospice. Arohanui Hospice provides free palliative care to patients in the terminal phase of incurable disease.

This chapter introduces the concept of QoL and outlines issues related to the assessment of QoL within a health setting. A QoL assessment continuum is suggested and it is this framework that provides the basis for contrasting nomothetic versus idiographic approaches to QoL assessment. The chapter concludes with a discussion on the assessment of change, and in particular, the concept of response shift, which is a phenomenon particularly relevant to individuals who are undergoing changes in their health state.

Quality of life

According to Fitzpatrick, Fletcher, Gore, Jones, Spiegelhalter, & Cox (1992) the concept of QoL first appeared in the mid-1950's and represents an attempt to view the individual as comprehensive or holistic. QoL, as a concept, has been approached in many different ways (Schipper, Clinch, & Olweny, 1996). Some perspectives include treating QoL as equivalent to physical well being, other approaches to QoL include spiritual and psychological aspects of life, while still others treat the social, economic and political environment as constituting what QoL might be. The context for this thesis is health-related QoL. In healthcare, QoL is best understood, although not exclusively, in the context of health outcomes (O'Boyle, 1997). While low or unstable income, a lack of freedom, inadequate access to education, poor housing and a perceived low quality environment may adversely affect health, these problems are often distant from a health or medical concern (Guyatt, Jaeschke, Feeny, & Patrick, 1996).

When we consider health outcomes, it would be wrong to take account of only the symptoms of a person. As proposed by Rosenberg (1995) social functioning and psychological well being may be of greater relevance to the individual as well as to society. Each of us, as individuals, has our own set of aspirations and expectations as to what we consider to be an ideal life. QoL, in this sense, may well be a state of mind, reflecting feelings of well-being and other subjective, personal reactions to our own state of health as well as to those non-medical features of life that affect us.

The WHOQoL Group, a working party established by the World Health Organisation (WHO) provided the following definition of QoL:

> Quality of life is defined as the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence and their relationships to salient features of their environment. (Szabo, 1996, p.356).

This definition clearly locates QoL within the context of health, including concepts of physical, mental and social well being. QoL functions as the interface between medicine and research in psychology (Jasmin, 1997). But despite the WHOQoL Group definition, there remains some controversy and a lack of consensus as to how QoL should adequately be defined. QoL is an amorphous construct that is used in different ways in many disciplines (O'Boyle, 1997). As a result, any chosen definition will often depend upon the user and the particular agenda that the user has in mind for the concept. As Slevin, Plant, Lynch, Drinkwater, & Gregory (1988) suggest, what constitutes QoL is a personal and individual question that lends itself to a philosophical rather than a scientific approach. It is not the intention of this thesis to explore the philosophical issues surrounding competing definitions of what

QoL might be. For my research purposes, the concept of QoL will be located in a health setting. In particular, QoL and its assessment will be discussed in the context of palliative care.

Palliative Care

QoL is particularly relevant to people with advanced terminal illness and concern with QoL is at the core of palliative care (O'Boyle, 1996). Palliative care provides the setting for the assessment of QoL in this study.

'Palliative' is a term derived from the Latin 'pallium' which means to 'cloak'. Used in a medical sense, 'palliative care' can be seen as an attempt to 'cloak' the process of an incurable disease. This might mean attempting to mitigate the consequential problems caused by the disease, problems such as physical symptoms, emotional distress, social difficulties or spiritual issues. Morris (1997) cited in Clark & Fallowfield (1986) suggests that a better and more positive etymology replaces the "cloak" with a "shield" metaphor.

> The act of shielding or protecting the patient offers the care giver a more active and possibly even heroic role.... It avoids the pejorative idea of merely covering over or covering up. It implies the need for skill and knowledge...... The shield .... signifies contingency as well as protection, weakness as well as strength..... It is designed to offer a measure of practical security amid circumstances full of risk and uncertainty. It affirms life at a time when life is under threat (Morris, 1997, p.11).

Palliative care has been defined as "the active total care of patients whose disease is not responsive to curative treatment" (Cohen, Mount, Bruera, Provost, Rowe, & Tong, 1997). So while it is not possible to cure the patient of their disease, the purpose of palliative care is to alleviate the consequences of the disease as much as possible. Doyle (1996, p. 2) suggests:

> Palliative care is the relief of pain and suffering, and the restoration of comfort, when cure is impossible or not an objective.

Palliative care often takes place within the context of a hospice. Hospice programmes are directed toward symptom management and the support of persons who are nearing the terminal phase of their illness with the goal of maintaining QoL as that life nears its end (Kane, Klein, Bernstein, Rothenberg, & Wales, 1985). If we take the above view of palliative care, then many of the services offered by a hospice should be seen as restorative in nature. Pain control and the provision of medication to assist with sleeping problems and the suppression of nausea become key concerns. But the majority of "needs" that a patient may have could well focus upon not so much the symptoms as the consequences of their illness. Maintaining the status quo becomes a priority: being able to continue the same level of relationship with spouse and family, maintaining friendships and social activities, being able to carry on with life as it was before cancer. Here the shield metaphor suggested above by Morris (1997) becomes useful. Palliative care should be able to contribute towards protecting that which is important to the patient.

The idea of meaning related to the illness, spiritual requirements, new found purposes in life and feelings of fulfillment, may all be seen as enhancements to the life that the patient has now, as compared to life experienced pre-cancer. Needs in a palliative care sense must be thought of as being much more than just health related. The assumption that health is the only, or indeed the major need priority for patients appears to be unjustified. McGee, O'Boyle, Hickey, O'Malley, & Joyce (1991) suggest that patients are as concerned, or more concerned in many instances, about aspects of their lives other than health. Palliative care, within a hospice setting, should ideally be provided by a multidisciplinary team, including nurses, social workers, physicians, clergy, aides and volunteers (McMillan & Mahon, 1994). So while there is a large emphasis placed on the physical and psychological management of symptoms within palliative care, such care should also address potential issues like financial problems, legal concerns and spiritual needs (McMillan & Mahon, 1994).

The assessment of quality of life in a health setting

Despite the difficulties inherent in defining what QoL might be, the assessment of patient QoL is becoming increasingly important in medicine and the behavioural sciences (see for example, Spilker, 1996a and Bowling 1997). QoL is particularly important and relevant for people with incurable diseases and terminal illnesses. Improving QoL is an important goal of palliative care (see for example Byock & Merriman, 1998, and Cella, 1995).

Typically QoL assessment, within the health context, follows a psychometric approach. Under this approach, the basis for the selection of a particular assessment instrument depends upon how well the instrument performs in a required situation and the psychometric properties of that instrument. Psychometric properties refer to those statistical methods that empirically investigate whether a test measures what is intended (for example, face and content validity) and yields consistent findings over time (for example, test-retest reliability). These methods produce quantitative indices that represent both the amount and type of reliability and validity associated with a test (Ferris & Norton, 1992). There are many QoL assessment instruments available to choose from (see for example Bowling, 1997, for such a discussion) with some measures being disease-specific, while others can be classified as generic, covering a wide range of disease and health-related dimensions.

In contrast to the psychometric QoL tradition, some would suggest that 'quality of life' as a construct is not suited to measurement at all. As Hunt (1997, p. 156) suggests:

> Human beings are reflective self conscious agents who interpret the world and events in a manner which is partly a consequence of social and cultural background and partly idiosyncratic. It is not the presence of symptoms or limitations of function which affect quality of life but rather the meaning and significance of them for individual patients. Thus, patients with an identical health status may experience a range of existential states from despair to happiness.

Above all, QoL is a subjective concept and varies according to the individuals perspective and particular circumstances. The assessment of QoL then becomes more a task of establishing what important aspects exist for the individual and attempting to provide some means by which the person is able to communicate these needs to some other party, whether the results are used for counseling or medical purposes. A key function of an assessment tool for QoL in this context then is the enhancement of communication. QoL in this sense should be able to be assessed from the perspective of the individual patient, so that the patient is able to communicate important and perhaps changing needs to health professionals. In turn, health professionals are able to communicate among themselves as to what individual patient needs might be.

I would suggest that instead of attempting to 'measure' the construct 'quality of life', which suggests that we are able to arrive at an objective result with its concomitant feelings of accuracy and definiteness, we instead use the term 'assessment'. 'Assessment' more closely reflects the estimation process associated with the subjective nature of patients perceptions of what constitutes QoL for them. The Danish philosopher Kierkegaard (1944), (cited in Rosenberg, 1995), argues for the subjective truth which is associated with the "self" and which differs from individual to individual. At best, an assessment instrument can attempt to capture elements of subjective truth for that unique individual - an individual who has unique experiences and expectations. Not all elements of QoL can be easily reduced to objective measurement.

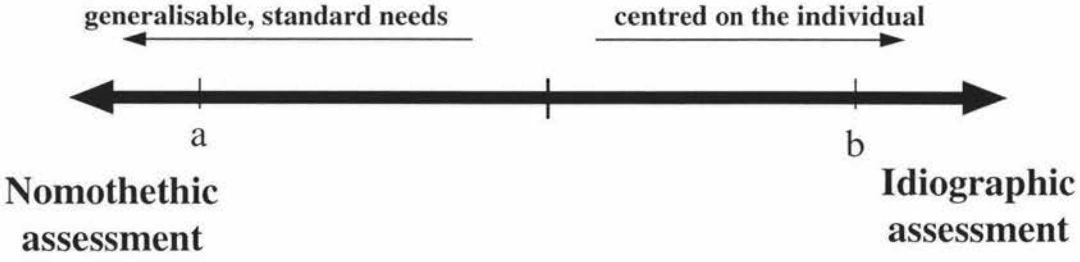
The QoL-assessment continuum within a palliative care setting

There are literally hundreds of instruments used to assess one or more aspects of QoL. Spilker, Simpson, & Tilson (1992) offer a prototype list of 54 specific core instruments. The 1,259 page second edition of *Quality of life and pharmacoeconomics in clinical trials* (Spilker, 1996b) also offers a wide cross-section of instruments that claim to assess QoL. But, as Leventhal & Colman (1997) suggest, investigators may not always be assessing the same thing when they discuss and write about QoL. The European Organisation for Research and Treatment of Cancer (EORTC) has established what is referred to as a continuum for QoL measures (Aaronson, Cull, Kaasa, & Sprangers, 1996). According to Aaronson et al. (1996) this continuum reflects the spectrum of intended applications of various QoL measures. The first category on this continuum can be described as generic instruments. These generic instruments have been designed for both the general population and for a wide range of chronic disease populations. The second category on the continuum is that of disease-specific measures that have been designed especially for use with cancer patients in general. The third category on the continuum includes diagnosis-specific measures that target a particular form of cancer; and finally, the fourth category on the continuum includes ad hoc, study specific measures.

I suggest that the categories listed above, rather than being on a continuum, provide a useful classification system of QoL assessment. Each category, in the order presented, provides a more specific patient population of interest.

The idea of a continuum, however, does provide a useful framework for contrasting two different approaches to assessing QoL: nomothetic versus idiographic assessment. The use of a continuum can be thought of as a matter of degree, where a particular assessment instrument will have elements of one or other of the two approaches. Assessment instruments can therefore be linearly located on the continuum depending upon certain criteria. It is for these reasons that I will use a continuum to compare nomothetic and idiographic assessment. The criteria that I will use to compare the two approaches includes: the relevant domains or content areas for the assessment, group statistics and indices, the weights associated with QoL domains, the need for a reference point within the assessment instrument and finally the assessment of change.

Figure 1 The QoL-assessment continuum



Key:
a: skewed towards nomothethic with idiographic elements
b: skewed towards idiographic with nomothetic elements

At one extreme of the continuum is the nomothetic approach to QoL assessment with modern medicine and its associated general laws concerning biology and behaviour (Rosenberg, 1995). Nomothetic assessment typically leads to the process of categorisation of an individual (Richards & Ramirez, 1997). That is, an individual is categorised according to his or her comparison with group norms. Data are gathered at the level of functional limitation, symptom distress, or global well-being, without fully understanding the meaning that these terms carry for each individual patient (Rapkin, Smith, Dumont, Correa, Palmer, & Cohen, 1994). At the other extreme of the continuum is the idiographic approach. An idiographic approach to QoL maintains that:

> Individuals define life domains in different ways, use different criteria to evaluate the domains, and place differing emphases on their importance to overall life quality. (Browne, McGee, & O'Boyle, 1997, p. 740)

Nomothetic assessment: the standard needs approach to quality of life

The original intention for many of the QoL instruments developed for use in cancer research was to provide a point of comparison for patients undergoing different anti-cancer treatments in randomised clinical trials (Richards & Ramirez, 1997). Assessment that is based upon the standard needs approach aims to describe the circumstances of an individual's life and assign numerical values which indicate the individual's position on a scale assumed to have universal validity (Browne et al., 1997). Thus, QoL instruments developed for research purposes have been typically standardised in order to perform aggregate level analyses. Most of these instruments comprise a fixed number of preselected items that enable comparison between individuals and groups. For example, the European Organisation for Research and Treatment of Cancer (EORTC QLQ- C30) (Aaronson et al., 1996) is a paper-and-pencil questionnaire which consists of 7 dichotomous-response items and 23 Likert-type items. It contains six functional scales: physical, role, emotional, cognitive, and social functioning and a global health status QoL scale. It also contains 9 symptom scales or items: fatigue, nausea and vomiting, pain, dyspnea, sleep disturbance, appetite loss, constipation, and diarrhea and a financial impact item (Broadhead, Robinson, & Atkinson, 1998). The psychometric properties of EORTC QLQ-C30 show adequate reliability and validity with cancer populations (Niezgoda & Pater, 1993).

The standard needs approach is at the extreme nomothetic end of the nomothetic-idiographic continuum. An individual's score on a particular measure is compared to the range of scores across a suitable reference group. Another example of a standard needs approach is the Spitzer Quality of Life Index which was developed in the context of a research project to test the safety and efficacy of a cancer chemotherapy outreach program (Spitzer, Dobson, Hall, & Chesterman, 1981).

As already mentioned, a standardised approach to QoL assessment allows the assessor to categorise the patient in some way. Using a particular assessment tool, it may be possible, for example, to compare the individual patient against a cohort of patients to assess the individual's level of mobility, pain levels and degree of anxiousness in order to assign some quantitative score to these domains. Exploratory factor analysis, such as principle components, is often used to generate QoL scales that literally sum responses to items asking about QoL with questions asking about emotional and cognitive functioning (see for example the Functional Assessment of Cancer Treatment (FACT), (Cella et al., 1993)).

When comparing differences in QoL, it is often convenient to talk about a single meaningful holistic score for QoL and this is what the standard needs approach purports to offer. As Fries & Singh (1996) suggest, the ability for a health status measure of QoL to provide a single number, at a particular point in time, which summarises a cumulative series of health status measurements, is a highly desirable feature of such an instrument. To illustrate, it could be concluded from a clinical study that the QoL for a patient undergoing treatment A was 86, whereas with treatment B, QoL was 93; hence treatment B is preferred (Fries & Singh, 1996). A good example of a measure that yields a single, overall score reflecting the sum of the individual items is the Functional Living Index - Cancer (FLIC), (Schipper, Clinch, McMurray, & Levitt, 1984). Dimensions related to QoL are combined into either a single index or a set of indices that is smaller than the total number of dimensions.

A major advantage associated with nomothetic QoL measures is that they allow for comparison of results across studies of different patient populations. This is particularly relevant if research is primarily interested in larger health policy and resource allocation issues. The purpose of studying the QoL of large populations of patients is to learn what treatments have optimal effects on large groups of patients and to understand the burden of different diseases (Spilker, 1996a). The information gained from such studies can, in turn, be used by government and care decision makers in the allocation of funds to treatments that give the "best" QoL outcomes. Use of QoL instruments for such purposes is not without controversy (see for example Draper, 1997), however the surrounding philosophical issues will not be explored here.

But a major disadvantage of the standard needs approach concerns the ability of such instruments to detect either small, but clinically meaningful, group differences in QoL, or changes in QoL over time (Aaronson et al., 1987). This latter point will be revisited and explored in greater depth as a separate discussion section.

There is also an inherent danger in that by accepting such generic standards, we may be inclined to equate QoL as being primarily related to human functioning in terms of optimal physical ability, the ability to fulfill social roles and maintain certain acceptable psychological levels of 'normality'. As Hunt (1997) suggests, good QoL can be equated with optimal functioning defined within narrow confines of doubtful relevance to patients.

The idiographic approach to quality of life

At the other end of the QoL continuum is the idiographic approach to QoL assessment. In recent years, due in part to the limitations of the nomothetic approach for clinical assessment, there has been a growing interest in idiographic assessment techniques (Browne et al., 1997). Browne et al. (1997) assert that the standard needs model is an inadequate account of the nature of QoL at the individual level. So, in contrast to the standard needs approach, no attempt is made to compare a patient's score with a reference group. An idiographic approach takes account of the individual person and is tailored to that individual's needs: their subjective experience of ill-health, reflected in reported symptoms and subjective accounts of pain, distress and discomfort (O'Boyle, 1997).

In contrast to the nomothetic approach, idiographic assessment seeks to assess the personal goals, problems, concerns, and interests that matter most to a given patient at a given point in time (Rapkin et al., 1994).

According to Draper (1997, p. 51), an idiographic approach "emphasises the analysis of subjective accounts generated by 'getting inside' situations and involving oneself in the flow of everyday life." The concept of QoL refers to a person's degree of satisfaction with certain aspects of his or her life; the individual concerned is in the best position to judge the amount of satisfaction she or he feels (Draper, 1997).

Two idiographic approaches to measuring QoL will be discussed here. Both are based upon the proposal that QoL is what the individual says it is, and that it should therefore be measured by a patient-generated questionnaire with no externally imposed questions and values. The first example of an idiographic approach to QoL is the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) as developed by researchers at the Medical School of the Royal College of Surgeons in Ireland (McGee, O'Boyle, Hickey, O'Malley, & Joyce, 1991); . As stated by (O'Boyle & Waldron, 1997, p. S21) the starting assumptions for the SEIQoL were:

> That quality of life is individual in nature, that a person judges his or her quality of life based on how they are doing in a number of salient areas, that the yardstick against which each of us judges our quality of life is individual

in nature and that only the individual can adequately judge his or her quality of life.

The second example of an idiographic approach to the assessment of QoL is the Patient-Generated Index (PGI) (Ruta, Garratt, Leng, Russell, & MacDonald, 1994), which is based upon a definition of QoL as being: "the extent to which our hopes and ambitions are matched by experience." The aim of the developers of PGI was to produce a self-administered measure that could be used by patients to improve their individual QoL. In order to improve a patient's QoL through medical care the PGI developers believe it is necessary to "narrow the gap between a patient's hopes and expectations and what actually happens" (Ruta et al., 1994).

Two disadvantages of an idiographic approach to QoL assessment are proposed by Schipper, Clinch, & Olweny, (1996). The first disadvantage is that the effects of treatments on specific QoL areas can only be determined for the subset of patients that chose that area. Taken to an extreme level, treatment must be tailored for each patient. The second disadvantage is somewhat related to the first in that individual procedures are very time and resource intensive compared to nomothetic methods of QoL assessment. By its very nature, idiographic assessment means one-on-one procedures and tailor-made solutions for individual patients.

Comparative criteria: the QoL-assessment continuum

It is useful to continue the discussion of a QoL-assessment continuum in order to highlight some important differences in the two extreme end-points: nomothetic at one end of the continuum and idiographic at the other. Some assessment instruments are clearly at one of the extreme end points, while others may be predominantly located under a particular approach but still contain elements of the "competing" approach, hence the idea of the continuum.

Relevant domains

The word "domain" refers to those components of QoL which indicate the physical, functional, social, emotional, spiritual and psychological aspects of daily living (Donnelly & Walsh, 1996; see also Spilker (1996a). The use of nomothetic scales such as the Sickness Impact Profile or the Nottingham Health Profile as measures of QoL implies that QoL means the same to everyone and can be defined in general terms. Even the European Organisation for Research and Treatment of Cancer (EORTC) and the modular approach to QoL assessment in oncology that its developers advocate covers "four basic quality of life domains - physical symptoms, physical and role functioning, psychological functioning, and social functioning (Aaronson et al., 1996). The developers of the EORTC core questionnaire believe that, when compared to other QoL measures, their instrument contains a relatively large number of items assessing disease-related symptoms and treatment-related side effects:

> This was done primarily at the insistence of the clinicians within the study group who argued that physical symptoms are of central concern when assessing the quality of life of cancer patients under active treatment. They also predicted that their clinical colleagues would be more apt to accept the more psychosocially oriented components of the questionnaire if physical symptoms were first adequately addressed (Aaronson et al., 1996 p.182).

Indeed, one of the critical assumptions that the standard needs approach relies upon is that there is a consensus as to what constitutes a good or poor QoL and that this standard is able to be determined through research (Browne et al., 1997). This assumption is highlighted in the above quote from Aaronson et al. (1996) where it is suggested that *physical symptoms* are of central concern. As Browne et al. (1997, p.738) suggest, within the standard needs approach, it is assumed that "needs (as opposed to wants) are the most important determinant of quality of life, and that these needs are common to all and that they are known to the researchers involved in evaluation."

Cella (1992) asserts that the evaluation of QoL should cover key domains such as physical symptoms, physical role and functioning, psychological distress, cognitive function, body image and sexual function. The WHOQOL facet and domain structure covers six separate domains covering 29 different facets (Skevington, Bradshaw, & Saxena, 1999). The McGill Quality of Life Questionnaire (MQOL) (Cohen, Mount, Strobel, & Bui, 1995) specifically assesses general domains of QoL which the developers believe are relevant to all people (physical, psychological, existential and support). The Quality of Well-Being Scale (Anderson, Kaplan, Berry, Bush, & Rumbaut, 1989) is made up of five domains: mortality, mobility, physical activity, social activity and symptoms/problems. In contrast, the Nottingham Health Profile (Hunt, McEwen, & McKenna, 1985) assesses six domains: energy levels, sleep, emotions, pain, mobility and social isolation.

The problem of inter-individual variability for standard needs approaches to QoL means that there is a lack of consensus when it comes to agreeing upon a common taxonomy of domains (Browne et al., 1997). As can be seen, it isn't too difficult to conclude from the above discussion that there might not be *one* taxonomy that suits all individuals. Some domains within the QoL construct may be irrelevant for one individual but may be of critical importance to another. As already stated in the opening section under the heading "Quality of Life", the World Health Organisation (Szabo, 1996, p.356) defined QoL for an individual as the: "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." Acceptance of this definition makes it difficult to believe that there is one universal standard whereby we are able to assess what QoL might be for all people. Improving the quality of a patient's life generally involves attention to some elements that are highly valued ('prized') by us all, and some elements that are highly valued ('prized') to a special degree, by the patient (Cohen, 1982). Difficulties arise in choosing appropriate domains, because life circumstances or personal beliefs may not always match the preselected items. So while generic standard need questionnaire approaches to the measurement of QoL provide important information, they do impose a predetermined value system on the patient. Such information is useful when examining between-subject responses, but not so useful in clinical situations where the individual patient and their within-subject responses may be more important.

QoL, like life itself, is by its very nature a multidimensional construct. The multidimensionality of QoL refers to a broad range of content, including physical, functional, emotional, and social well-being. The standard needs approach, often reduces a measure to one of its individual dimensions. The aggregation of these dimensions through a process of combining means that many generic QoL measures approximate a single index of QoL. This process implies a hierarchy in which the structure is collapsible and yet still meaningful. The Functional Living Index-Cancer (FLIC), (Schipper et al., 1984) is an example of a measure that yields a single, overall score reflecting the sum of the individual items. The downside of aggregating scores in this manner is that the final result might be distorted because it is assumed that there is equivalence across dimensions (Cella, 1994). Feinstein (1997) points out the risks inherent in such statistical reductionism. When psychometric principles are used to prepare an aggregate score of weighted items, Feinstein suggests that face validity is often neglected. Feinstein uses an example of a sign on the outskirts of Sonoma to illustrate this problem:

Founded	1812
Elevation	560
Population	6387
Total	8759

As Feinstein suggests, (p.13) "in the psychometric quest for unidimensionality, the combination and weight of the selected items are chosen by statistical principles."

Thus, it may be possible for a patient to score 8 out of 10 for back pain, and for this score to be added to a score of 3 out of 10 for emotional depression. The two can then be combined (possibly with a weighting procedure) to produce a single number that reflects that particular patient's QoL. In certain circumstances, such a generic approach for comparing groups may well be legitimate. As already stated, the generic class of QoL measures allows for comparisons of results across different patient populations.

An idiographic approach to assessing QoL, because it allows the patient to choose the domains and sub-domains, should be more likely to reflect the multiple dimensions that are important to the individual patient. Different domains may be nominated by the same individuals at different times, and some individuals may ignore domains that, to the observer, might seem important in a particular context (McGee et al., 1991); (O'Boyle, McGee, Hickey, O'Malley, & Joyce, 1992). QoL, in this sense, is what the individual says it is and so the content itself (i.e. what makes that person's life and what aspects are important for him or her) is dependent upon that individual person. There are no externally imposed questions or values. When allowed to nominate their own domains that are important to their QoL, large differences emerge across individuals in terms of domains chosen and the ways that these domains are defined (Browne et al., 1997).

SEIQoL, in the process of a semistructured interview, asks respondents to nominate and describe five domains that they believe are most important to their QoL at that moment. They are asked to rate how good or bad life is in each of the five domains at that time by drawing five corresponding vertical bars which, through a visual analogue scale, range from "worst possible" to "best possible".

The PGI asks patients to list the five most important areas or activities (domains) of their life affected by their medical condition. The patient also rates a sixth domain, which represents all their other areas of life. The measure is designed to be completed only by individuals with an illness or disease.

The distinguishing factor between the nomothetic approach and the idiographic approach, is that the latter allows the patient to decide upon the content and domains that should be included for the assessment of their individual QoL. In contrast, the former has pre-selected domains and content. Many of the scales that can be classified under a nomothetic approach have been developed by assessing the QoL of individuals, but the specific items and response categories do not represent the free choice of the individuals who are subsequently investigated using the measures (O'Boyle, McGee, & Joyce, 1994).

While both SEIQoL and PGI can be classified as idiographic in their approach to QoL assessment, both of these instruments contain elements of the nomothetic approach. Thus in the SEIQoL, patients are constrained to choosing 5 aspects and the scoring system standardises scores so that patients can be compared. Similarly, in the PGI, patients are asked to list the five most important areas or activities of their life affected by their condition, while the sixth domain reflects the rating on all the other areas of life for the patient. This necessity for comparing patients (between-subject analysis) means that the assessment instrument must impose some form of standardisation. In the case of these two assessment instruments, there is an imposed constraint of a fixed number of important aspects. An idiographic approach that is more concerned with the comparison of within-subject analysis (and ignores between-subject comparisons) could be said to be closer to a "pure" idiographic approach. i.e. closer to the idiographic extreme end than either SEIQoL or PGI on the QoL-assessment continuum.

Indices and group statistics

Results of QoL studies are generally presented in the form of sample statistics and provide little or no data on the QoL of individual patients. (Carr-Hill, 1991) proposes that indices, which are commonly found in standard needs approaches to QoL assessment, be treated with caution because often the scores given to scale points are arbitrary in their derivation. Carr-Hill (1991) suggests that considerable effort is often made on the part of the researcher to 'force' individual responses of different illness states onto a single index, either by the choice of procedure used for eliciting responses or by the statistical manipulation of the data. According to Carr-Hill (1991, p.355):

> In extreme cases, the same index value can stand for very different response patterns. If used at all, such methods need a great deal of circumspection and statistical expertise.

Joyce (1997) illustrates the problematic nature of grouped statistics when looking at an individual patient. Table 1 shows hypothetical observations of the QoL of a group of five individuals at baseline and on four successive occasions. While the mean score is 4 each time, it is made up in very different ways and can only make sense when it is looked at individually. As Richards & Ramirez (1997) suggests, numerically equivalent results from separate individuals may have very different clinical meanings.

Table 1 Quality of life scores measured over time (from Joyce, 1997)

	Scores	GP mean	Individual Changes
Pre-treatment	1 3 4 5 7	4 ± 2.2	-
Time A	1 3 4 5 7	4 ± 2.2	5 no changes
Time B	4 4 4 4 4	4 ± 0.0	2 ↓ 2 ↑ 1 no change
Time C	20 0 0 0 0	4 ± 8.0	4 ↓ 1 ↑
Time D	2 4 5 6 3	4 ± 1.6	1 ↓ 4 ↑

The idiographic approach to QoL attempts to focus on the salient aspects for individuals. By contrast, the standard needs approach is used at the group level to make decisions about the value of health interventions. However, as Browne et al. (1997) point out, it is not of much use to learn that on average, the mobility of a sample of patients improved following an intervention, without knowing whether this domain is as important as other domains that over the same period, have got worse. For example, the same degree of nausea in two patients might lead to acute social or daily living disruption in one and little change in the other. This could be because of differences in severity of emotional reaction to nausea, or it could be because of differences in patients' roles such that one can function reasonably well with the nausea while the other cannot (Cella, 1992).

Weighting of quality of life domains

The standard needs approach to QoL typically applies standard weights in relation to the importance of life domains. These weights are usually derived by measuring the preferences of a sample of the population for various QoL states over others and averaging the responses (Browne et al., 1997). Traditional methods for weighting are based on the assumption that there is *one* fixed value assigned to each health state which applies to *all* individuals (Björk & Roos, 1994). In the Nottingham Health Profile, for example, the item "I'm tired all the time" contributes a weight of 39.2

towards the score for the energy domain if answered "yes", whereas the item "I soon run out of energy" only contributes a weight of 24.0 if answered "yes" (Browne et al., 1997). Because the standard needs approach is not as concerned with inter-individual variability, such weighting concerns are not as important.

Proponents of an idiographic approach advocate that, just as it is not possible to assign a generic set of life domains that are equally applicable to each and every individual, it is also not possible to prescribe a generic set of weights that reflect the relative importance of these domains to every individual. In judging QoL, the individual assesses the various aspects of his or her life in the context of their relative personal importance, which cannot be defined without reference to that individual (McGee et al., 1991).

Some standard needs approaches to QoL assessment contain elements of an idiographic approach, and can be located to the right (shown as position *a* on the continuum) of the nomothetic approach. For example, the EuroQoL Instrument (Kind, 1996) allows respondents to use a self-rated visual analog scale to score their personal value for a health state. According to Kind (1996, p. 195), this "value may, or may not, accord with valuations arising from a general population tariff." Similarly, the Quality of Life (QLI) (Padilla, Grant, Ferrell, & Presant, 1996) uses linear analog scales as the basis for respondents to rate their own QoL.

An idiographic approach such as SEIQoL makes use of judgement analysis to quantify the relative importance that respondents attach to each domain they nominate for their QoL. Thus, the SEIQoL allows patients not only to rate their chosen areas, but also to indicate the relative importance of each area using a moveable piechart device. Allowing patients to choose and weight their QoL aspects provides a more individualised assessment.

Similarly, the PGI also uses a weighting system to ascertain the relative importance of patient specified domains. Patients are asked to rate how badly affected they are in each of the domains they select. PGI uses a scale of 0-100, where 0 represents the worst possible state and 100 an ideal state. Individuals are then "given" 60 points which they can "spend" according to how much they would like to improve each of the six domains they have chosen. As with SEIQoL a unitary index may be derived by multiplying domain ratings by weights.

Both SEIQoL and PGI, although at the idiographic end of the QoL-assessment, contain elements of a nomothetic approach (which locates both instruments at position *b* on the QoL-assessment continuum in Figure 1) with each claiming delivery of a global QoL score that allows for comparison between individuals. SEIQoL, for example, determines a composite QoL score which is determined by multiplying the five relevant domains by the perceived weights assigned by individual patients. Theoretical aspects of concern for two different patients along with the associated weights for these aspects are shown in the next two tables:

Table 2 Aspects of concern for Patient A

Patient A					
Aspects	**Levels**		**Weights**	**Sum**	**Global QoL**
Financial issues a concern	10	X	30	300	
Feelings of depression and anger	5	X	25	125	
No confidence to drive my car	15	X	20	300	
Feel of the unknown	10	X	15	150	
Son's having difficulty with my illness	5	X	10	20	
				925	**9.25**

Table 3 Aspects of concern for Patient B

Patient B					
Aspects	**Levels**		**Weights**	**Sum**	**Global QoL**
Feelings of nausea	20	X	20	400	
Posture pain in back	25	X	15	375	
Sleeping problems	35	X	30	1050	
Problems with remembering	30	X	20	600	
Going to the toilet too often	15	X	15	225	
				2650	**26.5**

The two patients whose cases are illustrated in Tables 2 and 3 are different individuals. If we accept a purely idiographic approach to QoL assessment, then a comparison of the above patients global QoL scores is unnecessary. That is, by taking an idiographic approach, it is not possible to conclude that patient A has an inferior QoL standard than patient B just because the global score is lower. Because the individual patient selects the aspects (or domains) as well as the weights for each issue, the aspects themselves are likely to be different, the assigned perceived weights are also likely to be different and the final scores will therefore also be different.

The use of a unitary index for both SEIQoL and PGI in order to compare patients, moves both instruments away from the purely idiographic extreme end of the QoL-assessment continuum.

The need for a reference point within the assessment instrument

The standard needs approach to measuring QoL, while indexing the levels of a patient's QoL, falls short of providing a reference point which can be applied to the individual in any straightforward fashion. As a result, the standard needs approach has limited value in enabling clinical diagnosis and action. QoL is normally expressed indirectly by measuring components of achievement, which may include physical ability, as well as elements of emotional and existential health. But the standard needs approach does not attempt to equate such findings with the aspirations of the patient, and the two are not expressed as an explicit relationship (George, 1997). Many formal definitions of QoL involve a reference point at least implicitly, but measures of QoL render it invisible. For example, QoL has been characterised as an appraisal of one's current state against some ideal (Cella & Tulsky, 1990). QoL has also been described as the anticipated satisfaction of personal goals (Sartorius, 1987), or the degree to which an individual succeeds in accomplishing his desires (Calman, 1984). George (1997, p.47) suggests that measurement of QoL may be the gap between aspiration and achievement:

> With the passage of time, changes in a person's situation, such as the threat of death, intuitively mean a fall in quality of life. Yet this can be restored into the acceptable range by focusing on the non-physical dimensions of care. The loss from declining physical capabilities may be substituted very effectively with improved psychological health and well being by attending to questions of meaning, existence and the spiritual.

From the above, one could ask what is the "acceptable range"? The standard needs approach to QoL does not allow for the explicit expression of such a reference point and as a result, there is no attempt to ascertain the difference between a patient's current state and where that patient might like to be.

By contrast, an idiographic approach to the assessment of QoL attempts to allow the individual to establish a frame of reference for responses. In SEIQoL, for example, patients are able to assess the domains they have nominated on a vertical scale anchored at the two extremes by the terms "best possible" and "worst possible". According to the developers, these anchors were designed to allow individuals to use their own criteria, based on the assumption that the gap between the current and ideal states is the most important assessment; the larger the gap, the poorer the QoL (Browne et al., 1997). Similarly, with PGI, patients rate how badly affected they are on each of the proposed six domains on a scale of 0-100, where 0 represents the worst possible state and 100 an ideal state.

QoL is often seen as an outcome measure (O'Boyle & Waldron, 1997). But it is possible that QoL might be an influencer of pathological processes (see for example, Ganz, Lee, & Siau (1991) and Spiegel, Bloom, Kramer, & Gottheil (1989) for a discussion of such influences). The suffering that a patient might undergo in one domain might be outweighed by an enhanced sense of personal meaning in another domain. The end result might provide a net increase in QoL, despite coexisting suffering.

Calman (1984) proposed an important model for the assessment of QoL which emphasises an individual perspective. Under Calman's model, QoL is seen as the difference, at a particular period in time, between the hopes and expectations of the individual and their present experience. The gap between hopes and realities may be narrowed by improving the patient's functions (reality) through treatment, or by reducing expectations (hopes) through informed understanding of the limitations of their disease and acceptance of the risks involved in treatment in relation to expected benefits.

Paradoxical implications need to be considered when we begin to look at patients hopes and expectations. The first of these paradoxes becomes apparent if we accept that perceived QoL depends on the gap between a person's reality and his or her hopes and expectations. Under these circumstances it is possible that a high perceived QoL may stem from a low expectation (Ruta et al., 1994). For example, an elderly man who has learned to live with the pain of angina, and is unaware of the improvement that might be possible as a result of surgery, may record a high QoL because his expectation is close to reality. Ruta et al. (1994) suggests that it is wrong for us to assume that some hopes and expectations are genuine while others are unreal. The distinction between real and unreal expectations is not relevant to patients. Their expectations are formed by their perception and interpretation of the world around them, which may lead them to be contented or miserable. The expectations that some consider to be unreal are valid for the people who subscribe to them; they simply conflict with the expectations of others. The happiness that they experience because the gap between reality and experience is narrow is also valid for them. By asking patients what their particular expectations might be and what their hopes for the future might include, critics might suggest that many proposed expectations and hopes should be classified as "unrealistic". In reality, patients may never be able attain these stated expectations. But the goals that an individual patient possesses will still be real to that patient, as an individual. Such goals may provide the patient with the will to continue to live and lead a functioning life. The absence of such goals, or a dismissive approach by a QoL assessment instrument (however unrealistic the goals might be), could contribute to feelings of defeat and hopelessness for the patient.

A second paradoxical implication is that patients could have their perceived QoL improved through a reduction in their expectations without any change in the areas that they feel are important. For example, a medical counsellor may be able to help a patient who has been diagnosed with terminal cancer to come to terms with the limitations that this condition places on his or her life, and thus enable him or her to enjoy the life that is left, because expectations have changed. Individuals also may adapt their expectations to suit their particular social or economic circumstances. Ruta et al. (1994) propose that it is quite legitimate to reduce a patients expectations. Few would argue that it is wrong to raise a patient's expectations by informing him or her of a treatment he or she was unaware of, provided that one is able to administer that treatment. But for a doctor to intentionally elevate a patient's expectations beyond his or her present experience without altering the reality of his or her daily life is to condemn him or her to poorer QoL. By asking a patient what is important for him or her (i.e. establishing what might constitute QoL), false expectations are not being raised. Instead, we are attempting to discover the difference between where patients currently perceive their present state on some criteria to be and what their expectations might be for the future. It is the patients' future expectations that might need to be diluted to the extent that they are brought into line with a more realistic and perhaps achievable outlook. But this process can be iterative. It might be an evolutionary process of compromise designed to bring some state of equilibrium between hopes and current assessments. Thus, enhanced communication between patients and caregivers is crucial to reaching such equilibrium, and a QoL assessment instrument which takes account of the individuals needs, hopes and expectations, as well as how these may change over time, will be an important vehicle for allowing such communication to take place.

As already stated QoL is a dynamic concept and when defined as the gap between reality and expectations, and assessed in patients' own terms, the areas of concern that generate those expectations and the final value ascribed to QoL are likely to change frequently - perhaps even from day to day (Ruta et al., 1994). This makes the interpretation of conventional test-retest reliability somewhat problematic.

Because cancer tends to limit functional ability and role performance, patients' expectations of themselves are subject to change as the disease progresses. Indeed, the QoL rated by a patient who successfully lowers expectations may well be better than that rated by one who continues to expect the unrealistic. People who can lower their expectations to conform more closely to their compromised physical status will be in a better position to avoid disappointment (Cella, 1992). As a result, self-reported QoL will be improved. Therefore, psychotherapeutic treatment can be geared toward changing patient expectations when functional status is chronically compromised. Effective palliative care often includes compassionate patient education that addresses patients' needs for understanding and modification of expectations in addition to pure symptom control (Cella, 1992).

The assessment of change

Individuals value health states differently and in addition, will change their valuations over time. A sixteen-year-old youth values a health state differently in comparison to an eighty-year-old individual (Björk & Roos, 1994). Similarly, an individual who has recently been diagnosed with cancer may have a very different outlook on life; this individual's evaluation of what constitutes his or her QoL may change dramatically over the course of the illness. For example, Muldoon, Barger, Flory, & Manuck (1998) propose that many cancer patients report benefits from their illness, ranging from an increased ability to appreciate each day to greater feelings of personal strength, self-assurance and compassion, such that they are sometimes more satisfied with their global QoL than healthy comparison groups. Muldoon et al. (1998) go on to suggest that this paradox reflects a psychological adaptation, referred to as "response shift". The internal standard by which patients appraise their current state shifts and the same questionnaire items on well-being can elicit fundamentally different answers.

The standard needs approach, at the nomothetic end of the continuum, sometimes assesses change at the aggregate level but does not assess change at an individual patient level. Indeed, QoL research frequently seems to lack sensitivity to the subtleties and complexities inherent in human behaviour (Schwartz & Sprangers, 1999a), especially at the individual level. As already stated, the standard needs approach largely overlooks the idea that QoL means different things to different people (between-subject differences). The standard needs approach also overlooks the idea that QoL can mean different things to the *same* person (within-subject differences) over the course of a disease trajectory. It is possible, and indeed highly probable, that as a patient progresses through his or her illness, especially in a terminal situation, that the important salient areas nominated by the patient will change over time. Psychological adaptation to illness and efforts to accommodate the complex and dynamic consequences of the disease trajectory may well mean that patients change their internal standards, their values and their conceptualisation of QoL over time (Sprangers & Schwartz, 1999). Clearly, those providing care need procedures to detect changes so that appropriate interventions can be initiated and their efficacy assessed. In general, much of the communication between patients and medical staff, and among medical staff themselves, is about changes or stability in a patient's QoL status. Despite the central role of change assessment, there is surprisingly little critical discussion of it in the palliative care literature, or indeed in the broader QoL literature. It seems to be generally assumed that once issues of test reliability, validity, responsiveness and sensitivity have been addressed, change may be assessed unproblematically from simple differences in repeated measurements (Testa & Simonson, 1996).

As already stated QoL is a dynamic concept and when defined as the gap between reality and expectations, and assessed in patients' own terms (for example the PGI) the areas of concern that generate those expectations and the final value ascribed to QoL are likely to change frequently; perhaps even from day to day (Ruta et al., 1994). This said, the idiographic approach to QoL assessment is also inadequate in accounting for change assessment. Because of the importance of this concept, and the inability of existing QoL assessment instruments to address change issues, the assessment of change and response shift will be discussed in greater detail in the next section.

Response shift: assessing change

How people perceive their particular QoL, and the elements that constitute individual versions of what QoL might be for a person, vary over time. This is particularly the case when individuals undergo a change in their health state. A person may go through a process of reassessment of internal standards, change his or her personal values to meet life's new circumstances or reconceptualise those aspects that constitute QoL for him or her. Such changes can be defined as response shift. Sprangers & Schwartz (1999, p.1508) provide a working definition of response shift as being the change in the meaning of one's self-evaluation of a target construct as a result of: (a) a change in the respondent's internal standards of measurement (scale recalibration, in psychometric terms); (b) a change in the respondent's values (i.e. the importance of component domains constituting the target construct; or (c) a redefinition of the target construct (i.e. reconceptualisation). Allison, Locker, & Feine (1997) define QoL as a dynamic construct which has important implications for assessment. If the standards by which an individual judges QoL change, if the individuals values as to what is important to him or her are reevaluated, or if QoL and what it means to the individual is reconceptualised over time, then the answers a patient might give in response to a series of questions in one time period may not be comparable to answers given in another time period.

Response shift as a concept is based upon the typology of change developed by Golembiewski, Billingsley, & Yeager (1976) for evaluating the effects of interventions in organisational psychology. The three types of change alluded to here are (1) alpha change, which refers to "true" behavioural change that can be accurately measured (2) beta change, which refers to alpha change but with some contamination resulting from scale recalibration and (3) gamma change, which refers to concept redefinition (Golembiewski et al., 1976); (Armenakis, 1988); (Norman & Parker, 1996); (Wilson, 1999).

Table 4 A comparison of change definitions:

Golembiewski, Billingsley, and Yeager, 1976 (p. 134-135)	**Sprangers, and Schwartz, 1999; Wilson, 1999**
Alpha change involves a variation in the level of some existential state, given a constantly calibrated measuring instrument related to a constant conceptual domain.	A "true" behavioural change. An actual change in the target construct being assessed.
Beta change involves a variation in the level of some existential state, complicated by the fact that some intervals of the measurement continuum associated with a constant conceptual domain have been recalibrated.	Scale recalibration in psychometric terms. A change in the respondent's internal standards of measurement.
Gamma change involves a redefinition or reconceptualisation of some domain, a major change in the perspective or frame of reference within which phenomenon are perceived and classified, in what is taken to be relevant in some slice of reality.	Concept redefinition brought about through either a) A change in the respondent's values (i.e. the importance of component domains constituting the target construct). Or b) A redefinition of the target construct (i.e. reconceptualisation).

Response shift and the working definition presented by Sprangers & Schwartz (1999) avoids the use of the terms 'beta' and 'gamma' change because in their view, the meaning of these terms is not self-evident and does not reveal their content (Schwartz & Sprangers, 1999b). In addition to the change typology, Schwartz & Sprangers (1999b) suggest that changes in a respondents values, although inherent within the Golembiewski description, should be a distinct additional aspect for assessment purposes. In summary then, alpha change reflects an actual change in the target construct being assessed. A change in the respondent's internal standards of measurement (beta change) is a change in the respondent's reference points to the extent that the scale is recalibrated. And finally, gamma change reflects a change in the respondents values and/or a redefinition/reconceptualisation of the target construct.

Allison, Locker, & Feine's (1997) proposal that QoL is a dynamic construct suggests that QoL assessment is very likely to be influenced by response shift (beta and gamma change contamination). This influence will be even more pronounced in the context of palliative care where physical and psychological states may change rapidly and radically over relatively short time periods. If this is so, then change assessment in QoL may be a major threat to validity in the palliative care setting.

Wilson (1999) suggests that the production of response shift may ultimately be one of the goals in achieving clinical understanding and successful intervention. Patients in palliative care are in terminal states. Medical science and technology has no more to offer such patients, because all known 'conventional" therapies have been tried and exhausted. At such a point, the focus of palliative care must change and concentrate upon assisting the patient to understand and cope with their situation and circumstances. As Wilson (1999, p.1578) suggests:

> To put it in the language of change typology, when biological or physiological change is no longer possible, a principle goal of care sometimes becomes the induction of scale recalibration, concept redefinition, or a change in values.

It is appropriate to again raise the sociolinguistic history of "palliation". As already discussed, Morris (1997) (cited in Clark & Seymour, 1999) suggested two "rival histories" of palliation which can be summarised as the "cloak" versus the "shield".

As Morris suggests, the more helpful metaphor may be that of the "shield". So rather than concealing or disguising, which can be inferred from "cloaking" the disease, it may be better for caregivers to "shield" the patient by offering security, advice and assistance that encourages coping and understanding strategies on the part of the patient. Response shift may be the demonstrable consequence and required outcome inferred from this shielding process. Therefore, enhancing communication becomes a necessary focus for much of palliative care. An assessment procedure for QoL within a palliative care setting should be regarded as a structured way of enhancing communication about changing QoL needs between patients and health professionals and among health professionals.

If we accept that one of the goals for palliative care is to produce a response shift, then we must also accept the need for assessing whether or not a response shift might have occurred. That is, there is a need for the development of an assessment tool that can identify changes in patient's internal standards, changes in their values, and changes in their conceptualisation of what constitutes QoL for them.

A variety of solutions to the problem of assessing a response shift have been proposed (Thompson & Hunt, 1996 and Schwartz & Sprangers, 1999b). These include design approaches and statistical approaches as well as qualitative methods. Under the design approach method, a response shift is assessed by imposing study design changes (Schwartz & Sprangers, 1999b). One of the procedures for detecting a response shift using this method is the ideal scale approach. The origins of this approach can be found in organisational change research (Armenakis, 1988). The ideal scale approach consists of obtaining serial ratings of actual and ideal states. Respondents are effectively asked to complete a questionnaire in two modes. The first time in reference to their perceived actual status (what they believe their current status to be for a given aspect) and the second time in reference to their ideal status (where they would like to be with respect to this aspect). Norman & Parker (1996) provide evidence that the patterning of the actual-ideal difference scores over time can be used to detect changes in internal standards which amounts to a recalibration of the rating scale on the part of the respondent. While the ideal scale approach is aimed at detecting changes in internal standards, Schwartz & Sprangers (1999b, p. 1540) suggest that it is conceivable that this method may also be useful in detecting changes in values and conceptualisation. Changes in the ranking of a number of important aspects that a person has identified as being key to their QoL may be indicative of value changes. Over a period of time, changes in terms of what the important constituents for QoL are, might reflect a process of reconceptualisation for the patient.

Zmud & Armenakis (1978) have argued that patterns of actual and ideal ratings over time can be interpreted as indicators of alpha and beta change. Specifically they identify five patterns as shown in the following table.

Table 5 Patterns of Alpha and Beta Change (Zmud & Armenakis, 1978):

Description of the case	Does C1 = C2?	Does I1 = I2?	Does G1 = G2?	Type of change	
1. Perceptions of current behaviour are the same. Perceptions of ideal behaviour are the same. Gap scores are the same. ***It is not likely that change has occurred.***	Yes	Yes	Yes	-	-
2. Current and ideal scores have both changed from T1 to T2. However, the gap between current and ideal scores has remained the same. The respondent has redefined the measurement scale, but has not changed his/her perception of the concept. ***Beta change has occurred***	No	No	Yes	-	**Beta**

(Continued overpage)

Table 5 (cont.) Patterns of Alpha and Beta Change (Zmud & Armenakis, 1978):

Description of the case	Does C1 = C2?	Does I1 = I2?	Does G1 = G2?	Type of change	
3. The current behaviour remained the same but expectations related to ideal behaviour changed. There has been a shift in the measurement scale. ***Beta change has occurred, but little can be inferred about alpha change.***	Yes	No	No	**Alpha?**	**Beta**
4. Both current and ideal behaviour have changed and as a result, the gap between each has also changed. ***Beta and alpha change have probably occurred.***	No	No	No	**Alpha**	**Beta**
5. The ideal behaviour remained the same but current behaviour changed. The stability of the ideal responses is taken to mean no measurement scale change. ***Alpha change has probably occurred.***	No	Yes	No	**Alpha**	**-**
Key: C1 = Current (actual) assessment in time 1; C2 = Current assessment in time 2 I1 = Ideal state in time 1; I2 = Ideal state in time 2 G1 = Gap between ideal state and current assessment in time 1; G2 = Gap between ideal state and current assessment in time 2.					

The alpha and beta change patterns shown in the above table will be applied to the data derived from QoL-Steps, and shown in Chapter 4 of the research results.

In summary, this chapter introduced the concept of QoL and its assessment in relation to a health setting. A QoL assessment continuum was suggested and it was this framework that provided the basis for contrasting nomothetic versus idiographic approaches to QoL assessment. The final section within the chapter discussed the assessment of change, and in particular, the concept of response shift, which is a phenomenon particularly relevant to individuals undergoing changes in their health state. An objective of the current research will be to explore patterns of change for individuals, such as those suggested by Zmud & Armenakis (1978).

Chapter Two

Method

This chapter includes a review of the research objectives for QoL-Steps. It also contains a description of the instrument, the procedure for its administration, sample details of the hospice patients interviewed, ethical considerations related to the study, as well as a brief summary of the analytic strategy that was used in the data analysis.

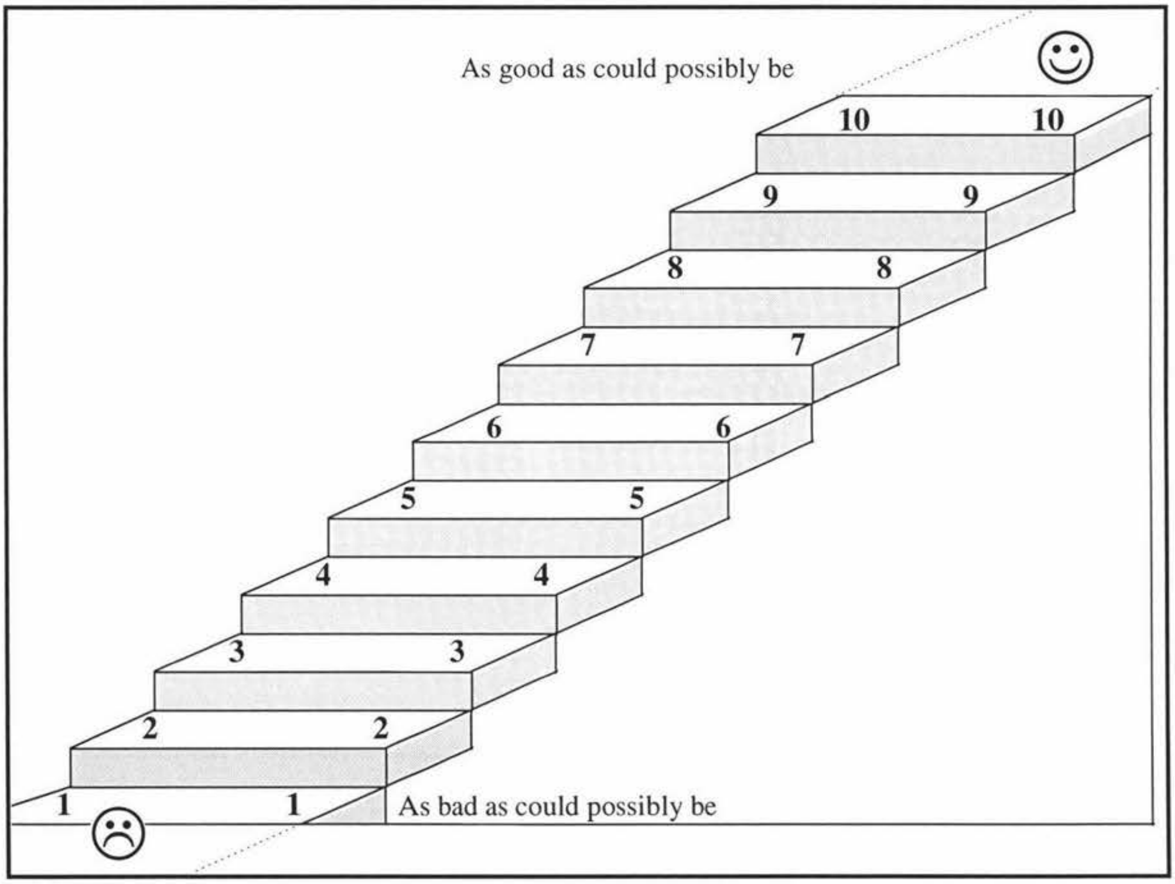
The development of QoL-Steps as a QoL assessment instrument included the following research objectives. The first objective was that QoL-Steps would allow patients to express important aspects of their personal QoL. The variability of patient nominated aspects was an important part of this objective. A second objective related to patients being able to prioritise the aspects they had nominated into an order of personal importance. A third objective was that QoL-Steps would enable a difference score to be calculated showing the gap between a particular patients current and ideal positions on a scale. The fourth and final objective related to the assessment of change for a particular patient over time and to examine the patterns of change for that individual.

As outlined above, one of the key objectives for QoL-Steps was that in addition to allowing patients to nominate their own important aspects of QoL, it would also enable them to show their evaluation of current status for an aspect and their assessment of where they would ideally like to be, using a simple stepped scale (reproduced in Figure 1). This scale was anchored at the bottom extreme with the number 1 and the statement "as bad as could possibly be", while the top extreme point had the number 10 with the corresponding statement, "as good as could possibly be". While the anchor statements were borrowed from SEIQoL, the steps themselves can be likened to an evolution of Cantrill's Ladder (Cantrill, 1966).

Cantrill's Ladder elicits respondents to rate their current life satisfaction on a ladder that ranges from 0 to 10, where 0 reflects worst imaginable life satisfaction and 10 reflects best imaginable life satisfaction.

The name QoL-Steps was adopted as an initial title for the instrument because the steps themselves are an integral part of the assessment procedure.

Figure 2. Version 1 of the steps



Procedure

QoL-Steps was administered with an interview. Patients were advised that a family member or friend could be present during the interview and often patients preferred to have a spouse or other family member to accompany them, at least for the first interview. Interviews were of varying length and could be as short as fifteen minutes or as long as three hours. There was no effort to standardise the length of interview with patients and patients were able to raise any aspects that they believed applicable to their QoL. The length of interview often appeared to be a function of the psychological and emotional needs of the patient; some patients found it a therapeutic aid to talk about aspects that were important to them. (This point is raised in Chapter 6 where the therapeutic benefits of QoL-Steps are suggested).

All interviewing was conducted by the writer. As such, the interviewer was not part of the Hospice or medical staff attending patients and indeed, had no medical background. Interviewing was semi-structured and designed to build rapport with patients. The interviewer noted points of reference (family interests, hobbies, former occupations, names of other family members, etc.) to assist the process of building rapport with patients. Importantly, patients were not hurried in their discussions, so even if not needed, large blocks of time were set aside for interviewing purposes and patients were able to dictate how long the interview lasted. Several patients admitted to being initially unsure as to what the procedure was attempting to do, and it was important to try to relax such patients, taking away the formality of the assessment as much as possible, and stressing to patients that they were not being tested in any way and that there were no right or wrong answers with their responses.

Initial Interview

For the first interview in QoL-Step, patients were asked to think about aspects of their lives that were most important for them at that time. In the introductory section of the interview script, examples were provided for patients to enable them to contextualise their particular needs and concerns. Verbatim instructions for this section were as follows:

> Some people have said that important aspects of their lives include being able to function properly in their daily lives. This might mean being able to keep up with friends and having a social life. For others, maintaining a certain level of independence might be most important - things such as being able to do your own shopping, keeping the house tidy and so on.
> Other important aspects might include having a positive attitude and feeling OK about yourself, that is, not feeling depressed or anxious. How you feel physically may be very important; or perhaps family issues or how you think about what is happening to you and what it's all about are the most important things for you. Remember, each person's needs are far reaching, and aren't only related to physical health. Everyone is different, so your personal aspects are unique to you - there are no right or wrong answers here.

Patients were asked to provide as many important aspects as they thought applicable. In addition to the examples listed in the script, and only when patients had exhausted their own ideas for important aspects, patients were also prompted by a list of domains and content areas (the list and its subparts are reproduced in Appendix A). This list was derived from the content of the QoL literature. The list ensured that a wide range of domains and concerns were taken into account by the patient. Each domain and content area was read out to the patient by the interviewer, even if topics had already been covered by the patient without prompting. Once patients had been prompted through the list of domains and content areas for additional aspects, patients were again asked if there were any further important aspects that were applicable.

As patients mentioned important aspects of their lives, these aspects were written down by the interviewer as simple statements onto showcards. These statements were shortened verbatim comments and the interviewer checked back to the patient concerned to ensure that the statement had captured the essence of what the patient had meant. This procedure was repeated until the patient had exhausted all the aspects deemed important for him or her from both the unprompted aspects and the prompted list of domains and content areas. To ensure that all aspects of concern to the patient were accounted for, patients were asked if there were any additional aspects that should be written down on the cards. This process continued until the patient said there were no further aspects applicable.

The next stage of QoL-Steps asked patients to rank the showcards that had been created into an order of importance for them. To accomplish this, the actual showcards, with aspects written in bold lettering, were placed on a surface in front of the patient in a random order. Patients were able to physically move the showcards around (or have the interviewer do this on their behalf), until they were ordered in a ranking that reflected the patients' personal level of importance for each aspect shown. Related aspects were able to be ranked on an equal level if this seemed most appropriate for the patient. The actual instructions for this stage of QoL-Steps were as follows:

> .....we have a number of aspects that you have suggested as being important. Having a look at the cards in front of you, I would like you to put them in some order of importance for you. That is, if you had to choose between all of them, which aspect is *the* most important for you. Now which is the *next* most important aspect. *[Repeat for each aspect and then sort the cards into rank order from the most important to the least important. Patients may rate more than one need at a similar level.]*

Once the aspects were rank ordered, patients were shown a flight of steps (see Figure 2 above). Patients were then asked to take each aspect, one at a time, in order of importance, and rate the aspect on the set of steps. For the first interview, numbers on the left hand side of the steps were used to mark the patients' responses.

> Now we are going to look at these *[aspects]* in more detail, and to do this we are going to use this picture of a flight of steps that is numbered from 1 to 10. At the bottom of the steps is a picture of an unhappy face (number 1), which reflects the lowest step or "as bad as could possibly be". At the top of the steps (number 10) is a happy face, which reflects the highest step or "as good as could possibly be". In total there are 10 steps that I would like you to think about.

Each aspect that a patient nominated was dealt with on its own set of steps. If a patient nominated seven aspects or concerns, then there were seven corresponding sets of steps.

The first number on the steps chosen by a patient was his or her assessment of where he or she believed his or her *current position* on the steps to be for that particular concern:

> Thinking about the most important aspect to you (read from the first card) - either in terms of you not wanting this aspect to get any worse or wanting this aspect to get better for you, I would like you to show me where on the 10 steps you currently see yourself *as of today*.

The current position was marked for patients by circling the number they had chosen and labeling it with the letter *C*. Once the current position was marked on the steps, patients were then asked to think about this aspect again, but this time to assess where they would *like to be* on the steps for this aspect.

> So you told me where you currently are on the steps, as of today, for *[the aspect suggested]*, but now I would like you to think about where you would like to be on the steps for *[this aspect]*. It could be that you simply want to maintain your current level, or you might wish to improve a particular aspect

> so that you are higher (or lower) on the steps. When thinking about where you would like to be, try to be realistic in your expectations.

The "ideal" position was marked for patients by circling the number they had chosen and labeling it with the letter *I*.

This same procedure was repeated for each aspect raised by patients. Each set of steps related to one aspect for a patient and showed where patients currently thought themselves to be with respect to this aspect, as well as where they would ideally like to be with respect to this aspect.

Modifications to the Rating Procedure

An evaluation of the initial results for the first 29 patients interviewed suggested that patients were inclined to choose high numbers to express their ideal position on the steps, thus resulting in a bias towards the upper end of the scale. With this in mind, some modifications were made to QoL-Steps that might alleviate this tendency.

The first change was to alter the anchor statements at each extreme of the steps. The new statement at the bottom extreme was changed from reading "as bad as could possibly be" to now read "as bad as I could possibly imagine". Similarly, the top extreme was changed from "as good as could possibly be" to "as good as I could possibly imagine".

As a consequence of altering the anchor statements, the interviewer instructions were also changed to emphasise that these positions at either end of the steps were extreme positions and realistically, may never be attained by patients.

> In your experience, you may never get to either the top or the bottom step. Remember that the highest point on the steps is as good as you could possibly

> imagine and the lowest point on the steps is as bad as you could possibly imagine for a particular important aspect of your life; so these are extreme positions.

When asking patients to assess their ideal positions on Version 2 of the steps, the modified instructions were even more explicit:

> Now I would like you to think about where you would realistically like to be on the steps for *[this aspect]*. A realistic view on your part might mean some form of compromise. That is, you might have to accept that you could never get to a 10, but instead, have to settle for a lower step that is nevertheless one that you would like to work towards, or might hope to achieve.

Second interview

For the second interview, patients were reminded of the purpose of the study and shown their showcards with the list of aspects that they had nominated in the first interview. Patients were then asked if there were any new aspects that may have arisen for them in the intervening period. If a new aspect was nominated, then a new card was used to record this additional concern. Patients were able to nominate as many new aspects as they thought applicable. In addition, patients could suggest that a previously nominated concern was no longer important to them.

Once reminded of the aspects that had been nominated in the first interview (with reference to the statements recorded on cards), and taking account of any new concerns, patients were then shown their previous importance rankings and asked to consider whether these rankings had changed. Patients were able to re-order their concerns depending upon how they now felt after a set time period from the first interview. If new rankings were given, these were recorded for the patient and the cards reorganised to show the new rankings.

Once the new importance rankings were determined (or the old rankings confirmed), patients were shown their previous assessments for the aspects they had nominated on the individual sets of steps. With reference to these prior assessments, patients were then asked to state their updated current and ideal positions on the steps. For the second interview, numbers on the right hand side of the steps were used to mark patients' responses where the current position was marked with a *C* and the ideal position was marked with an *I*.

> I would like to firstly go through each of the steps that we discussed last time. Remember how you positioned yourself on the 10 possible steps, both in terms of where you saw yourself on that day, as well as where you would like to have been.
>
> We are going to go through the same thing again except that this time, I would like you to think about whether your current position has changed since the last time we met. Which number on the steps now matches your current position?

An actual patient example is shown in the following table to illustrate the procedure and the type of resulting data:

Table 6 QoL-Steps Data Example

Issue	**Time One (T1)**				**Time Two (T2)**			
	Rank	Current	Ideal	Gap	Rank	Current	Ideal	Gap
Pain management - important I don't feel pain	1	7	9	2	1	8	9	1
Can only sleep on one side or back	2	6	9	3	2	8	9	1

Two important aspects nominated by this patient are shown for the two time periods, T1 and T2. In T1, each aspect was ranked by the patient and then with reference to the steps, the current position was ascertained followed by the ideal position for this aspect. The same process was followed in T2. The gap reflects the difference between the ideal and the current position in each time period.

Modifications to the Time Interval

The length of time between interviews was changed during the data collection period. Initially, two weeks was allowed between T1 and T2 for 24 of the patients sampled. However, an analysis of the change scores suggested that there was not much change for many of these patients over the two week period. Therefore, the length of time between the two interviews was extended to four weeks. The change to four weeks between interviews was applicable for a further 7 patients. In this thesis, stage one refers to patients who had a 2 week interval between T1 and T2 while stage 2 patients had a 4 week interval between T1 and T2.

Sample

Recruitment:

Names of patients were selected by the Director of the Hospice, Dr Simon Allan. Dr Allan determined patients' suitability for inclusion in this study and assessed whether a particular patient might still be alive for the second interview. Patients entering the Hospice Programme normally have been given a prognosis of twelve months or less to live. Other criteria used by Dr Allan to decide the suitability of respondents included selecting patients with variable prognoses and ensuring that patients were coherent and literate, without major cognitive impairment, and emotionally stable enough to be exposed to the interview process. After an initial contact by Dr Allan to determine that the patient was agreeable to participating in the research, patients were phoned by the writer and an appointment made.

Participants

Overall, forty two patients participated in this study. All patients had been diagnosed with terminal cancer and were patients of Arohanui Hospice, Palmerston North. Arohanui Hospice provides free palliative care to patients in the terminal phase of incurable disease. The Hospice operates 10 in-patient beds, but most Hospice patients are out-patients and are catered for by the Hospice staff and other community care-givers within patients' own homes.

QoL-Steps was conducted with individual patients, face-to-face, usually in the patients' own home. However, two patients were interviewed in Arohanui Hospice; for one patient this was a second interview and was conducted in the Hospice because the patient's health had deteriorated. The other patient interviewed in the Hospice was not well enough to be at home and died before a second interview could be conducted.

The mean age of the sample was 66 years (the youngest patient interviewed was 18 years, while the oldest was 87), 19 patients were male and 23 were female. Patients were at varying stages of their illness, from recent diagnosis (within one month of the interview) to having lived with their illness for some time (sometimes several years) before becoming Hospice patients. A variety of different cancers were evident among the sample of patients. Six patients from the sample had been diagnosed with pancreatic cancer, and 5 each with colon cancer, lung cancer, and prostrate cancer respectively. Breast cancer, rectal cancer and carcinoma (with unknown origin) accounted for another 3 patients each. The remaining 12 patients all had different cancers, including angiosarcoma, carcinoid tumour, cervical, heart, lymphoma, melanoma, mesothelioma, multiple mycloma, oesophagus, ovarian, sarcoma, and stomach cancers.

Eleven patients died during the course of the data collection which meant that they were interviewed only once rather than twice, as intended. For the analysis of change, the effective sample size was therefore 31 rather than 42 patients, where stage one of the research involved interviewing 24 of the 31 patients with a two week period between interviews, and stage two, involved interviewing the remaining 7 of the 31 patients with a 4 week period between the first and second interviews. Patients were interviewed between October 1998 and September 1999. The following table provides a summary of the sample for Stage One and Stage Two of the research.

Table 7 Sample Details

	Stage One Oct 98 - Apr 99 (2 weeks between interviews)	**Stage Two May 99 - Sep 99 (4 weeks between interviews)**	**Total**
1st interview	29	13	42
2nd interview	24	7	31
Patients who died before 2nd interview	5	6	11

Ethical Considerations

Interviewing patients who are dying of cancer is a sensitive area of research and the rights of individual patients were obviously of paramount importance. The research reported here, in terms of the procedure, patient information letter and consent form were scrutinised and approved by the Manawatu-Whanganui Ethics Committee and the Massey University Human Ethics Committee.

Potential participants were offered the opportunity to take part in the study, with no obligation and with participation being purely voluntary. Patients were given a copy of an information letter (see Appendix B) and upon reading this were asked to sign a consent form (see Appendix C). Importantly, the information letter and consent form stressed voluntary participation, the patient being free to withdraw from the study at any time with no ramifications as to future health care. As well, patients were assured that all patient related information resulting from interviews would be treated confidentially.

The changes made part way through the data collection, which involved extending the interview period from two weeks to four weeks, were also approved by the two ethics committees.

Analytic Strategy

The data generated from patients took the form of ranked lists of important individual aspects. The current and ideal scores for these individual patient aspects, obtained from the stepped scale, allowed the calculation of simple difference scores. The two time periods of data collection meant that assessments made by the one patient in T1 could be compared to assessments made on the same aspects in T2. The resulting data was therefore quantitative, but was only subjected to simple analyses at the individual level. Descriptive statistics were used to show patterns for individual patient responses. Of most importance was the demonstration of individual patient variability which was one of the key objectives for the development of QoL-Steps. This variability is central to an idiographic approach to the assessment of QoL.

Chapter 3

Results

Results of the data generated from QoL-Steps have been divided into 3 chapters. The current chapter examines the variability and diversity of aspects nominated by patients and supports the idiographic approach to the assessment of QoL taken. Chapter 4 also explores individual variability, but in the context of rankings and weights that patients assigned to aspects of personal importance. An important objective covered in Chapter 4 also relates to the ability of QoL-Steps to record individual patients assessments of their current and ideal positions based upon the steps, and the differences that resulted. A further objective discussed in this chapter relates to the assessment of change over the two time periods. Chapter 5 looks at particular case studies that illustrate, using actual patient data in conjunction with additional contextual information, difference scores between current and ideal positions, as well as change assessment on a more global scale for individual patients.

QoL-Steps was developed as an idiographic approach to the assessment of QoL. As such, QoL-Steps was designed to allow patients to nominate important aspects of their lives, rank these in order of personal importance, assess the current and ideal positions for these aspects on a stepped scale, and allow for these ratings to be monitored over time as a means of assessing change for that patient. The gap or difference between a patient's current and ideal positions represented a shortfall in that patients QoL and could be defined as the gap between reality and expectations.

Unlike standard needs approaches to the assessment of QoL, the use of an idiographic approach means that results of one patient's assessment are not comparable to those of another. The unique context, experiences and expectations of different patients means such comparisons become problematic. Instead, it becomes more meaningful to compare the various assessments made by an individual in relation to their current situation (reality) and their expectations (ideal) and the resulting difference between these two positions. Such assessment for an individual patient should be looked at over time, to enable improvements or deterioration of aspects to be monitored for that individual.

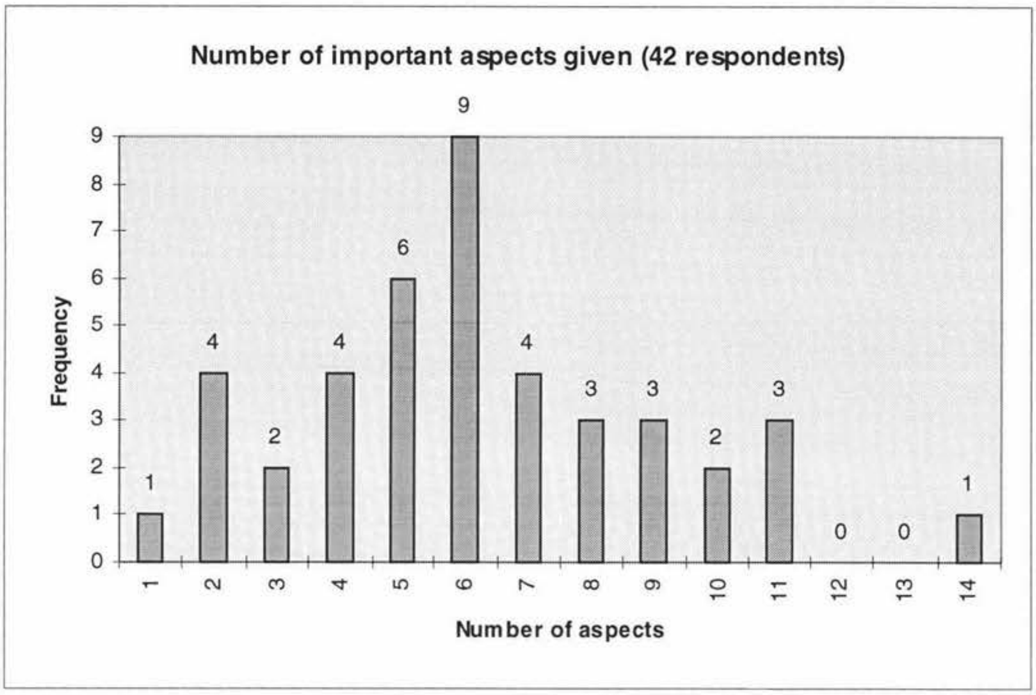
The first few sections reported here take a global approach to the data that illustrates the need for treating patients in an individual manner. The comparative criteria for the QoL-assessment continuum introduced in Chapter 1 will be used as a framework to present these findings.

Variety of content and range of aspects

One of the initial stages of QoL-Steps was to ask respondents to report aspects of their lives that were most important to them at the time of interview. When asked to think about aspects that were important to them as individuals, the 42 patients sampled proposed a wide range of aspects.

The following frequency distribution lists the number of important aspects elicited per patient. So while across the sample the average number of aspects raised by a patient was 6, one patient nominated 14 different aspects, and another proposed only one.

Figure 3



A key idiographic perspective for the assessment of QoL is that individuals are able to choose their own content as to what is personally important and relevant for them. This was an important objective for QoL-Steps. In addition to allowing patients to define what their own important aspects might be, QoL-Steps also allowed patients to determine the *number* of important aspects that may be applicable to them as individuals. No attempt was made to force respondents into nominating a set number of aspects.

To illustrate the variability and diversity of aspects for individual patients, the following tables group patients' aspects into themes where the patients' own descriptions from the showcards were used to differentiate particular aspects. When allocating aspects to themes, each aspect per patient was allocated only once to a theme, so there is no double counting of aspects for particular patients, although more than one patient may have proposed the same aspect. Where this occurred, the number of patients proposing an aspect was shown in brackets after the description of the aspect. Aspects were derived from both the patients first and second interviews, so adding all of the aspects together from each of the summary tables gives a total of 263 individual patient aspects.

The themes themselves were derived from the "Checklist of Quality of Life Domains" (see Appendix A). However, not all of the important aspects that a patient proposed could be neatly categorised into such a framework. As a consequence, an additional category, titled Future Hopes/Goals/Concerns, was proposed. This is an important theme in its own right and central to the assumption that QoL is a dynamic concept that can be defined as the gap between reality and expectations.

The allocation of patients' aspects to themes provides a useful categorisation that illustrates the diversity of individual patient needs. In contrast to developing a "standard" taxonomy of relevant domains for patients, the range of aspects listed demonstrates the need to allow individual patients to specify their own unique aspects and describe these in their own words.

Individual patients have individual needs and important aspects that are "uniquely" important to them. But as already mentioned, there was some duplication of aspects. Patients in palliative care will likely experience common concerns such as suffering pain, feeling tired, and experiencing sleeping problems. Although certain aspects may be common across patients, it is important to realise that concerns and needs of patients are often individualised, and it is this uniqueness that is important when taking an idiographic approach to the assessment of QoL.

The first theme relates to patients' physical well-being. This was divided into three parts: symptoms, treatment side-effects, and the patients' overall sense of their physical health. There were not always clear boundaries between these areas, and as a result, assigning aspects to certain categories was somewhat arbitrary. For example, is breathlessness a symptom or is it part of physical health? Similarly, tiredness could relate to physical health, treatment side-effects (patients reported feeling tired as a result of being prescribed morphine based medication), or as a symptom of the persons illness. Locating a particular patient's aspects within the classification system outlined was not intended to be definitive. Instead it aims to provide a summary by way of examining the wide range of aspects covered.

Looking first of all at symptoms, it can be seen from the table that there were common aspects for many patients. Sleeping was a common problem, but this differed, depending upon circumstances such as the type of cancer (for example, tumourous lumps in the back making it physically difficult to sleep), and the type of medication/treatment. Pain was also a common concern, but taken individually, patients felt pain in different areas of their bodies, often the source of pain being dependent upon the cancer site itself.

Table 8: Physical Well-Being - Symptoms:

Breathlessness	
Breathlessness after physical exertion	
Burning feeling in throat - short of breath	
Feelings of pain (2 patients said this)	
Can only sleep on one side or back - so affects sleep	
Dull pain in chest	
Feel pain	
Feeling itchy	
Feeling more pain	
Vision blurry/repeating	
Voice - takes away my speech through lack of air	
Feet-burn (worse at night)	
Lot of pain - especially in my legs	
Need to sit down a lot - to relieve my back	
Pain in back	
Piles- affecting life - difficult to sit	
Sleeping	
Sleeping is a problem (lumps causing problem)	
Sleeping is important for coping with everyday life	
Sleeping problems	
Sleeping problems - discomfort from sore legs	
Sleeping problems - more related to prostrate problem	
Posture pain in back	**24 aspects**

The second sub-category of physical well-being refers to treatment side-effects. The most common aspects cited by patients were related to feelings of nausea which were often attributed by patients to chemotherapy treatment and/or medication. Similarly, toileting problems were often an unwanted side effect that resulted from the medication patients were prescribed for pain-relief.

Table 9: Physical Well-Being - Treatment Side-Effects:

Feelings of nausea (4 patients said this)
Can't bend over without feeling sick
Dizziness and confusion as a side effect of treatment
Constipation
Going to the toilet too often
Having to get up at night to the toilet **9 aspects**

The final sub-category of physical well-being related to the patients overall physical health:

Table 10: Physical Well-Being - Physical Health:

Can only move about in a wheelchair
Don't have the same strength I use to have
Feel as if I am falling to pieces - e.g. I have a limp for no reason
Feeling healthy; energy levels
Feelings of tiredness
Feeling of tiredness related to stamina
Frustration - tumour slowed (not really well but not ill either)
Like to have more energy
Mobility
Mobility - it's become more difficult
Tired - breathless and lack of energy
Tired - energy related
Tired - when I've walked to the shops, etc.
Tiredness - related to energy
Tiredness and listlessness and lack of energy
Energy to do things
More energy - feeling exhausted
Haven't as much stamina
Haven't got full energy - like to be more active
Lost my energy
Motivation to eat is less
No energy/motivation
Not as strong as would like to be
Physical strength/effort **24 aspects**

Feelings of tiredness, lack of energy, and motivational problems were commonly nominated as being aspects of concern for patients. This highlights the difficulty inherent in attempting to classify aspects into sub-headings. As an example to illustrate the within-domain classification problem, there may well be connections between energy, tiredness, sleeping and motivation, but these concerns are differentiated for classification purposes. Not only is demarcation within a domain difficult, but so too is differentiating between domains. Take for example, mobility. Is mobility only related to physical health, especially when the patient is confined to a wheelchair? Or does mobility, as a patient nominated aspect start to impact upon other domains, such as being able to participate in social activities and sports and leisure past-times? One patient expressed her concern as feeling that she was "falling to pieces", and had developed a limp for seemingly no apparent reason. While this aspect might be classified as related to physical health, there are clearly issues of psychological well-being at stake for this patient as well. It is important to reiterate that there are necessarily overlaps, both across domains and within domains. Such overlap suggests the need for caution when assigning aspects to particular domains and also the need for flexibility to the extent that it is essential that the individual patients own circumstances and context is taken into account.

The next domain to describe was classified as Daily Activities and Functions. This domain was sub-divided into four areas: domestic tasks, work activities, social activities and sports and leisure activities.

The first sub-category contained aspects related to domestic tasks:

Table 11: Daily Activities and Functions - Domestic Tasks:

Don't feel confident to drive my car	
Being able to cope by myself (because I live by myself)	
Being able to do things like puzzles	
Being able to function properly in everyday things	
Being able to go shopping	
Can't think of shopping	
Can't walk any distance	
Difficult to complete some domestic tasks	
Difficult to sit for long periods	
Difficult to walk	
Domestic chores becoming more difficult	
Domestic tasks - gardening and so on.	
Domestic tasks more difficult - legs sore	
Independence	
Independence - do things I want to do when I choose to do it	
Independence - for as long as possible	
Independence for me - toileting, showering - to have control	
Independence: do own shopping etc.	
To be independent e.g. shopping, housework, showering	
Important to be able to keep functioning - household chores, shopping, etc.	
Important to have a daily purpose - things to do today	
Keeping on going - everyday things	
Losing total independence - not being able to do my own housework	
Help with domestic chores (like cleaning cupboards)	
I haven't driven (a car) since this happened	
Remaining independent e.g. domestic tasks	
Takes a longer time to do things (e.g. around the home)	**27 aspects**

Common themes for patients under this sub-grouping included the patient's need for independence, and their ability to be able to cope with everyday tasks around the home. Again, the individual context is an important criterion when analysing specific aspects for patients. Independence meant different things to different people, reinforcing the need to look at such a concept from an individual's perspective. Some patients viewed independence as being able to look after themselves (dressing, eating, shopping, etc.), while for others, independence meant being "in control" of their situation (even if they couldn't manage many of the daily activities around the home for themselves). One patient felt it was important for him to be able to physically carry the firewood up a flight of internal stairs to where he and his wife's woodfire was located. He could only carry one piece of wood at a time, and although his wife was still physically mobile, it was still important to this man to be able to keep up "his" tasks around the home. Other patients proposed that their still being able to do domestic tasks was an important aspect, but they had come to terms with the fact that it was necessary to rely on others for help around the home for some tasks such as cleaning and gardening.

Under the sub-heading work activities, some patients were obviously still coming to terms with the fact that they could no longer work and the resultant void that this loss had had on their lives. Statements such as "shattering of dreams" and " sense of working life being wiped out" dramatically reflect this feeling.

Table 12: Daily Activities and Functions - Work Activities:

Work - just want to get back to work	
To be able to carry on with work (can do some work from home)	
Functioning in work and social activities	
Huge adjustment now that I don't work	
More permanent teaching position at school rather than just relieving	
Sense of working life being wiped out	
Shattering of my dreams related to my work	**7 aspects**

Social activities, as a sub-category, contained some interesting contrasts for patients. Many patients indicated that although this was an important aspect for them, social contact had decreased as a result of their illness. Social activities had to be planned much more, in terms of location, food that could be eaten, clothes that could be worn, degree of pain that could be endured as a result of travelling and participating in social events, confidence with others, and so on. While some patients reported cutting back on social activities as a result of their illness, others rated contact with others as being more important to them now that they had been given a terminal diagnosis and had limited life remaining.

Table 13: Daily Activities and Functions - Social Activities:

Change in social activities - what I eat has to be planned
Changed clothing to loose fitting clothing
Can't see friends like I use to
Don't like driving a car now - which affects social activities
Energy - would like to have more, but pain related - interferes with social activities
Social Activities
Social activities - lessened because of my voice
Social activities - lot of places I won't go to now
Social activities are important
Social activities more important - visiting with friends
Social contacts - Bridge
Social life - enjoy watching kids play sport and keeping up with friends
Keeping in contact with friends
To be able to have a social life
To socialise with family and friends
Influence of social activities - e.g. Going to shops etc.
Pain related and interferes with social activities
Sharing music with people
Making friends **19 aspects**

Sports and leisure activities as a sub-grouping, were often patient specific and dependent upon the patients own interests. Although many patients rated sporting and leisure activities as being important aspects for them, very few were able to participate in such activities at the time of interview and most spoke of such pursuits in the past tense. This was an interesting result, given that many patients admitted that it was unrealistic for them to expect to participate in such activities ever again, but that they still believed these activities to be an important part of their lives and critically associated with individual patient aspirations.

Table 14: Daily Activities and Functions - Sports and Leisure Activities:

Can't play bowls as I use to be able to	
Can't play golf as I use to be able to	
Can't read like I use to be able to	
Use to bike a lot - but can't now	
Use to play golf - but can't now	
Can't do gardening - too painful to bend over	
Can't help my wife as much (in the garden and so on)	
Can't write like I use to be able to	
Would like to be able to do more painting	
Like to participate in social activities - car club	
Knitting - can't be bothered now	
Like to be able to play golf again	
Like to be able to travel	
Important to be able to concentrate on crossword puzzles and so on	
Keep up being able to edit magazine	
Miss being able to power walk and swim	
Swimming	**17 aspects**

The third domain to be described related to psychological well-being and included two sub-categories: emotional health and the ability to be able to concentrate and remember.

Looking first at emotional health, it can be seen that there were a lot of important aspects in common for patients. Feelings of anger, anxiousness, and depression were commonly held concerns for patients and were proposed as important parts of patients' lives. But once again, it is important to provide some context to individual patient concerns. As can be seen, many patients had feelings of "anxiousness" at a domain level, but often these feelings of anxiousness were in specific directions. For example, feelings of anxiousness could be directed at what might happen to other family members when the patient was no longer alive. Anxiousness in this context could relate to financial concerns (when it was the main income-earner who was terminally ill) or future child raising concerns (when it was the main home-maker who was dying). Feelings of anxiousness could relate either to the cancer process itself, in terms of treatment and side-effects, or to feelings of something just "not being right".

Table 15: Psychological Well-being - Emotional Health:

Anger
Anger - self-pitying
Feelings of anger (2 patients said this)
Anxious about what will happen to my wife and son
Anxiety and concerns e.g. how will my husband cope when there is no me?
Depression (2 patients said this)
Feelings of anxiousness (3 patients said this)
Feelings of anxiousness - worry about things before they actually happen
Feelings of depression
Feelings of depression and anger
Emotion - fear of the unknown
Emotional health - feeling loved
Emotions
Callousness of doctor at hospital (time left to live)
(Having a positive) Attitude
Feel anxious
Feel anxious about what will happen after I've gone
Feeling of anxiousness (feel as if something is not right)
Wish I didn't feel so anxious
Feeling anger over bowel problem (toileting)
Feeling good about myself
Feeling loved - hard to visualise us as a couple (in hospice) vs. what we feel at home
Feeling of panic and anxiousness
Feelings of slight anger
Having a positive attitude
Having feelings of good spirits
Frustration (rather than anger)
Positive attitude is important
Slight depression - self-pity and I get weepy sometimes
State of mind - having a positive attitude

34 aspects

The ability to concentrate and remember was another sub-category of psychological well-being. But as already noted, the assignment of aspects for particular patients to this sub-category was somewhat arbitrary. For example, perhaps a sub-category like treatment side-effects could have been just as applicable for many patients. Many patients attributed their lack of ability to concentrate and remember upon the medication they were prescribed, rather than a deterioration in their psychological well-being.

Table 16: Psychological Well-being – Concentration and Remembering:

Ability to concentrate	
Ability to concentrate and remember has worsened	
Can't concentrate	
Concentration is a problem (can't read like I use to)	
Difficult to remember	
Problems with remembering	
Inability to concentrate	
Need to be able to concentrate better	
Short-term memory isn't good	**9 aspects**

Family issues was the fourth domain that patient concerns were assigned to. Family issues could be subdivided into sources of support, relationship issues and financial issues.

The first, sources of support, was a common aspect for many patients. The family was seen as a necessary support for many, in terms of offering contact, love, and assistance. But once again, it is important to look at the context of patients' statements. Some patients were concerned about the effects of the cancer on other members of the family in terms of coping and accepting the illness. For some patients, their concerns were that there was support for them as patients but not for their families. Maintaining communication within the family and with friends was important for some patients, whereas for others, there were definite needs that were not being met, such as being able to talk about the illness with others. Such shortfalls, in the words of patients, could have been due to the patient not having contact with other family members, being too frightened to talk about it, or in some cases, the illness just not being accepted by other family members.

Table 17: Family Issues – Sources of Support:

Assistance for my daughter	
Assistance for my wife - the impact on her	
Family - frightened to talk about it	
Family - having contact with them	
Family - how this affects them	
Family - I've always been there for them, but have to let my husband fill in	
Family - made sure they know how things stand	
Family - well provided for	
Family certainty - stress on partner	
Family issues - assistance of daughter	
Feel frightened for my family and indispensable	
Good support from a lot of sources within my family - different ages	
Good support from family and friends	
Feeling of love and support	
Friends and family (just being there)	
Keeping communication open - with husband and family	
Lack of contact/support with parents - which hurts	
Little support for family	
Support of family and friends	
Supportive loving family	
Having contact with church people (house groups)	
Important to support my support	
Need for stability - safe where I'm staying	
Need to feel loved and supported	
To get on well with people	**25 aspects**

Relationship issues could just as easily have been incorporated within sources of support as a category, given that only two aspects were proposed. But it is useful to look at overlap between sub-categories. For example, the statement "lack of contact/support with parents - which hurts" could just as easily have been assigned to the category "relationship issues" as it was to "sources of support".

Table 18: Family Issues – Relationship Issues:

Affecting sexual feelings	
Son's having difficulty with my illness	**2 aspects**

Financial concerns were listed as being of concern for seven of the patients and this concern was often related to the fact that the patient was no longer able to work and earn an income.

Table 19: Family Issues – Financial Issues:

Financial benefit stand-down period from employer - too long	
Financial issues - husband in a resthome and costs associated	
Financial issues - making things in order	
Financial issues a concern	
Financial issues now I'm not working	
Future financial issues	
Income assessment - anxiousness that is associated with this each year	**7 aspects**

Spiritual issues were the fifth domain in terms of categorising patients aspects. "Spiritual" in this context includes issues relating to death and personal feelings that patients might have had. There was some contrast apparent in terms of whether patients accepted death or were asking the question as to why this was happening to them.

Table 20: Spiritual Issues – Issues Relating to Death:

Don't accept this. Don't want to die	
Why me?	
I have a strong faith (2 patients said this)	
Keeping the spiritual/Christian faith ongoing	
Issues relating to death - don't want it to be drawn out	
Issues relating to death becoming more important	
My acceptance of the disease	
Sense of meaning that this isn't senseless	**9 aspects**

Table 21: Spiritual Issues – Personal Feelings:

Feel guilty because my children are so young	
Sense of fulfillment	**2 aspects**

The final category for the assignment of patients concerns relates to future hopes, goals and concerns of the patient and encompasses what could be considered the patient's aspirations and expectations. In some respects this category might be seen as a catch-all for aspects that did not fit easily into the domains and sub-categories already described. This was not necessarily the case, it was just that the wording of these aspects seemed to differentiate them by denoting a goal or hope of the patient.

In a similar fashion to sporting and leisure activities, patients may have realised that some of these goals may well be unrealistic and unattainable. But this realisation shouldn't make such aspects any less important to the patient or less legitimate in terms of reflecting some standard that has been lost or hoped for in the future. Often patients provided a context to an aspect that they believed to be important to them. For example, being able to travel became important for one patient because she wanted to be able to visit her extended family in a distant rural community. Another patient also mentioned that wanting to be able to travel was important, because she wanted to attend her daughters wedding. Often these statements became goals - they were something to look forward to and to plan and prepare for. One patient was gradually building up to longer and longer trips in a car to ready herself for a visit back home. In contrast, statements could also be centred on loss or what could have been. The need to "feel normal", or to be able to "carry on as I was before", and the need for "respite from the current degrading process" were examples of patients having "lost" important parts of their lives due to cancer. One particular patient spoke about the "suddenness and completeness of change" and the associated difficulties that this meant for him and his ability to cope.

The ability to maintain current states was deemed important by some patients. That is, patients did not necessarily seek improvement for a certain aspect, but they certainly did not want that aspect to deteriorate either. A particular patient indicated that she would like to be able "to keep feeling as well as I am". For another patient, it was important for her to be able to "be well enough to be a support and sounding-board for my family." Maintaining independence was an aspect proposed by several patients. While "independence" as an aspect was categorised under "domestic tasks" for most patients, it could just as easily have been assigned to the category of "expectations" if a patient saw this concern as a personal future goal.

Context related to loss was also important. One patient spoke of still having things she would like to do, such as seeing her grandchildren grow up. Still other patients, planning for the inevitable, were concerned about getting their affairs and estates up to date, completing wills and planning for spouses who would be left alone. One patient spoke about completing renovations on his house so that the house would be in order when he died.

Patients were often concerned about other peoples' reactions to them now that they had been diagnosed with terminal cancer. For example, one patient described people she met as being frightened of cancer and as a result she believed others avoided her. Another patient described people as not knowing what to say to her and that their reactions were upsetting. Sometimes the attention from other well-meaning family and friends was too much for the patient, "too much - feeling loved from family".

Table 22: Future Hopes/Goals/Concerns

Certain things I want to get done - renovations on house
Being able to live life to its fullest
Can I physically cope (stamina) with travelling (to attend my daughters wedding in April)?
Carry on as I was before
Complete body - both inner and outer
Concern about the future of my son
Difficulty in being able to communicate where I am at (sense of having to be positive rather than defeatist)
Don't want pain (towards the end)
Don't want to be ill for a long time
Don't want to have to face pain like I had before
Feeling of being useful - to be able to pass something on
Weight related - I want to put on weight
Getting house/estate in order
Getting things in order for the future (discussing things with my wife)
How I felt when I was told I had cancer
Feelings of self-consciousness
Like to have contact/visit with family
Tomorrow - the future
Want to be able to travel back to Bay of Plenty (to see family)
Want quality time (respite) away from the current "degrading" process - e.g. needing toileting help

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Table 22: Future Hopes/Goals/Concerns (cont.):

Want a normal life
Still think there are things I would like to do (see grandchildren grow up)
Well-being of family and myself
To feel normal
To function independently - do my own thing
Future needs of my family and myself
Having control over my life in terms of planning things
Keep having an appetite
Maintaining independence (without disturbing friendships)
Make sure we are provided for
Pain management - important I don't feel pain
People don't know what to say - people's reactions upsetting
People you meet are frightened of cancer - won't come forward/avoid me
Poor follow-through from hospital to hospice (communication over shunt)
Quality of life: still do the things I've always done
Rather be at home than in hospice (but not if it is a burden to my wife)
Stress on spouse - being self employed, running home etc.
Suddenness and completeness of change - difficult to cope with
Thinking I might have to be a burden to my family
To be able to look after myself
To be positive
To be able to walk properly
To be well enough to be a support and sounding-board for my family
To do things for myself
To keep feeling as well as I am
Too much - feeling loved from family (visiting from Auckland)
Too much sleeping instead of normal living
Want to be independent (going to shops, etc.) **48 aspects**

In summary, the purpose of listing the above categories and assigning particular patient aspects to themes was to examine the range and content of aspects proposed by patients. The tables provided are not meant to highlight the similarities of patient aspects (even though at face value, such similarities may well exist), but rather to illustrate the large number of individual aspects nominated by patients as being important concerns for their individual QoL. This finding suggests that a "standard" taxonomy of patient domains will be too restrictive for collecting the wide range of applicable aspects relevant for individual patients in palliative care.

Chapter 4

Weighting of quality of life issues

This chapter explores the rankings that individual patients assigned to the nominated aspects they deemed important for their personal QoL under QoL-Steps. In addition, current and ideal assessments are aggregated in order to summarise the results, along with frequency distributions which summarise the difference scores. The final section within this chapter examines some change patterns as proposed by Zmud & Armenakis (1978) as well as suggesting that changes in the rankings of patients over time may reflect reconceptualisation (gamma change) for patients.

Recall that a primary objective for QoL-Steps was that it would enable patients to rank aspects they had nominated in an order of personal importance. Allowing patients to make such choices, based upon their own criteria, again illustrates the importance of variability associated with QoL assessment. Therefore, in addition to patients being able to select their own criteria as to what contributed to their personal QoL, patients were also able to choose the relative importance of each of the aspects nominated. Ranked aspects are synonymous with importance weightings for individual patients. Allowing patients to rank order their important aspects had at least two aims. The first aim was that in clinical situations, medical staff or counsellors, by knowing the priorities of patients' aspects, might be able to place more emphasis on those that are most important to the patient. This might be in the hope that by resolving gaps between realities and expectations for more highly ranked aspects, more immediate and maximum benefits to the patient may result. The second aim of allowing patients to rank order important aspects was to assess change and how these rankings might change over time (this second objective will be discussed later in this chapter).

The following table lists the most importantly ranked aspects for each of the 42 patients interviewed. Only patient aspects from the first interview have been used in this summary. Five patients changed their most importantly ranked aspect between interview one and interview two. All of the other 31 patients who completed both interviews retained the same most importantly ranked aspect. The aspects shown have again been ordered by the researcher into categories that summarise the information based upon the Checklist of Quality of Life Domains (Appendix A). Aspects were assigned to categories based upon the researcher's judgement rather than individual patient's judgements.

Table 23: Most Important QoL Issue for each patient:

Physical well-being:
Symptoms
Burning feeling in throat - short of breath
Feeling itchy
Sleeping is a problem (lumps causing a problem)
Sleeping problems - discomfort from sore legs
Treatment Side-effects:
Going to the toilet too often
Physical Health:
Feel as if I'm falling to pieces - e.g. I have a limp for no reason
Tired- when I've walked to the shops (etc.)
Mobility
Daily Activities and Functions
Domestic Tasks:
Difficult to walk
Being able to cope by myself (because I live by myself)
Work Activities:
Functioning in work and social activities
Social Activities:
-
Sports and Leisure Activities:
Use to play golf - but can't now
Psychological Well-Being
Emotional Health:
State of mind - having a positive attitude
Feeling of anxiousness (feel as if something is not right)
Feelings of anxiousness
Feel anxious
Feel anxious about what will happen after I've gone
Anxious about what will happen to my wife and son
Difficult to remember
Important to be able to concentrate on crosswords and so on.

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Table 23: Most Important QoL Issue for each patient (cont.):

Concentration/Remembering:
Ability to concentrate
Family Issues
Sources of Support:
Assistance for my wife - the impact on her
Family issues - assistance of my daughter
Family -made sure they know how things stand
Feeling of love and support
Family - how this affects them
Supportive loving family
To get on with people
Relationship Issues:
-
Financial Issues:
Financial issues -husband in a resthome and costs associated with this
Financial issues a concern
Financial issues - making things in order
Spiritual Issues
Issues Relating to Death:
I have a strong faith
I have a strong faith
Personal Feelings:
Sense of fulfillment
Future Hopes/Goals/Concerns
Carry on as I was before
Future needs of my family and myself
Pain management - important I don't feel pain
To feel normal
To function independently - do my own thing
To be able to walk properly
To be positive
Thinking I might have to be a burden to my family

While it would appear that some of the most important aspects for individual patients listed in the above table may be relatively easily resolved, for example, those aspects related to physical well-being, many other aspects listed do not have such simple solutions. Issues related to psychological well-being, family support, financial issues and patients' future hopes/goals/concerns were some of the aspects of most importance to individual patients where no straightforward medical intervention can assist.

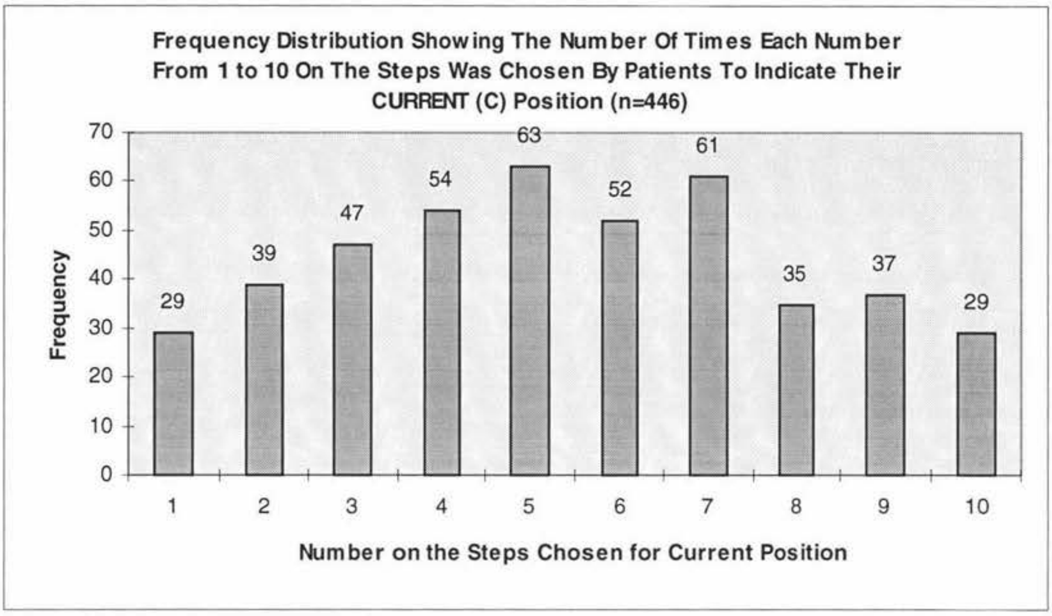
While the above table lists the most importantly ranked aspect for each of the 42 patients interviewed, again the results illustrate the large variety of aspects deemed most important for these patients. This variety in turn supports the need for an idiographic approach to the assessment of QoL.

Current, Ideal and Difference Scores

A primary objective for the development of QoL-Steps was to explore the variability between different patients and this was again illustrated with the results from the current, ideal and subsequent difference scores derived from QoL-Steps. As already mentioned, QoL-Steps allowed patients to nominate important aspects of their lives, rank these in an order of personal importance, and then assess the current and ideal positions for these aspects on a stepped scale. The gap or difference between a patient's current and ideal positions represents a shortfall in a patient's QoL. This shortfall can be defined as the gap between a patient's reality and his or her expectations. Using an idiographic approach to the assessment of QoL entails the examination of the current and ideal positions for individual patients, as well as the differences between these positions and importantly, the variability that results. For illustrative purposes, it is useful to examine these findings based upon aggregated patient assessments.

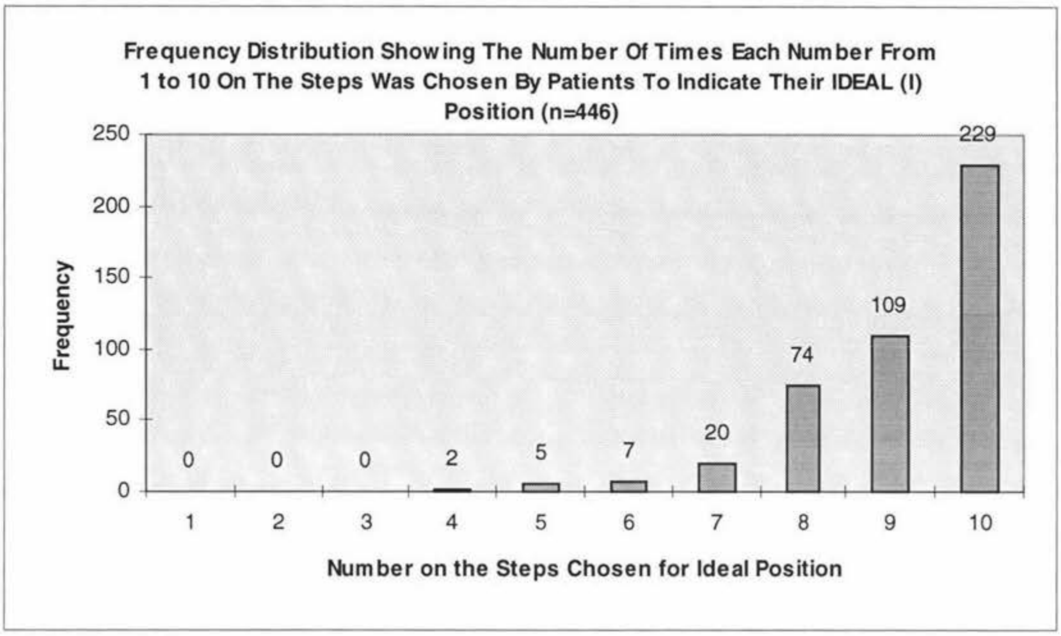
The following chart shows a frequency distribution for all 42 patients in the sample. The chart shows a frequency count of the numbers nominated by patients when they were asked to place their ***current*** position on the steps from 1 to 10. The frequency count includes responses from both the first and second interviews, but recall that not all patients were able to be interviewed twice. T1 resulted in 252 ratings from patients giving their current positions, while T2, based on a smaller sample, resulted in 194 ratings. The total base was therefore 446 ratings for the two time periods. The chart shows an approximate normal distribution, although there is a slight dip in the centre. Figure 4 shows, for example, that the number 5 was chosen 63 times by patients to indicate their current position. This count of 63 could have included patients who indicated this position in either T1 and T2 (which would mean that the position 5 was counted twice for this person) or only in T1 or only in T2.

Figure 4



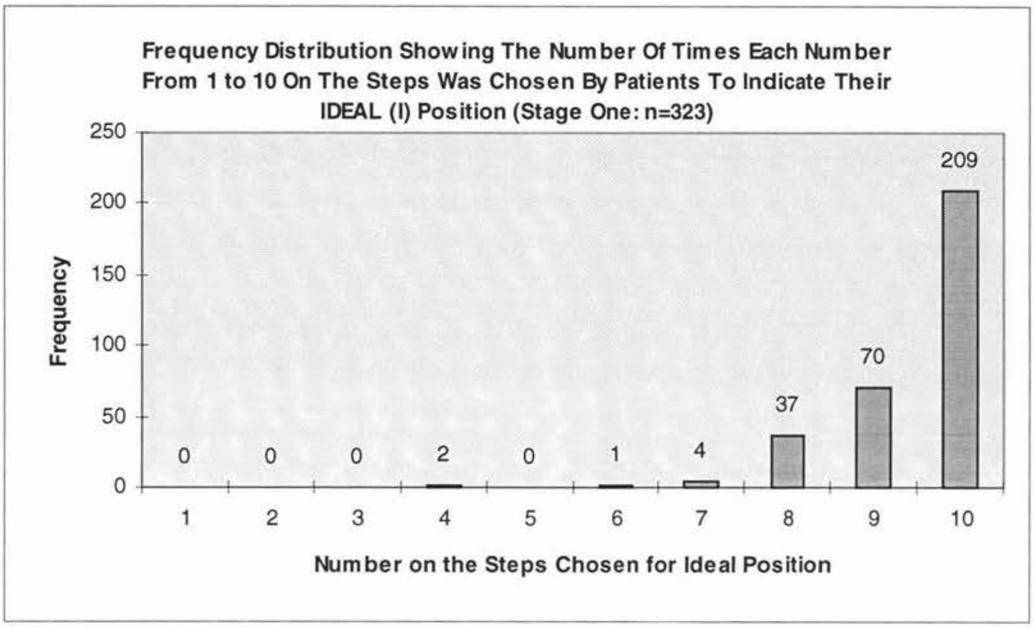
The next chart is again a frequency distribution, but in this case the frequency count is of the numbers nominated by patients when they were asked to place their ***ideal (I)*** position on the steps from 1 to 10. Again, the frequency count includes responses from both the first and second interviews. When asked to nominate their ideal position on the steps, patients were inclined to select numbers that were high on the scale, as can be seen from the large number of patients who selected 10 as being their ideal. As a result of patients choosing numbers in this upper range, modifications to the procedure were suggested (as outlined in Chapter 2).

Figure 5



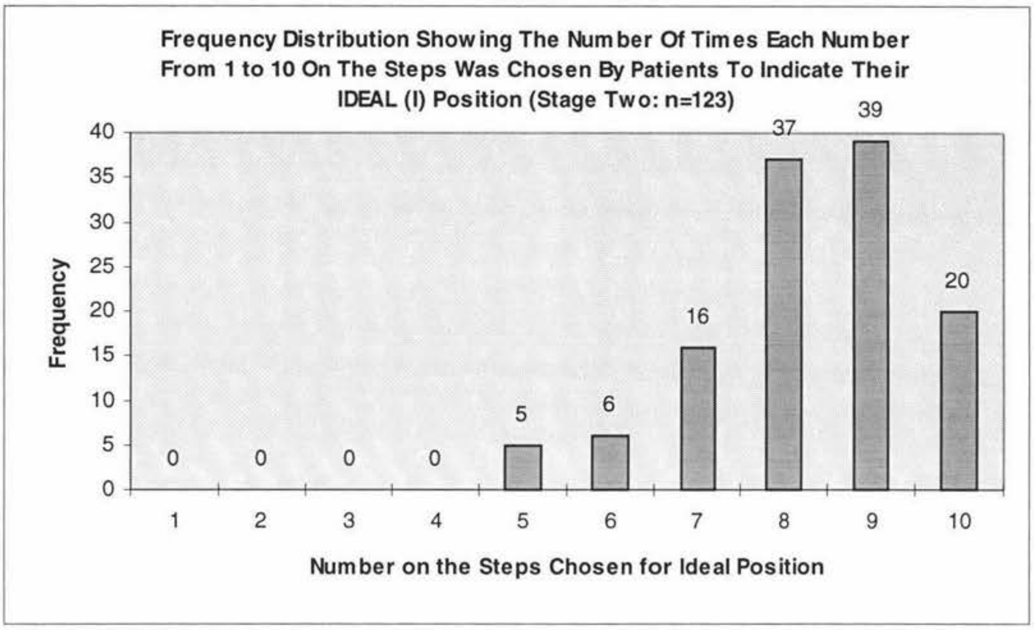
The next two distributions (Figures 6 and 7) again summarise the results of the frequency counts of numbers nominated by patients when they were asked to place their *ideal* position on the steps from 1 to 10. However, the first chart shows the frequency count of patients' ideal positions before modifications were made to the procedure. Recall that the sample size in stage one, before modifications, was 29 patients. The frequency count includes responses from both the first and second interviews, but not all patients were able to be interviewed twice. T1 resulted in 172 ratings from patients giving their ideal positions, while T2, based on a smaller sample, resulted in 151 ratings. The total base was therefore 323 ratings for the two time periods. As can be seen, there was a clear bias towards the upper end of the scale on the steps, with patients more likely to select high numbers on the steps to indicate their ideal position. The highest point on the steps, 10, was chosen by patients 209 times.

Figure 6



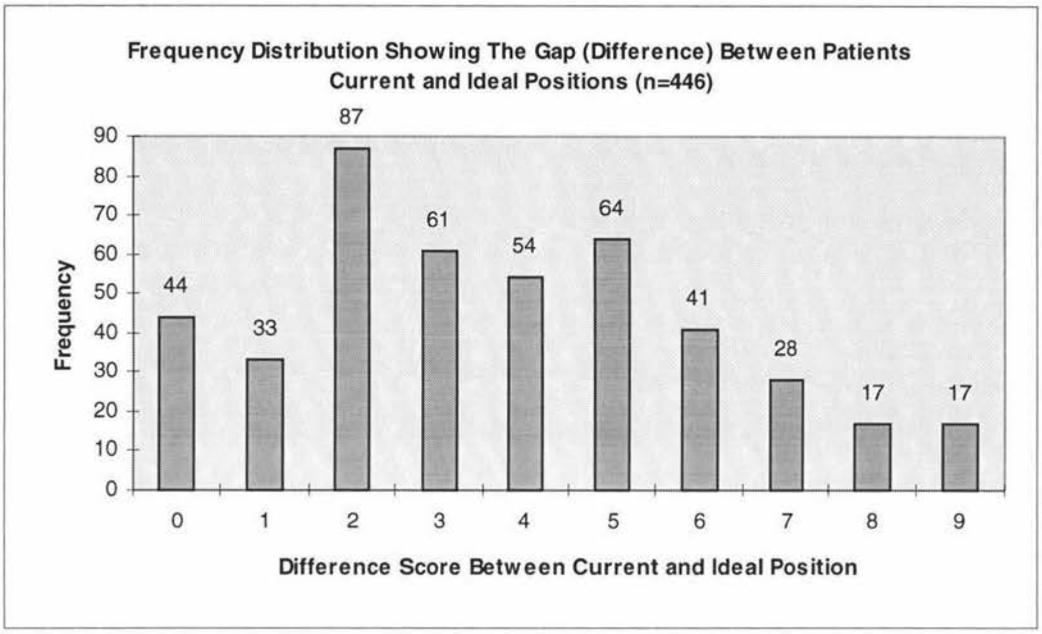
This bias by patients, towards selecting the highest numbers on the scale to represent their ideal position, prompted modifications to the QoL-Steps procedure. Recall that modifications to QoL-Steps included changing the anchor positions and also making the instructions to patients more explicit in terms of encouraging a realistic perspective for patients when asked to select their ideal positions. The next frequency distribution (Figure 7) was based upon data from stage two of the research (the modified procedure) and included a sample of 13 patients. The frequency count for stage two also included responses from both the first and second interviews, but again, it was not possible to interview all patients twice. T1 resulted in 80 ratings from patients giving their ideal positions, while T2, based on a smaller sample, resulted in 43 ratings. The total base was therefore 123 ratings over the two time periods. While patients' ideal scores were still relatively high on the steps, it seems that modification to the QoL-Steps procedure had some effect in lowering patients' ideal positions.

Figure 7



The difference scores between patients' current and ideal positions on the steps are also shown as a frequency distribution in the following chart (Figure 8). Recall that the difference or gap between a patient's current and ideal positions represents a shortfall in a patient's QoL and can be defined as the difference between a patient's reality and his or her expectations. The difference scores shown are for all 42 patients from both the first and second interviews giving a total base size of 446 ratings for the two time periods. As can be seen from the chart, the most common difference score was 2 but gaps of 3, 4, and 5 were also common. Note too, that for some patients, there was no difference between their current and ideal positions (a score of zero). Again, QoL-Steps demonstrates the variability objective inherent within an idiographic approach to QoL assessment.

Figure 8

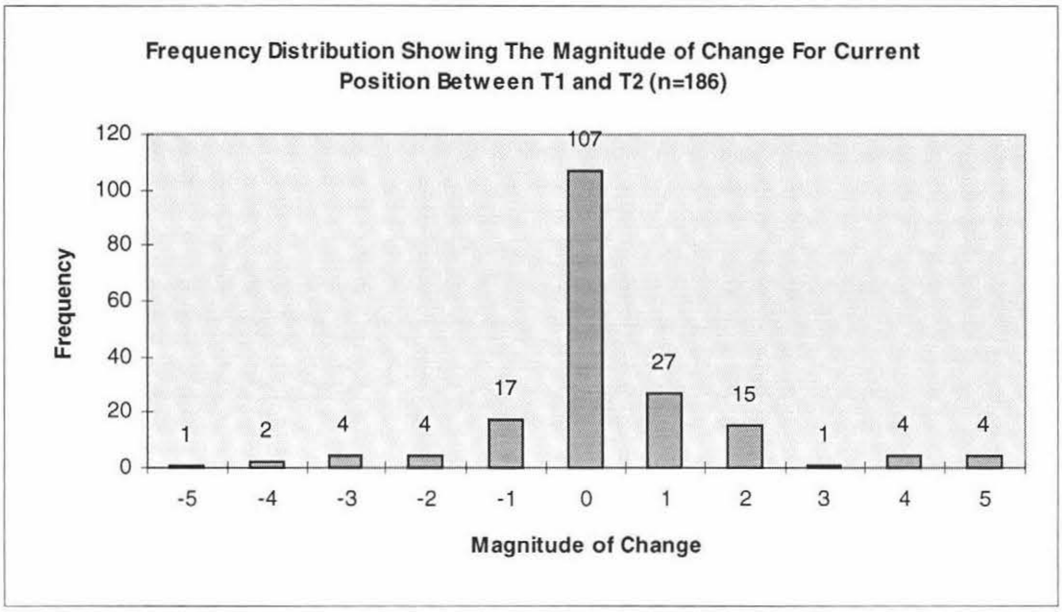


Changes in Current, Ideal and Difference Scores

In addition to eliciting important aspects of a patient's life, a further objective for QoL-Steps was to explore the concept of change. If one of the goals for palliative care is to produce response shift, where a patient may reassess his or her internal standards, change his or her personal views to meet new life circumstances, or reconceptualise what constitutes his or her QoL, then response shift assessment becomes a necessary requirement. QoL-Steps asked patients to nominate important aspects of their lives and evaluate these aspects with respect to both their current (actual) and ideal positions on a set of steps numbered from 1 to 10. Taken over two time periods, this process provided an assessment of each patient's current and ideal position for time period one (T1) as well as an assessment of the current and ideal position of the same aspect for time period two (T2).

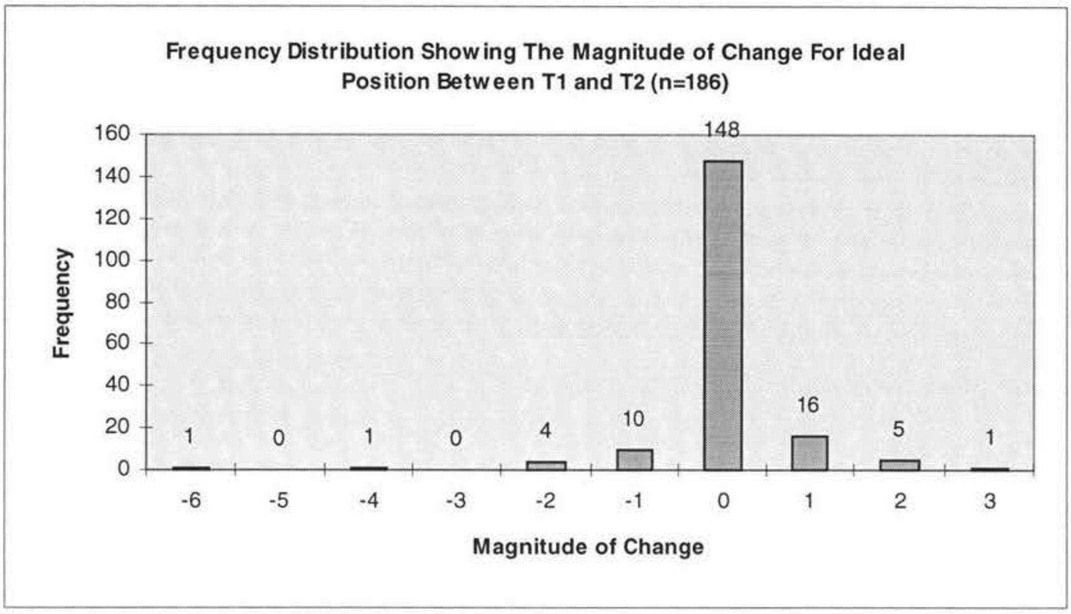
The following chart (Figure 9) shows a frequency distribution that is based upon data from the 31 patients who completed interviews in both T1 and T2. The chart illustrates both the number of times patients' ratings of *current* position changed between the two time periods as well as the magnitude of change for these patients. As can be seen from the distribution, most patients' ratings of their current position did not alter. However, there were 51 instances where the current position improved, while 28 ratings worsened.

Figure 9



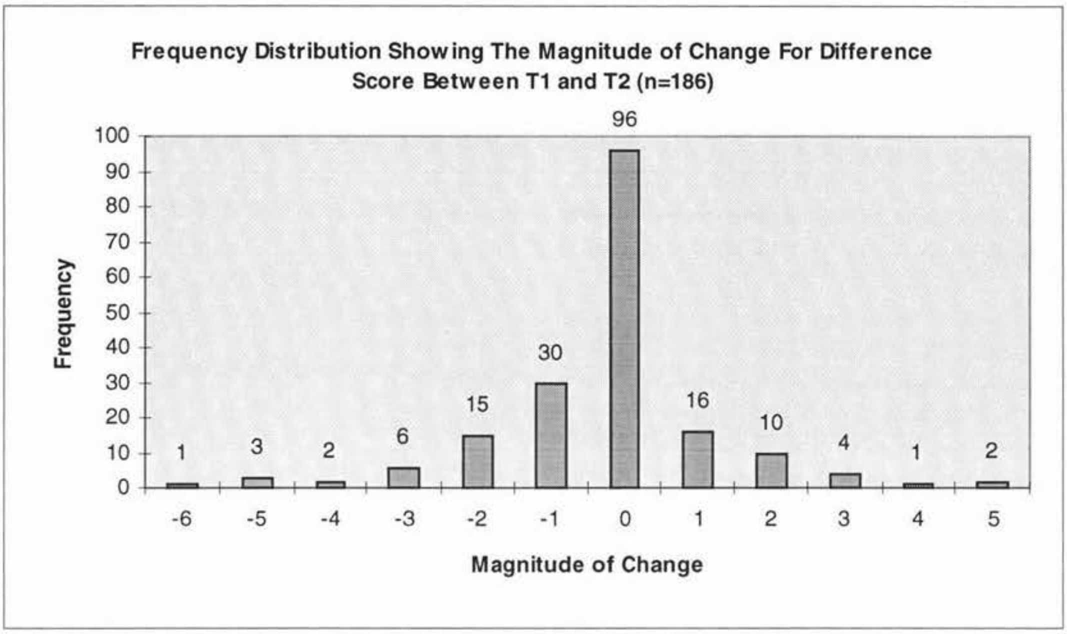
The next frequency distribution shown is again based upon data from the 31 patients who completed interviews in both T1 and T2. In this case, the chart illustrates both the number of times patients' ratings of *ideal* position changed between the two time periods as well as the magnitude of change for these patients. Again, most patients' ratings of their current position did not alter. However, for the ideal position, there were 22 instances where the ratings improved between T1 and T2, while 16 ratings got worse for patients over the two time periods.

Figure 10



The final frequency distribution (Figure 11) shown in the next chart, was again based upon data from the 31 patients who completed both interviews and illustrates the magnitude of change for difference scores between patients' current and ideal scores. The difference scores between current and ideal positions for most patients remained unchanged, however there were 33 instances where the difference score improved and 57 instances where the difference score deteriorated.

Figure 11



Alpha and Beta Change

Zmud & Armenakis (1978) have argued that patterns of actual and ideal assessments, taken over time, can be interpreted as indicators of alpha and beta change and that the actual-ideal technique itself is a way of disentangling alpha and beta change . The five patterns that Zmud & Armenakis (1978) proposed are shown in the following table (Table 24) along with the number of times each of these particular patterns occurred within the data.

As discussed in Chapter 2, the effective sample size that generated the data for change analysis was 31 patients, given that 11 patients died before being interviewed for a second time. Even with this reduced sample, there were still 186 aspects nominated by patients, which included aspects nominated in both first and second interviews. 186 aspects approximated 6 concerns per patient in the sample.

Table 24: Alpha and Beta Change

Description of the pattern:	Number of times pattern appeared in the data	Type of change	
1. Perceptions of current behaviour are the same. Perceptions of ideal behaviour are the same. Gap scores are the same. ***It is not likely that change has occurred.***	**91**	-	-
2. Current and ideal scores have both changed from T1 to T2. However, the gap between current and ideal scores has remained the same. The respondent has redefined the measurement scale, but has not changed his/her perception of the concept. ***Beta change has occurred***	**5**	-	**Beta**
3. The current behaviour remained the same but expectations related to ideal behaviour changed. There has been a shift in the measurement scale. ***Beta change has occurred, but little can be inferred about alpha change.***	**16**	**Alpha?**	**Beta**
4. Both current and ideal behaviour have changed and as a result, the gap between each has also changed. ***Beta and alpha change have probably occurred.***	**17**	**Alpha**	**Beta**
5. The ideal behaviour remained the same but current behaviour changed. The stability of the ideal responses is taken to mean no measurement scale change. ***Alpha change has probably occurred.***	**57**	**Alpha**	-
Total number appearing in data	**186**		

It is noteworthy that we found examples of each of the five patterns despite the short time interval between interviews. Recall that 24 of the 31 patients were interviewed with an interval of two weeks between interviews. The remaining 7 of the 31 patients were interviewed with an interval of four weeks between the first and second interview.

Pattern 1 was where the gap scores were the same for each time period, therefore it was unlikely that any form of change had occurred. In QoL-Steps, 91 of the concerns raised by patients could be categorised into this pattern. As a pattern, this may seem unexceptional, but the accurate detection of stability is important, especially in the palliative care context. In certain cases, it is perhaps reassuring that patients were able to at least maintain their current position on the scale even if this fell short of their ideal position. Maintenance of ideal and actual states is often an important goal in palliative care. An example of this pattern, reflecting no change, was the patient who indicated that he would "like to be able to carry on as before (prior to being diagnosed with cancer)". In time period 1 the current assessment of this aspect was 5 and the ideal was 10. The current and ideal assessment in time period 2 was still 5 and 10 respectively. Given no intervention strategy and everything remaining equal, such a pattern might be expected, and the result was important to the extent that at least the assessment did not worsen over the two time periods. We could speculate that the relatively high number of instances for pattern 1 could be the result of the short interview time frame. Twenty-four patients generated 78 instances of pattern 1 (just over 3 instances per patient) when there was an interval of two weeks between interviews. When the intervening period was extended to 4 weeks, it was less likely that patients reported a "no-change" pattern. Under these circumstances, the 7 patients concerned only generated 13 instances of pattern 1 (less than 2 per patient). However, due to the small bases involved, these results remain speculative.

In pattern 2, both the current and the ideal scores changed between the two time periods. But what was perhaps more important was that the gap between the current and ideal assessments remained constant. So the patient's evaluation remained the same, but the measurement scale that was used to assess the current and ideal positions had changed for the patient. Only 5 aspects proposed by patients fitted this particular pattern, a pattern that Zmud & Armenakis (1978) suggest reflects beta change. An example that illustrates pattern 2 was shown by a patient who proposed that she felt frightened for her family but at the same time felt indispensable to her family's needs. In time period 1 the current assessment on this aspect was 8 while her ideal assessment was 10. In time period 2, four weeks later, this patient evaluated her current position on this aspect as being 6 and her ideal as now being 8. As can be seen, the gap is exactly the same, a parallel shift of two in both cases, but perhaps given the intervening time period involved, the patient had recalibrated the scale with the resultant beta change implied. Pattern 2 was much more likely to have occurred with patients who were interviewed 4 weeks apart rather than just 2 weeks. Although this pattern occurred in our data only 5 times, three of these instances were with patients that were interviewed 4 weeks apart. From the data we could speculate that recalibration was more likely to occur over a longer time period or (although not so easily supported here) when a patient was subjected to dynamic changes in his or her life circumstances.

Pattern 3, according to Zmud & Armenakis (1978), reflects a change in expectations related to the ideal position, while the current position remains unchanged. Such a pattern reflects beta change because of the shift in the measurement scale, but it is difficult to infer anything that may relate to alpha change in such a pattern. QoL-Steps results suggest that 16 aspects proposed by patients fitted this pattern. The ideal position could increase or decrease in relation to the first time period assessment. So, for example, one female patient who was particularly concerned about financial issues indicated in time period 1 that her current assessment was 1 and her ideal position was 8. In time period 2, (two weeks later for this patient) the current assessment was still 1 but now the ideal position had increased to 9. Zmud & Armenakis (1978) suggest a shift in the measurement scale (beta change), but predictions as to what might be happening to alpha change are not possible.

Pattern 4 reflects both alpha and beta changes due to the patients change in assessment of both current and ideal positions. Within the QoL-Steps data, this pattern occurred 17 times, almost half of which (8 instances) occurred with patients who were interviewed 4 weeks apart rather than 2 weeks apart. Notice that pattern 2 and pattern 4 differ because, although ideal and current scores increased in both cases, the ideal-current gap changes only in the latter. An example of pattern 4 was reflected in the following example. This patient proposed that a concern for him was the reaction of other people to finding out that he had cancer. It was their reactions to him that were particularly upsetting and the fact that they often didn't know what to say to him. At the first interview, this patient assessed the current position for this concern as being 4 and the ideal position as being 8. In time period 2, the current position had improved to 7 but the ideal position had also increased, and was now 9. So although the current position had improved, there was also a non-parallel shift in the ideal score for this patient.

Finally, pattern 5 reflected some stability in the ideal scores and it was the current assessment of behaviour which contributed to change. As a result, change under pattern 5 was probably made up of alpha change (Zmud & Armenakis, 1978). There were 57 instances of pattern 5 present in the QoL-Steps data. An example of this pattern was reflected by one patient's concerns related to his previous working life. In this case, the patient had a feeling that his working life had been "wiped out". In period 1, this patient assessed this aspect as being currently 5 on the scale, but ideally he would have liked to have been situated at 9 on the scale. In period 2, two weeks later in this case, the ideal position was still 9 on the scale but the patient had changed his current view, which was now 7 on the scale. Such a change might reflect the patient's coming to terms with significant life events. Often the set of circumstances facing patients in palliative care was difficult, both in terms of comprehending and coming to terms with a new set of expectations. In this case, the patient had had a successful career and had been physically fit, but within the space of a very short time, had been forced to give up work, as well as his mobility, and was now dependent upon a wheelchair.

In summary, one of the objectives for QoL-Steps was that it would allow for the assessment of change for a particular patient over time and provide data to examine the patterns of change for that individual. QoL-Steps, as an assessment instrument, did generate change data, and in turn, this data was fitted to the five patterns proposed by Zmud & Armenakis (1978) as a way of disentangling alpha and beta change. Results suggest that both alpha and beta change did occur for patients, which supports the suggestion that response shift should be taken into account within the context of palliative care, where physical and psychological states may change over relatively short time periods.

Gamma Change

One of the objectives for QoL-Steps was that it would enable patients to rank order the aspects of QoL most important to them. As already discussed, allowing patients to rank order important personal aspects had at least two aims. The first aim has already been discussed, and includes clinical situations where medical staff or counsellors, by having access to a list of important aspects, may be able to place more emphasis on those aspects which are deemed of most importance to the patient. In allowing patients to rank order important personal aspects, the second aim of this study was to assess gamma change.

As previously defined, gamma change involves "a redefinition or reconceptualisation of some domain, a major change in the perspective or frame of reference within which phenomenon are perceived and classified, in what is taken to be relevant in some slice of reality" (Golembiewski et al., 1976).

The importance rankings of aspects nominated by patients were recorded in both time period one (T1) and time period two (T2) for the 31 patients who completed both interviews. For most patients, the rankings remained constant between the two time periods. But for 12 patients (out of 31), the rankings proposed for their individual aspects changed between T1 and T2. In some cases, the order of importance was changed around slightly, and this might have been dependent upon how the patient was feeling on that particular day. So, for example, if a patient had had a bad night, then certain aspects could be more important to him or her. In other cases, the order of importance for the patient was considerably different. Aspects that had been relatively important previously, might now no longer be relevant at all. Other aspects that had been less important, could now suddenly be of much more significance.

A good example of redefining what was important, was a female patient who in T1 nominated an aspect related to feeling frightened for her family and feeling indispensable to them. The patient ranked this concern as being 3 in terms of its importance to her. In T2, the ranking for this aspect had decreased to 5. So in the intervening 4 week period, the patient had re-evaluated this concern for her family and perhaps come to terms with the belief that her family would survive without her. For this same patient, work was ranked 4 in importance in T1 and was reflected in her belief that her work "dreams had been shattered". In T2, work expectations now no longer played a part in her life at all. In the patients own words, she described how she didn't even think about work anymore - it was no longer important to her and she didn't concern herself with it. This reflects a major turn-around between the two time periods. It demonstrates the dynamic and variable nature of individual concerns and it also suggests that change between time periods should include the ability of patients to reconceptualise the order and specific content of aspects that are important to them.

In summary, this chapter explored rankings of aspects deemed important by individual patients. Results of the individual patient's most important rankings, along with the frequency distributions that summarised current, ideal and difference scores for patients, demonstrated the variability that could be obtained from approaching the assessment of QoL from an idiographic perspective. Patterns of change were explored and results suggest that alpha and beta change were present. Results of changes in rankings also suggest that gamma change may have occurred for some patients.

Chapter 5

Case Results

The results presented for QoL-Steps up to this point have largely been summaries of data collected during interviews. These summaries provide a useful overview of the instrument and support the objectives for the initial development of QoL-Steps. Recall that the objectives set for QoL-Steps were: that it should allow patients to express important aspects of their personal QoL, prioritise the aspects they had nominated in an order of personal importance, enable a difference score to be calculated showing the gap between a particular patient's current and ideal positions on a scale and finally, allow for the assessment of change for a particular patient over time and provide data to examine the patterns of change for that individual.

In order to show the true idiographic nature of QoL-Steps, it is important to explore some actual cases of patient data. As well as providing evidence for the support of the objectives set above, looking at individual cases allows us to take a closer look at the procedure taken within QoL-Steps. With the addition of extra patient information, particular case studies allow more context to be built up around a patient, assisting in the picture that may be obtained of the circumstances facing a patient as an individual. As a consequence of exploring particular cases, it is suggested that issues such as the assessment of change can not easily be reduced to simple studies of patterns that may occur in the data. Change assessment needs to take place within a context, and it is the individual patient that provides this context.

The Gap Profile - Difference Scores (Patient A)

For one particular patient (Patient A), a special case was made and he was interviewed three times. All other patients were interviewed only twice, (or once if the patient died before the second interview). Patient A specifically asked to be interviewed on three occasions. The reason he gave for this request was that he was using the procedure as a gauge to monitor his own improvement over the three interview occasions. He found it useful to use each assessment period as a reference point and to monitor improvement or decline for each aspect deemed important to him.

The first interview (T1) established six aspects that were important and these were ranked by Patient A as follows:

Table 25: Important aspects for Patient A at T1

Aspects	Importance ranking
Mobility	1
Positive attitude	2
Being able to swim	3
Keeping up social activities	4
Feelings of depression	5
Having to get up at night to go to the toilet	6

So for Patient A, being mobile was of greatest importance, where mobility included being able to drive a car that had recently been purchased. The second aspect was to have a positive attitude and the third aspect was being able to swim. Swimming was seen by Patient A as being necessary to keep fit and active, as well as to keep his body moving and relatively flexible. Patient A set himself a goal to be able to swim a little bit further each week. Keeping up social activities was ranked 4th in terms of importance. Patient A lived in a retirement village and as Chairman of the Advocate Committee for the village, took an active part in organising activities, village functions and welcoming new residents. Feelings of depression were ranked 5th, with Patient A trying to keep on top of these feelings. The last aspect, ranked 6th, related to having to get up at night to go to the toilet. Patient A had been diagnosed as having prostrate cancer with secondary bone cancer.

Once aspects were ranked, Patient A was asked to provide his perceived current position on the steps, from 1 to 10, for each important aspect he had nominated, and subsequently, his perceived ideal position for each aspect, also from 1 to 10, on the same set of steps.

The following table provides the patient-derived assessments for Patient A:

Table 26: Assessments for Patient A at (T1)

Aspects	Current	Ideal	Gap
Mobility	7	9	2
Positive attitude	9	10	1
Being able to swim	3	9	6
Keeping up social activities	7	9	2
Feelings of depression	8	10	2
Having to get up at night to go to the toilet	6	9	3

The data for Patient A demonstrates the relatively high scores for assessments of ideal positions, but current scores were also mostly in the upper region on the 1 to 10 scale. The gaps shown are the difference scores between ideal and current ratings and reflect deficiencies in QoL. The biggest gap was between the ideal rating for swimming (9) and the current rating for this aspect (3). This was an aspect that Patient A wanted to work towards improving in the future. Having to get up at night to go to the toilet was a problem, but it wasn't ranked highly in terms of importance, meaning that Patient A could live with the inconvenience, but it was still an issue. For Patient A, there were gaps for every aspect nominated, between where the patient currently perceived himself to be and where he would like to have been.

The second interview (T2), two weeks after the first interview for Patient A, established that the same six aspects were still important for the patient, and that the ranked order for these aspects also remained the same. However, between T1 and T2, current and ideal ratings had changed and consequently, so too had the difference scores.

Table 27: Assessments for Patient A at (T2)

Aspects	Current	Ideal	Gap
Mobility	7	9	2
Positive attitude	9	10	1
Being able to swim	5	10	5
Keeping up social activities	7	9	2
Feelings of depression	9	10	1
Having to get up at night to go to the toilet	7	9	2

For Patient A, there were now two time periods in which to compare current, ideal and difference scores. This comparison provides change data that is useful for looking at particular aspects of change. However, analysis of the data in terms of patterns, may be misleading. The first two aspects: "mobility" and "having a positive attitude" did not change between T1 and T2. The third ranked aspect, "being able to swim", did change however, with the gap between current and ideal decreasing in magnitude by 1 from 6 to 5. The difference score (gap), could be treated as a final measure of QoL, but there is a danger in doing so. It is important to examine how the gap is arrived at i.e. what are the numbers that make the gap and how do these change. In T1, Patient A indicated that his current score related to swimming was 3, whereas he would have liked to have been able to achieve 9 (his "ideal"). The gap between the two assessments was 6. In T2, the current score had now improved to 5. Verbally, Patient A expressed this improvement as being able to swim more lengths of the pool, and as a result he had elevated his current position on the steps to reflect this improvement. But interestingly, as a result of this better performance, his expectations (reflected by his "ideal") also increased from an ideal score of 9 to the highest limit on the steps, 10. So although the current score improved by a magnitude of 2, the actual gap only decreased in magnitude by 1. By improving on his current assessment in (T2), the patient had also inflated his ideal expectations.

The 4th aspect "keeping up social activities" did not change from T1 to T2, but the last two aspects, "feelings of depression" and "having to get up at night to go to the toilet" both improved between the two time periods. The gap between current and ideal positions for each of the last two aspects reduced in magnitude by 1.

Assessment of change related to gap scores is further complicated when the special case of a third interview period (T3) for Patient A is added. Recall that a third interview was a one-off exception within the current research and results of T3 data have only been taken into account for this current chapter. The following chart provides the assessments for Patient A in T3, which was an interview conducted two months after the first interview:

Table 28: Assessments for Patient A at (T3)

Aspects	Current	Ideal	Gap
Mobility	4	8	4
Positive attitude	9	10	1
Being able to swim	5	8	3
Keeping up social activities	1	8	7
Feelings of depression	8	10	2
Having to get up at night to go to the toilet	-	-	-

Looking at the data from T3 and comparing this with T2 shows some quite dramatic changes as reflected in the gap measures. Between T2 and T3, Patient A had experienced quite a downturn in health. On two separate occasions, he had had to travel to a private hospital some 145 kilometres away to receive scans.

Of the original aspects, "mobility", "the ability to keep up with social activities" and "feelings of depression" all deteriorated in terms of the gap between current and ideal positions. Much of this change could be attributed to the patient's deterioration in health and a physical fall (evidenced by bruising to the head) that the patient had experienced between T2 and T3.

As mentioned previously, Richards (1997) suggests that numerically equivalent results from separate individuals may have very different clinical meanings. This demonstrates the dynamic nature of what might constitute QoL, where both current and ideal positions can show considerable variability. In conjunction with results that show larger gap scores, it is important to examine the numbers that contribute to the gaps. For example, the current score for "mobility" in T2 was 7 whereas the ideal score was 9 (gap = 2). But in T3, the current score for "mobility" had decreased to 4 and the ideal score had now decreased to 8 (gap = 4). Perceived mobility went down for Patient A but importantly, so did expectations reflected by the ideal score (even though the ideal score did not decrease to the same extent).

For Patient A, having a positive attitude remained a constant for all three interviews (T1, T2, and T3), and this aspect maintained a gap of magnitude 1 over all three interviews.

"Being able to swim" was an interesting aspect because although Patient A was not able to swim in T3, he still rated his current score for this aspect at 5 (the same as T2). However, the patient downgraded his expectations in terms of his ideal score to 8 on the steps. (This aspect had been 10 in T2). The resultant gap was now 3, whereas in T2, it had been 5. This result may seem inconsistent until it is put into the context of what was important to the patient with respect to ideals and expectations. Being able to swim was an important aspect of life for Patient A and even though it was not possible to achieve this goal in T3, it still remained an important goal for his future.

Changing aspects - reconceptualisation (Patient A)

So far, discussion has focused on change analysis related to gap scores. However, the data derived from Patient A also demonstrates another change profile which is potentially more global in its effects for a patient. Change in this sense concerns the reconceptualisation of aspects deemed important to the QoL of patients, over time.

When asked to nominate and rank order important aspects of his life, Patient A proposed the following aspects:

Table 29: Important aspects for Patient A at T1 and T2

Aspects	Importance ranking
Mobility	1
Positive attitude	2
Being able to swim	3
Keeping up social activities	4
Feelings of depression	5
Having to get up at night to go to the toilet	6

Between (T1) and (T2), there was no change in the ranking of these aspects. However, for the third interview (T3), conducted two months after the first interview, considerable change had occurred due to Patient A's deteriorating state of health.

The new aspects and their related rankings were now given as follows:

Table 30: Important aspects for Patient A at T3

Aspects	Importance ranking
Mobility	1
Positive attitude	2
* Tiredness - related to energy	3
* Weight-related - I want to put on weight	4
Being able to swim	5
Keeping up social activities	6
Feelings of depression	7
Having to get up at night to go to the toilet	-
* *New aspects for the patient*	

Swimming, although still deemed as important in terms of its ranking, was now "put on hold" in the words of the patient. But perhaps of most significance when discussing the assessment of change, the patient now included two new aspects that hadn't previously been important to him. As well, and to further complicate the assessment of change, one of the previous nominated aspects was now "solved" and was therefore no longer important to Patient A.

So in the two months between T1 and T3, Patient A had reassessed those aspects of life that were important to him. Due to his deteriorating health, this patient had added new aspects of concern: tiredness and the wish to be able to put on weight. Upon further questioning, the wish to put on weight was related to the patient's self-image and the status he had held in his former occupation as a bank manager. Weight, he asserted gave him "presence". One of the aspects that had been important in both T1 and T2 had been eliminated in T3. This related to bladder problems for the patient. Between T2 and T3 Patient A had been fitted with a catheter which meant that he longer needed to get up at night to go to the toilet.

Reconceptualising what is important to a patient illustrates the dynamic nature of QoL and how a patient's perception of QoL aspects may change over time. The ability of a QoL assessment instrument to record such changes is important, and preliminary results of QoL-Steps suggest that it is capable of detecting such global changes.

The Gap Profile - Difference Scores (Patient B)

Patient B was a female patient who had been diagnosed with cancer of the pancreas only 2 months before my first interview with her. As a consequence of the relatively short time period between diagnosis of terminal cancer and being interviewed about the important aspects of her life, Patient B was very much still trying to come to terms with her illness. This process was reflected in the aspects she nominated as being important to her. The first interview (T1) established six aspects that were important and these were ranked by Patient B as follows:

Table 31: Important aspects for Patient B at T1

Aspects	Importance ranking
I have a strong faith	1
How I felt when I was told I had cancer	2
Don't accept this. Don't want to die.	3
Having contact with church people (house groups)	4
Would like to be able to do more painting	5
I haven't driven (a car) since this happened.	6

So for Patient B, having a strong faith was of greatest importance - she was a member of the Pentecostal Church. Interestingly, aspect 4 was also related to the patients' church, and she obtained support from having contact with church people visiting her at home. The second most important aspect for Patient B was how she felt when she was diagnosed with terminal cancer. Aspect 3 was related to the devastated feeling she experienced, and she still had not been able to accept the diagnosis she had been given at the time of the first interview. Her feeling that she was not ready to die seemed to contribute to the denial she felt. The 5th most important aspect for Patient B related to her wish to be able to do more painting, which was something that she had enjoyed before her illness. Painting was now something that she could not be motivated to do, even though she felt that it might be beneficial to her. The 6th and final aspect related to being able to drive a car, something that she had not been able to do since her cancer diagnosis.

Once aspects were ranked, Patient B was asked to provide her perceived current position on the steps, from 1 to 10, for each important aspect nominated, and subsequently, her perceived ideal position for each aspect, also from 1 to 10, on the same set of steps.

The following table provides the patient-derived assessments for Patient B:

Table 32: Assessments for Patient B at (T1)

Aspects	Current	Ideal	Gap
I have a strong faith	8	10	2
How I felt when I was told I had cancer	7	10	3
Don't accept this. Don't want to die.	1	10	9
Having contact with church people (house groups)	7	10	3
Would like to be able to do more painting	2	10	8
I haven't driven (a car) since this happened.	1	8	7

The data for Patient B again demonstrates the relatively high scores for assessments of ideal positions, but current scores showed a wider range of numbers selected. The biggest gap was between the ideal rating for "Don't accept this. Don't want to die" (10) and the current rating for this aspect (1) (gap = 9). Such a large gap reflects a big deficiency between the reality and expectations for Patient A in relation to this aspect. The second largest gap related to the patient wanting to do more painting (gap = 8), while the third largest gap was in relation to not having driven a car since her diagnosis (gap = 7). This last aspect was lower down the rankings (6th) and was not as important to Patient B. The ideal for this aspect was also lower (8 on the scale).

The second interview (T2), two weeks after the first interview for Patient B, established that the same six aspects were still important for the patient, and that the ranked order for these aspects also remained the same. However, between T1 and T2, current and ideal ratings had changed and consequently, so too had the difference scores.

Table 33: Assessments for Patient B at (T2)

Important aspects for Patient B at T2	Current	Ideal	Gap
I have a strong faith	8	10	2
How I felt when I was told I had cancer	2	10	8
Don't accept this. Don't want to die.	1	10	9
Having contact with church people (house groups)	7	10	3
Would like to be able to do more painting	2	4	2
I haven't driven (a car) since this happened.	2	4	2

With two time periods to compare current, ideal and difference scores, it is possible to examine aspects of change for Patient B. The first aspect, which was ranked most importantly in both time periods, showed no change in the assessment scores. However, the current assessment for the second aspect "How I felt when I was told I had cancer" had declined by 5 points between T1 and T2 and the gap between current and ideal scores had now increased from 3 in T1 to 8 in T2. Patient B had still only had a short time to come to terms with her illness and was still having difficulty with this process. But instead of the gap improving for this aspect in the two intervening weeks, it had got much worse for Patient B when she thought back as to how she felt when told she had terminal cancer.

Assessments for aspect 3 remained the same between T1 and T2, and this aspect still contributed the largest gap (9 points). Similarly, assessments for aspect 4 remained constant over the two time periods. The last two aspects for patient B, however, illustrate a change in expectations for the patient. The ideal score for "would like to do more painting" decreased from 10 in T1 to 4 in T2 while the current score for this aspect remained at 2. This meant that the gap for aspect 5 decreased from 8 to 2. The ideal score for " I haven't driven since this happened" also decreased, in this case from 8 in T1 to 4 in T2. This meant that the gap for aspect 6 decreased from 7 to 2. Such a decline in expectations was recognised by Patient B herself. Although these aspects were still important to her, she proposed that she needed to be realistic in her expectations. So even though only two weeks had passed between T1 and T2, the assessments of some aspects for Patient B changed dramatically, while others remained relatively constant.

Changing aspects - reconceptualisation (Patient C)

The final case study presented here, relates to Patient C, and again illustrates the re-ranking of important aspects. Patient C was female and had been diagnosed with colon cancer. The first interview in T1, established 3 aspects that were important to the patient and these were ranked as follows:

Table 34: Important aspects for Patient C at T1

Aspects	Importance ranking
Takes a long time to do things (e.g. around the home)	1
Haven't as much stamina	1
Don't like driving a car now – which affects social activities	2

Because patients were able to rank aspects at equal levels, Patient C ranked her first two aspects first equal as she believed them to be related. The last aspect "don't like driving a car now", was ranked second in terms of importance. Patient aspects could contain more than one issue. For example, the last issue for this patient related to driving a car, but lack of transport also interfered with Patient C being able to attend social activities.

The second interview (T2), was conducted 4 weeks after T1. Patient C had reconceptualised the aspects she deemed important to her as shown:

Table 35: Important aspects for Patient C at T2

Aspects	Importance ranking
* Family – made sure they know how things stand	1
* Getting house/estate in order	1
Takes a long time to do things (e.g. around the home)	2
Haven't as much stamina	2
Don't like driving a car now – which affects social activities	3
* *New aspects for the patient*	

Between T1 and T2, Patient C's health had deteriorated markedly. In her own words, "cancer had taken its toll". Although still at home, Patient C was now confined to a bed and had full-time home help. The most important aspects for Patient C at T2 were getting things in order "and tidied up for when I die". She had accepted her illness and was concerned about getting issues such as her house tidy and ready for sale. Related to the nominated aspect "family", Patient C had divided up her jewelry between her two sons. So these two new aspects were now the most important for the patient. Aspects nominated in T1, while still important, were now re-ranked relative to more pressing aspects of the patient's life.

In summary, this chapter has illustrated the type of data that was generated by QoL-Steps by looking at some actual cases of individual patients. With additional context provided by the unique circumstances of individual patients, change analysis provides more meaning than collections of data patterns alone. QoL-Steps is an idiographic approach to the assessment of QoL and as such, takes account of the idiosyncrasies and nuances of individual patient situations. Change assessment needs to take place within a context, and it is the individual patient that provides this context. Change, for a patient, can take place at different levels. It can occur at the specific gap level, which indicates differences occurring for a patient between current and ideal scores over time periods. It can also occur at the more global level, where changing circumstances over time may mean the reconceptualisation of aspects deemed important for QoL.

Chapter 6

Discussion

The purpose of this study was to evaluate the use of QoL-Steps as an idiographic approach to the assessment of QoL. In developing QoL-Steps, objectives for the instrument included: firstly, that QoL-Steps should allow patients to express important aspects of their personal QoL. The variability of patient nominated aspects was an important part of this objective. Secondly, patients should be able to prioritise the aspects they had nominated in an order of personal importance. Thirdly, QoL-Steps should enable a difference score to be calculated showing the gap between a particular patients current and ideal positions on a scale. Fourth and finally, QoL-Steps should allow for the assessment of change for a particular patient over time and provide data to examine the patterns of change for that individual. Results from QoL-Steps suggest that these objectives were met. The instrument did provide a wide range of variability for individual patients, in terms of content, difference scores, rankings, and patterns of change. The discussion that follows is based upon the framework of comparative criteria for the QoL-assessment continuum previously introduced. This includes the range of aspects deemed important by patients, indices and group statistics, the weights applied to QoL domains, the need for a reference point, and the assessment of change. The discussion concludes with a suggestion that rather than being concerned with the psychometric properties of QoL-Steps, future research should extend the use of the instrument within the context of clinical assessment of individual patients. A major benefit of QoL-Steps may well be the contribution that such an instrument provides by enhancing the communication process between individual patients and their medical providers.

The range of aspects

QoL-Steps, as a QoL assessment instrument, can be located towards the idiographic extreme end of the QoL-assessment continuum. In keeping with one of the primary objectives for the development of an idiographic assessment of QoL, QoL-Steps demonstrated the variability that is inherent within individual patient perspectives of what is of most importance to that individual.

An idiographic approach allows a patient to define the content and determine the appropriate number of salient aspects deemed applicable for his or her QoL. Research methods and/or statistical techniques that fix or force a standard number of domains upon a patient may result in outcomes that are useful for comparative purposes between patients. But the use of such techniques moves an assessment instrument more towards the nomothetic rather than idiographic end of the QoL assessment continuum. QoL-Steps takes a more "pure" idiographic approach by allowing patients to define the number and content of important aspects they might have.

Recall that SEIQoL proposes 5 domains as being standard. Under SEIQoL's methodology, if a patient falls short of the required number of domains (or cues), they are prompted until the necessary five domains are obtained (O'Boyle, Browne, Hickey, McGee, & Joyce, 1995). Similarly, the number of domains cannot exceed 5. This requirement is forced upon SEIQoL due to its use of judgement analysis which treats 5 domains as optimum. Any less than 5, then providing a comparison between patients becomes difficult. Any more than 5, then people may start to experience cognitive problems related to the judgements they make.

Similarly, in the PGI, patients are asked to list the five most important areas or activities of their life affected by their condition, while the sixth domain reflects the rating on all other areas of life for the patient.

QoL-Steps allowed patients to select QoL aspects that were of personal concern to them as individuals. There were no restrictions as to how many aspects might be applicable. Hence, patients could have as few as one or two important aspects or, as many as fifteen or more.

When developing QoL-Steps, some thought went into whether there should be some limit imposed upon the number of aspects a particular patient should be able to propose. The concern was that if a patient nominated over 15 aspects, for example, then it may be difficult for the patient concerned to be able to rank the aspects into a meaningful order. The cognitive skill required to sort such a large number of aspects was considered too much of a burden. In addition, the more aspects proposed by the patient, the longer the interview process. Ascertaining assessments for more than 15 aspects may introduce respondent fatigue, a particularly sensitive issue when assessing patients in palliative care.

The highest number of aspects proposed by a patient in this initial trial of QoL-Steps was 14, with another three patients proposing 11 aspects each. None of these patients, including the one who proposed 14 aspects, appeared to have difficulty in rank ordering the aspects nominated. Recall that it was possible for patients to rank aspects at similar levels, which meant that similar aspects might have been grouped together by a patient. This grouping occurred for two of the patients who nominated more than 10 aspects. The ability of patients to be able to rank aspects also seemed to be enhanced by the procedure that was used. Recall that important aspects nominated by patients were written onto showcards. These showcards could be displayed in front of the patient who was then able to physically move the cards around until an appropriate order was arrived at. An examination of the ranks and the current and ideal scores over time, for those patients who proposed more than 10 aspects, suggested that results were still coherent and meaningful for the patient concerned.

Respondent fatigue did not appear to be an issue for the patients interviewed. The actual length of the interview did not seem to depend as much upon the number of aspects proposed by patients as it did upon the need of the patient concerned to be able to talk to someone about concerns they might have had. Because the interview itself was seen as a way of exploring various domains that might relate to a patient's individual QoL, there was no attempt made by the interviewer to curtail the discussion in any way, and patients were able to discuss a wide variety of aspects. For example, one patient spoke about his experiences in W.W.II, something which he had not even wanted to speak to his own family about. Talking about his experiences, and his memories were an important part of his life, but a difficult concept to capture easily, even within an idiographic assessment of QoL.

The wide range of domains and content areas shown in the summaries in Chapter 3, in addition to demonstrating the variability that an idiographic approach supports, also raise the question as to whether it is possible to treat domains and their content in a hierarchical manner. Recall that the aggregation of QoL dimensions that is often a part of standard needs assessment, implies that the structure of QoL is hierarchical. For example, the Functional Living Index - Cancer (FLIC) (Schipper et al., 1984) suggests that it is possible to collapse the various dimensions of QoL (physical, functional, emotional, social and spiritual) by combining elements and yet still maintain a meaningful single index of QoL. No such attempts were made in the present research. Instead, the broad range of patient derived aspects summarised in the tables illustrates the variability of both the domains and content of QoL. In summarising important patient aspects into themes, no patient information was lost (except for the context of that individual patient's other concerns) or combined, and no priority was given to one domain over another. Similarly, within a domain, no content area was assumed to be of greater importance to another. Each domain (or theme) was stand-alone and could not, therefore, be treated as hierarchical. While it could be argued that some patient aspects could be re-allocated to alternative themes, such a re-allocation becomes arbitrary when no theme has priority over another in terms of its contribution to QoL assessment.

In summary then, it appears questionable as to whether it is possible to treat QoL hierarchically. The reason being that both the number of important aspects that a person nominates as well as the actual content of those aspects, suggests a wide range of variability that is difficult to prioritise with the use of externally generated standards.

Indices and group statistics

QoL-Steps did not attempt to compare the assessments made by individual patients across domains or content areas. Chapter 3 outlines the themes and individual aspects of particular patients, and it can be seen from the summaries provided that common aspects for different patients occurred. Seven patients, for example, mentioned having sleeping problems, but for each patient, this problem was unique to them as an individual, and was important in the context of other aspects raised. Even if two different patients assessed their current position on the steps within QoL-Steps as being for example a 5, then this number must be taken in the context of what else was happening for each of the patients concerned. While it is possible to discuss similar needs for patients in palliative care, it was not the intention of QoL-Steps to provide comparison across aspects for different patients. Each patient, his or her unique aspects, and the assessments he or she made in relation to these aspects on the steps, were individual in nature and could only be compared with future assessments of that particular patient. When family members or spouses of the patient that was being interviewed were present, it was important to ensure that aspects of concern were elicited from just the patient. The presence of others was more for support than to offer opinion. While it is possible that certain aspects may not have been mentioned by a patient because of the presence of a support person, in the judgement of the interviewer, this did not appear to be an issue for the patients sampled.

As discussed in Chapter 3, even though similar aspects were nominated by more than one patient, often these aspects had specific direction and took on a personal relevance for the patient concerned. A simple example was pain, where pain was a common symptom under "Physical Well-Being". Pain was often individualised as to where it was located for the person concerned, how it was placed in terms of priorities with other important aspects the patient had, how the patient was able to cope with pain and the ability of medication to overcome immediate feelings of pain. All of these factors were individualised and by averaging an assessment of pain across aggregate groups of patients would mean losing the individual context and clinical meaning for the individual concerned. In keeping with the idiographic objective for the development of QoL-Steps, the aim was to examine the same patient over time (within-subject analysis) rather than compare different patients on the same criteria (between-subject analysis).

Weighting of Quality of Life Domains

In keeping with the objectives set out for QoL-Steps, the instrument succeeded in enabling individual patients to not only determine those aspects of most importance to QoL, but also rank order these aspects relative to some personal criteria. While only being ordinal in nature, the ranked results may suggest the relative importance of each aspect, and allow both the patient and the health provider to assess what aspects of QoL will be of greatest priority.

Other idiographic approaches to the assessment of QoL also utilise patient-derived weighting procedures for determining the importance of aspects nominated by patients. SEIQoL, for example, uses the technique of judgement analysis which has been derived from social judgement theory and allows individual judgements to be modelled mathematically (Schipper et al., 1996). A computer program based on multiple regression analysis uses respondent ratings to provide weights for cues that the respondent has nominated in SEIQoL. PGI also has a weighting procedure for ascertaining the relative importance of respondent cues. PGI allows respondents to "spend" 60 points on six domains according to how much they would like to improve each domain and this procedure provides a measure of the relative importance of each domain (Browne et al., 1997).

In comparison to both SEIQoL and PGI, the weighting procedure used in QoL-Steps was relatively simple. All that patients were asked to do was to rank the aspects they had nominated into an order of personal preference. For medical or counselling purposes, such a ranking provides the assessor with the information necessary to determine areas of need that should be given potential priority. Often when patients discussed such a ranking, it became clear that if it were possible to alleviate the most important concern then many subsequent aspects could also be potentially alleviated. As a simple example, if a patient had his or her bladder problems alleviated then this could in turn alleviate sleeping problems (the patient might not have to get up so much at night), feelings of tiredness, and subsequent discomfort for the patient. The ranking system that is inherent within QoL-Steps while simple, seems to capture the individual patient's assessment of relative importance for the aspects he or she nominates, which was the objective set for the instrument. It should be emphasised, however, that unlike an assessment instrument such as SEIQoL, which uses judgement analysis as the theoretical basis for determining the importance of aspects nominated by patients, QoL-Steps uses no such theoretical sophistication to determine aspect importance.

The need for a reference point

Results for QoL-Steps suggest that the assessment instrument enabled individual patients to nominate their own relevant and important aspects and derive their own reference points in relation to these aspects for both current and ideal positions on the stepped scale. Calman (1984) defined QoL as the gap between the patient's expectations and achievements. If we equate a patient's current position to Calman's idea of "achievements" and a patient's ideal position to "expectations", then the difference between the ideal and current positions provides an assessment of QoL. Thus, the smaller the gap, the higher the QoL. Conversely, the less the patient is able to realise his or her expectations, the poorer his or her QoL. As an objective for QoL-Steps, the concept of a gap appears to have succeeded.

By asking patients to determine their current state as at the time of the interview, QoL-Steps had a starting point: the patients perceived reference point, which was where the patient believed themselves to be on that particular aspect at that particular time. Allowing patients to derive their own reference point was in keeping with an idiographic approach to the assessment of QoL. In addition to patients being able to select their own important QoL areas, they were also able to provide an individualised assessment as to where they were currently positioned with respect to that aspect. The ideal position was determined by each patient with reference to his or her current position. This process appeared to be a viable and understandable undertaking on the part of the patient. In keeping with the objective for demonstrating variability, the results given in Chapter 4 again show this, with the wide range of different current and ideal positions provided by patients.

The success of modifications to the QoL-Steps procedure, the results of which are shown in Chapter 4, were heartening. Recall that modifications to QoL-Steps included changing the anchor positions and also making the instructions to patients more explicit in terms of encouraging a realistic perspective for patients when selecting their ideal positions. While patient's ideal scores were still relatively high on the steps following the modifications, results suggest that the new procedure had some effect in lowering patients ideal positions.

An important objective in the development of QoL-Steps was the ability to assess change. Part of the logic of employing an ideal scale was to obtain a criterion to enable detection of changes in internal standards (Armenakis, 1988). On a very basic level, the data generated from QoL-Steps took the form of simple difference scores between actual and ideal states, and between different time points. The resulting data was therefore quantitative, but subject to only simple analysis at an individual level. Change involved score differences, but such differences can be problematic. For example, is a change in a score from 4 to a 5 the same as a change from 9 to a 10? (Cliff, 1991). Strictly speaking, ratings on a scale are only ordinal and not interval because the difference between a 4 and a 5 may not be psychologically equivalent to the difference between a 9 and a 10 on the same scale. So, even though such ratings are frequently assumed to be interval in property to enable the computation of somewhat more sophisticated statistics, for the purposes of QoL-Steps, the data was treated as ordinal in nature. The general concern for the development of QoL-Steps was to explore alternative ways of generating the difference scores, and analysing the patterns that resulted. Interpretation of particular scores should be done in conjunction with the patient who has generated those scores and the context that that individual brings with him or her.

Assessment of change

One of the issues for the development of QoL-Steps was whether patients should view their prior assessments. That is, in order for patients to make their responses in time period 2 (T2), they were first shown their responses in time period 1 (T1) as a point of reference. Responses from T1 included the list of aspects deemed important by the patient, the rankings of these aspects, and the responses for current and ideal positions for these aspects. Because there is no gold-standard QoL measure to assess whether a true change has occurred, the results of test-retest are inconclusive according to (Ruta et al., 1994). When carrying out serial measurements of subjective states, it is customary to not allow respondents to see their prior responses (Guyatt, Berman, Townsend, & Taylor, 1985). The rationale for this practice is that the availability of previous responses will introduce biases, for example, by encouraging respondents to repeat their prior answers, even when real change has occurred. However, Guyatt, Townsend, Keller, & Singer (1989) suggests that by letting respondents see their previous responses, the validity of subjective measures of health status in clinical trials can be improved. There are conflicting views on this issue (see for example, Streiner & Norman, 1995) but in the current study, the benefits of allowing patients to view their prior assessments (such as imposing less cognitive burden) outweighed the disadvantages.

Alpha and Beta Change Scores

In keeping with one of the objectives for QoL-Steps, which was to record the assessment of change for a particular patient over time and provide data to examine the patterns of change for that individual, QoL-Steps data was fitted to the five patterns of alpha and beta change (as proposed by Zmud & Armenakis, 1978). While examples of each of the five patterns were found in the data, it is important to keep in mind that the reason for examining such patterns in the first place was to be able to disentangle alpha and beta change. Disentangling beta change only occurs when the ideal score for a patient changes over time. While this is an attractively simple proposition, there are at least two associated problems that can be suggested. The first problem is that there is an ambiguity about what an "ideal" position for a patient might be. An ideal position can be defined as a "perfect or model state" or an "idealised mental image", but recall that QoL-Steps operationalised the ideal as where the patient would like to be. In practice, there are various interpretations of what an "ideal" position might be, and these relate to the needs, expectations and context of an individual patient. A patient in palliative care may have very specific "ideals" related to their particular circumstances, not least of which could be the limited life they have remaining. Recall that modifications to the procedure for QoL-Steps resulted in patients lowering their expectations in relation to their ideal position. The issue of how to define the ideal position for a patient, both in conceptual terms and operational terms is something that future trials of QoL-Steps will need to address.

The second problem that is associated with using an ideal score strategy, is that the detection of beta change is based upon the assumption that recalibration of the relevant scale for a patient is only due to shifts in a single reference point for that patient. However, patients may compress part of a scale, or alternatively extend part of a scale both of which will also amount to a process of recalibration. As illustrated within Chapter 5, there are a variety of forms of recalibration that may be applicable for a particular patient, and these forms are unlikely to be detectable with reference to simple patterning techniques. While the patterns of alpha and beta change proposed by Zmud are interesting, future research is needed to further explore the assumptions, meanings and implications of the patterns.

Gamma Change

Gamma change, as previously defined, involves "a redefinition or reconceptualisation of some domain, a major change in the perspective or frame of reference within which phenomenon are perceived and classified, in what is taken to be relevant in some slice of reality." (Golembiewski et al., 1976, p. 138).

The techniques for detecting gamma change tend to be highly statistical and usually involve some comparison of factor structures taken from two time points. The more the factor structures differ over time, the more likely it is that gamma change has occurred. This means that many gamma change detection techniques require large samples of multiple standardised responses. QoL-Steps, in this early developmental stage, did not have such a base to draw upon.

However, as outlined in Chapter 4 and 5, results from QoL-Steps may suggest that gamma change did occur for some patients. If so, then important aspects nominated by patients, and the rankings associated with these aspects, taken over time, may be a simple way to detect the occurrence of gamma change.

Recall that in T2, an appeal to the patient for possible new important aspects of their lives was designed to elicit response shift to the extent that the patient may have changed his or her own values and conceptualisation of what was now important to him or her. There was also some discussion on previously defined aspects, and whether the rankings had changed since the last interview. The aim of this discussion was to utilise a type of card sort approach, similar to a Q-Sort methodology but without the need to examine correlation's between different conditions for the same person (Schwartz & Sprangers, 1999b). A change in ranking for previously defined important aspects could reflect changes in values for the patient and possibly reconceptualisation of the important constituents that contribute to QoL.

The re-ordering of patient aspects in QoL-Steps is suggested as a significant and meaningful process that reflects elements of gamma change. Patients are able to reconceptualise or redefine their lives within the context of their own experiences and expectations. Part of this context could well be the coming to terms with what is happening to them as individuals. Learning to accept that their lives are forever changed and that future expectations rather than past events are now important could be a major part of the psychological process involved in the evolution of their disease. Several patients discussed how certain parts of their previous lives were important to them. Such things might have included sporting activities, such as golf, swimming, cycling and so on. These were things that contributed to the person's life, and many accepted that they were unlikely to be able to participate in such events to the same level again. For others, social activities or work had played an important part of their lives. But many accepted that it was no longer realistic to place such a degree of importance on aspects of this nature. This might have meant relegating such aspects to lower levels of priority, or in some cases, ignoring such aspects altogether. New aspects of importance and the re-prioritising of previously important aspects demonstrates the dynamic nature of content within QoL as well as the rapidity of change that might occur for patients in palliative care.

QoL-Steps as an instrument for communication

The general objective for QoL-Steps was to develop an idiographic procedure that would allow patients in palliative care to communicate their changing QoL concerns. Psychologists inevitably frame such a procedure as a measurement issue. But as (Gill & Feinstein, 1994, p. 624) concluded in a review of QoL measurement:

> A prime question raised in this review is whether academic psychometric principles, although perhaps elegant statistically, are satisfactory for the clinical goal of indicating what clinicians and patients perceive as QoL.

By adopting an idiographic approach to the assessment of QoL, where patients are able to nominate aspects of life that are personally important, rank the relative importance of these aspects, rate them using current and ideal personal standards, and finally, suggest how these standards may change over time, leaves one questioning whether psychometric principles are relevant.

QoL-Steps, as an idiographic approach to QoL assessment, attempted to focus on salient aspects of importance for individuals. The same degree of breathlessness for two patients could perhaps be measured objectively by recording how short of breath each patient was after completing some physical exercise. However, the effects of breathlessness might be very different for the two patients. One patient might be able to accommodate the feelings of breathlessness, and carry on with life as best as possible with little alteration to his or her previous activities. But the other patient, may drastically alter his or her lifestyle to the extent that activities that might have caused breathlessness are now actively avoided. It is critical to assess important aspects of QoL for particular patients and ascertain what effects such aspects have on the individual concerned, rather than learning the average result for aggregated groups of patients. As Richards & Ramirez (1997) suggest, numerically equivalent results from different individuals may have very different clinical meanings.

Instead of regarding QoL-Steps as a psychometric approach to the assessment of QoL, with associated reliability and validity concerns, it is more appropriate to regard QoL-Steps as a structured way of enhancing the communication process between patients and health professionals. As part of this communication process, the starting point for discussions between patients and medical staff could be the changes in current and ideal scores for a particular patient, as well as the more global changes of the important aspects themselves. The current research did not provide any intervention as a result of the aspects that patients nominated. Indeed, the aspects nominated by patients were not communicated to Hospice staff at all during the interviewing process, (although individual patients may have chosen to do this independently).

An appropriate use of QoL-Steps, and the context for future research of this idiographic assessment instrument, is therefore in the area of clinical assessment. QoL-Steps has the potential to engage patients, provide a structured but individualised mode of communication, focus attention on salient aspects of importance to a particular patient, and provide a monitored record of changes in assessment for that patient over a period of time.

Future directions

One of the most interesting and important implications for assessing QoL, especially within an idiographic context, is being able to assist patients to communicate their QoL aspirations. In accomplishing such communication, the interview process itself becomes therapeutic in its own right. This is in keeping with the assertion made by

Fowlie, Berkeley, & Dingwall-Fordyce (1989, p.58), that their administration of the MacAdam scale questionnaire was therapeutic to many of the patients they interviewed:

> There was a sense in which the administration of the questionnaire was therapeutic, allowing patients to consider and explore areas of difficulty which might otherwise not be readily accessible. Several patients from each unit admitted that this was the first time they had talked to anybody about certain aspects of their illness.

In a similar fashion, many of the patients found that the process involved in QoL-Steps was an enlightening process. Far from being intrusive in nature, the informal and semi-structured questions became a positive tool that facilitated open communication between the patient and the interviewer. Areas of importance were explored that might not otherwise have been discussed. Indeed, some aspects of a patient's life that were deemed important may not have explicitly been thought about by the patient prior to this discussion. Some patients took the opportunity to discuss such matters with family and close friends after the initial interview, using this 'new' knowledge as a way of exploring and communicating their personal needs.

One of the best predictors of psychological adjustment after a cancer diagnosis is the extent to which patients' concerns have been disclosed and resolved (Maguire, 1997). However in practice, according to (Maguire, 1997), the majority of patients' concerns remain undisclosed. There is also a marked selectivity in patients' disclosure. They prefer to offer concerns about physical aspects of their illness and treatment rather than psychological and social concerns (Heaven & Maguire, 1996).

According to (Maguire, 1997), certain interviewing skills improve markedly the chances of patients disclosing their concerns thus allowing clinicians to try to resolve them. Having elicited their main concerns, it is important to ask patients to put these in priority order in case there is not sufficient time to deal with all of them within the consultation. Patients need to know their concerns have been elicited and acknowledged and that something will be done about them when possible (Maguire, 1997).

The skills of the interviewer and his or her empathy for patients, being able to take on board the patients concerns, and simply being there to listen to a patient in an understanding manner, were all critical components of the QoL-Steps procedure. The role of the interviewer was not passive, and nor was it entirely objective. Eliciting important patient aspects, which are often of a sensitive nature, means that characteristics of the interviewer become an integral part of the assessment instrument. Certainly for the administration of QoL-Steps in future trials, it will be necessary to experiment with different interview styles and personalities. The writer, as interviewer, found that while many of the discussions with patients were very rewarding, they could also be mentally and emotionally draining.

Often the disadvantages cited for taking an idiographic approach to the assessment of QoL include its time and resource intensity (Schipper et al., 1996). Individual procedures are very time and resource intensive compared to nomothetic methods of QoL assessment. By its very nature, idiographic assessment means one-on-one procedures and tailor-made solutions for individual patients. Traveling to patient's homes and dedicating lengthy blocks of time to listen to individual patients is certainly a time intensive exercise. It is intended that future trials of QoL-Steps will extend the use of the instrument into the Hospice setting itself. Thus, future samples will include in-patients, rather than only out-patients. The interviewing process will also be extended to include Hospice staff, rather than having a dedicated interviewer. Despite these future extensions to the research, the argument that an idiographic approach is more resource intensive is difficult to discount. Before being too critical however, we could ask the question as to how much time is currently spent in terms of informally judging the status of a patient, even with such simple statements as

"How are you today"? The extra expense that an instrument such as QoL-Steps may entail, could well be justified to the extent that an idiographic approach might provide a more formal procedure to a process that is already in place. QoL-Steps then becomes both a useful and appropriate facilitating instrument for clinical situations.

In summary, the purpose of this study was to evaluate the use of QoL-Steps as an idiographic approach to the assessment of QoL. Results from QoL-Steps suggest that the objectives set out for the instrument have been met. QoL-Steps demonstrated a wide range of variability for individual patients, in terms of content, difference scores, rankings, and patterns of change. Rather than being too concerned with the psychometric properties of QoL-Steps, it is suggested that future research should extend the use of the instrument within the context of clinical assessment of individual patients. A major benefit of QoL-Steps may well be the contribution that such an instrument provides by enhancing the communication process between individual patients and their medical providers.

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Appendices

Appendix A
Checklist of Quality of Life Domains

Physical Well-Being

Symptoms e.g. pain, sleeping problems

Treatment side-effects e.g. nausea, constipation

Overall sense of physical health

Daily Activities and Functions

Ability to complete domestic tasks e.g. dressing, eating, walking

Issues related to work activities

Influences on social activities

Problems related to sports and leisure activities

Psychological Well-Being

Emotional health e.g. feeling loved, anxiety, depression, anger

Ability to concentrate and remember

Family Issues

Sources of support

Relationship issues e.g. arguments with partners, sexual difficulties, children

Financial issues

Spiritual Issues

Affirmation of relationships

Issues relating to death e.g. coming to terms, finding meaning

Personal feelings e.g. guilt, shame, fulfilment

Appendix B
Information Letter To Patients

A NEW PROCEDURE FOR ASSESSING NEEDS OF PATIENTS IN PALLIATIVE CARE

Principal Investigator:

Andrew Jardine
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phone: [redacted]

Supervisor:

Dr John Spicer
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You are invited to take part in a study which aims to develop a new method for helping patients in the hospice programme communicate their particular needs to those who care for them. You can choose whether or not to take part, and can take as long as you wish to decide.

What is the study about?
The aim of the study is to develop a special form which patients can fill in to express their particular needs of any kind, so that medical and nursing staff can try to provide more effective care. On this form patients indicate the nature of any problems, and then rate themselves on a ladder to show how much progress is being made in dealing with the issue, and how much more progress they would like to make. We have produced a basic version of this form, and would like to try it out with a wide range of patients to see if it makes sense and helps patients to communicate their needs better.

Who is being approached?
We are seeking the participation of 50 patients who are diverse in terms of their age, gender, ethnic group and medical condition. This will enable us to find out whether the form can be used by a variety of patients. We are approaching inpatients and outpatients who have been identified by Dr Allan, the Medical Director of Arohanui Hospice, as being well enough to cope with up to three 30 minute interviews.

What are participants asked to do?

All participants will be interviewed by one of the researchers, Andrew Jardine. Inpatients will be visited by Andrew at the Hospice, and outpatients will be visited at their homes or anywhere else that they choose. Ideally we would like to interview each patient on two occasions, separated by an approximate period of 2 weeks *{this was changed to 4 – 5 weeks in Stage Two of the research}* . This means that your involvement would be limited to two separate interviews over the space of two to three weeks *{five to six weeks}* at most. During each interview you would be asked to talk about issues which are affecting the quality of your life. These might be problems with medication, emotional problems, family issues, or anything that you are finding difficult. Having identified any issues, you would then be asked to rate them on a ladder to show how much progress is being made in dealing with the issue, and how much more progress you would like to make. At subsequent interviews you would be asked to rate the issues again to see how they had changed. **If you wish, a friend or family member may also be present at the interview.** If English is not your first language and you need an interpreter, one can be provided.

What will happen to the information?

None of the interviews will be tape recorded, so the only information we will keep will be the forms you complete. All of these forms will be identified only by a code number, and will only be available to the research team. The forms will be kept securely for five years and then destroyed. No material which could personally identify you will be used in any reports on this study.

The information you provide will not be passed on to any medical or nursing staff involved in your care, since it is being collected only for research purposes. You should still communicate your needs and concerns as usual with those who are caring for you.

What can participants expect?

Participation is entirely voluntary; it is your choice. If you choose not to take part, this will not affect your current or future care or treatment. If you do participate, you are free to withdraw at any time without giving a reason. Withdrawal will also not have any effect on your care or treatment. During the interviews, you do not have to answer all the questions and you may stop an interview at any time.

We hope that participants will benefit from discussing their needs in more detail than usual. Discussing some issues may prove upsetting, but if this happens the patient can choose to change the subject or stop the interview. If there is any continuing distress, counselling help is available. In broader terms, participants may benefit from the knowledge that they are helping to develop a procedure which may enhance the care provided for future patients. Patients will be given the opportunity to talk through their responses during and after the question session; feedback and understanding is an important part of the process we are trying to develop.

Once the study is complete, participants will be sent a summary of the results if they wish.

Where can I get further information?
This study has received ethical approval from the Manawatu-Whanganui Ethics Committee and the Massey University Ethics Committee. If you have any queries or concerns about your rights as a participant in this study, you may wish to contact a Health and Disability Services Consumer Advocate, phone 0800 112 233. If you have any questions about the study in general, please feel free to contact Andrew Jardine or Dr Spicer, whose addresses and phone numbers are provided at the beginning of this information form.

Appendix C

Consent Form

A NEW PROCEDURE FOR ASSESSING NEEDS OF PATIENTS IN PALLIATIVE CARE

I have read and I understand the information sheet dated ?? ?? ?? for volunteers taking part in the study designed to evaluate a new procedure for assessing patients' needs. I have had the opportunity to discuss this study . I am satisfied with the answers I have been given.

I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time, and this will in no way affect my continuing health care.

I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

I have had time to consider whether to take part.

I know who to contact if I have any questions about the study.

I wish to receive a copy of the results
YES/NO

I...(full name) hereby consent to take part in this study.

This project has been approved by the Manawatu-Whanganui Ethics Committee. This means that the Ethics Committee may check that this study is running smoothly, and has followed appropriate ethical procedures. Complete confidentiality is assured. If you have any ethical concerns about the study, you may contact the Manawatu-Whanganui Ethics Committee on 0-6 356 7773.

Signature.. Date....................

Full names and phone numbers of researchers:
At Massey: Dr John Spicer - 3505799 ext. 2070, Mr Andrew Jardine - 3505585; At Arohanui Hospice: Dr Simon Allan – 3566606