A comparison of quality of and satisfaction with life between people with an intellectual disability and those without

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(Clin.Psy.D)

by

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Contents

Contents p. i

Acknowledgements p. iii

Statement of confidentiality p. iv

Overview p. v

Literature Review p. 1
Is satisfaction a valid concept in the assessment of quality of life of people with an intellectual disability?

Research Report (1) Empirical paper p. 34
Assessing subjective quality of life: a comparison between people with an intellectual disability and those without

Research Report (2) Brief communication p. 67
Carer judgements: proxy judgements of the quality of life of people with an intellectual disability

Appendices

Appendix (I)
Research Ethics Committee Approval p. 81

Appendix (II)
Instructions to authors
Literature review Research in Developmental Disabilities p. 83
Research report (1) Journal of Applied Research In Intellectual Disabilities p. 84
Research report (2) Journal of Intellectual Disability Research p. 85

Appendix (III)
Written information given to the participants who took part in the study described in Research Report 1 and Research Report 2, p. 86

Appendix (IV)
Written information given to controls who took part in the study described in Research Report 1 p. 91

Appendix (V)
Written information given to carers who took part in the study described in Research Report 2 p. 96

Appendix (VI)
Questionnaire given to participants with an intellectual disability In Research Reports 1 and 2: ComQol-ID p.101

Appendix (VII)
Questionaire given to controls in Research Report 1: ComQol-4 p.123

Appendix (VIII)
Questionnaire given to carers in Research Report 2: ComQolCa p.132

Appendix (IX)
Health questionnaire used in the studies reported in Research Report 1 And Research Report 2 p.143

Appendix (X)
Table of Pearson correlations reported in Research Report 1 p.144

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Statement of confidentiality

No names of any individuals have been presented in this work, and the analyses of responses do not allow anyone to be identified.

Overview

This thesis is bound in one volume and is made up of a literature review and two research reports. The aim of the work was to investigate subjective measures of quality of life in people with a learning disability and those without, in order to identify what factors led people to be satisfied with their life and particularly their health and primary healthcare.

The literature review, aimed for publication in Research in Developmental Disabilities, examines the development of measures of quality of life over the last three decades, and in particular, the development of subjective measures. The concept of satisfaction with life is explored, as is the evidence of its consistently high rating and stability. Methodological difficulties in assessing subjective factors in people with intellectual disabilities are taken into account in the consideration of whether satisfaction is an appropriate concept to use when assessing quality of life for people with intellectual disability.

Research report (1), aimed for publication in the Journal of Applied Research in Intellectual Disabilities, describes a study comparing 31 people with an intellectual disability, and 31 matched controls, using a quality of life questionnaire (ComQol). The questionnaire had three scales, covering objective data in seven domains, and the importance of and satisfaction with those domains. Extra questions were added to assess access to health promotion measures in primary care, and the importance and satisfaction respondents attached to their general practitioner. The aim of the study was to investigate the relationship between objective and subjective measures of quality of life, and between the two groups of people.

Research report (2) aimed for publication in the Journal of Intellectual Disability Research, explored how closely carers were able to estimate the objective and subjective quality of life of people they cared for. The people with intellectual disability who were interviewed using ComQol in Research report (1) were asked if a carer they nominated could be interviewed to see how good they were at assessing those people's lives. Sixteen carers were interviewed, and their responses compared with those of the participants.

Title:

Is satisfaction a valid concept in the assessment of quality of life of people with an intellectual disability? A review of the literature

Running title:

Satisfaction in learning disability

Key words:

intellectual disability, quality of life, satisfaction

This paper is to be submitted for publication in Research in Developmental Disabilities

Is satisfaction a valid concept in the assessment of quality of life of people with an intellectual disability?

A review of the literature.

Abstract

This paper examines definitions of quality of life that have developed over the last three decades and which reflect the increased awareness of the need to take into account individuals' own perceptions of their life. The concept of satisfaction is frequently used as an important subjective variable in quality of life studies, despite the evidence of stability of satisfaction over individuals and over time, which suggests that it would be a measure insensitive to change. This evidence is examined, and the idea of such stability being an adaptive psychological mechanism is considered. The use of satisfaction as a measure of quality of life in people with an intellectual disability is discussed. The methodological difficulties encountered in assessing subjective experiences of people with learning disabilities are also discussed. Finally it is argued that satisfaction may not be the most appropriate measure of quality of life for people with an intellectual disability.

Introduction

The concept of quality of life has been increasingly used over the last three decades as a framework for evaluating services, and for measuring the outcomes of service changes. Over that time there has been a growing recognition that quality of life is not just a reflection of material well being, but also of peoples' values and aspirations. There is now considerable agreement in the literature that both objective and subjective measures need to be used (e.g. Felce, 1997). Satisfaction is a variable that is often used interchangeably with well being and happiness, and as a significant measure of life quality despite the evidence that it is stable over time and conditions (e.g. Cummins, 1995a). This paper considers the evidence about the usefulness of satisfaction as a measure of life quality, particularly with people with an intellectual disability.

Quality of life

This section considers the concept of "quality of life", and its development from a simple listing of economic indicators, to a complex construct involving subjective judgements by individuals of their own life quality.

The pursuit of a definition of happiness is not new in Western society, nor are attempts to measure it. Oliver et al (1996) note that Western nations have traditionally assessed the level of welfare of citizens by the use of statistics. These have mostly been economic indicators, the use of which assumed a direct relationship between economic growth and well being of the population. By the middle of the twentieth century, it became clear that monetary measures alone were not sufficient to explain well being, and the 1960's researchers began to use social indicators, which included measures such as political activity, health status and leisure activity. Andrews and Withey (1976) state that social indicators were thought to enable policy makers to focus their attention on current social problems and thus make society more responsive to people's needs. They point out, however, that although social indicators are meant to be objective, they tend to involve subjective judgements. They propose that people's own "perceptions" of well being should be included in any analysis of social indictors. Felce and Perry (1995), in a review of the definition and measurement of quality of life, note that in the 1970s researchers began to develop social and psychological indicators to assess individual welfare, much of the work being directed to evaluating changes in services for people in need of support, such as people with intellectual disability, physical disability, psychiatric morbidity, or old age.

An agreed definition of quality of life has yet to be achieved. Hughes and Wang (1996) identified forty-four definitions of quality of life in the literature between 1970 and 1993. These definitions encompass fifteen dimensions of quality of life ranging from material well being, employment and residential environment to autonomy, personal choice and satisfaction. The wide range of definitions reflects the general recognition of the complexity of the concept. Hughes and Wang (1996) propose a model of quality of life that attempts to take account of the interrelationship between multiple environmental and personal factors. They suggest that a taxonomy of measures could be tailored to meet an individual's needs at a particular time, as the relevance of any dimension may change over time. They propose a taxonomy of empirical measures based on their literature review which has fifteen dimensions intended to cover all possible aspects of a person’s life, including social relationships, employment, self-determination and residential environment,

It has become increasingly clear that any assessment of quality of life is incomplete without a measure of how people perceive and judge their own life. Indeed, Taylor and Bogdan (1996) go so far as to say, “Quality of life is a matter of subjective experience. The concept has no meaning apart from what a person feels and experiences”. Emerson et al (1985) agree that “a comprehensive definition of quality of life (is) the satisfaction of an individual’s values, goals and needs through the actualisation of their abilities or lifestyle”. Despite the agreement that quality of life is more complex than a straight reflection of material reality, there are problems in determining which subjective factors need to be taken into account, particularly since there seems to be agreement that the correlation between both objective and subjective data is low (Cummins, 1996; Edgerton, 1996).

Felce (1996) and Felce and Perry (1995) have proposed a three-component model of quality of life, which encompasses objective life conditions, and subjective factors of well being (satisfaction) and personal values and aspirations (importance). They conducted a literature review which led them to postulate that there are five relevant life domains to be considered. These are physical well being, material well being, social well being, development and activity and emotional well being. Each domain must be weighted by a personal set of values to give an overall picture of quality of life. They did not, however, develop a measure for these domains.

Cummins (1995b, 1997) also argues for a multi-dimensional model covering objective and subjective dimensions, although he considers there are seven relevant life domains. These are material, health, productivity, intimacy, safety, community and emotion. He has developed an instrument (ComQol) to measure these seven domains for objective data, and reported satisfaction and importance. He proposes a subjective measure for each domain, that measure being reported satisfaction with a domain, weighted by reported importance. In other words, an individual's satisfaction with an aspect of their life will be mediated by the importance they attach to it.

Boyle (1994) believes that the links between objective criteria and quality of life are complex and difficult to predict and that this might be particularly true with regard to health. She reports on the development of the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) which allows individuals to determine discrete domains of their life, how satisfied they currently are and to evaluate those domains in terms of importance. Most other schedules of quality of life cover domains determined by the researcher and, according to Boyle, do not take account of individual differences. In this model, domains are chosen by the individuals concerned, and not imposed by the researcher. Five domains are elicited by asking individuals to identify the five areas of their life that are currently most important to them, and which make them happy or sad. They are then asked to rate these domains in relationship to each other. Although this is intended as an individual measure, it can also be used to compare populations as a global index can be calculated from the scores from the five domains. The author, however, counsels caution in its use this way, as it must be interpreted within the context of the responses of each individual.

Thus, it can be seen that, although researchers are clear about the need for a measure of life quality that allows comparisons between individuals and groups, and which involves individuals' subjective judgements about that quality, a common definition, of and agreement about the components of such a measure, has not been achieved. There is, however, a move towards a common approach that looks at various domains of life and the value people put on them. Cummins (1995c) feels that this is essential to allow comparison between groups of people irrespective of their precise characteristics. Felce and Perry (1995) also agree that such a common approach is vital if information applicable to one section of society is to be interpreted with confidence for other sections.

Satisfaction

This section considers the concept of satisfaction, as it is frequently used as an important subjective variable in judgements of quality of life.

Definitions

Subjective indicators of quality of life are those that reflect how a person feels and experiences life. (Taylor and Bogdan, 1996) Concepts that have been explored in the literature include satisfaction, importance, self-determination, personal values, and well being. Edgerton (1996) proposes that a conceptual difference should be made between happiness (transient affective states), life satisfaction (how well life expectations have been met) and well being (global satisfaction with life). Nevertheless, the term satisfaction is often used interchangeably with well being and happiness. Andrews and Withey (1976) in judging affective well being in an American population used the delighted –terrible scale, a seven point Likert scale of satisfaction. Harner and Heal (1993) use the terms satisfaction and happiness interchangeably. In the ComQol developed by Cummins (1993a,b) in the version developed for use with people with intellectual disability, the Likert scale for satisfaction asks individuals to rate how happy they are whilst the equivalent version for people without a disability asks them to rate their satisfaction. Cummins's (1995a) review of scales of satisfaction, notes that, although some questions are about happiness, some are about satisfaction and some are on a delighted-terrible scale, results are consistently high on all measures, and he suggests they may all be tapping the same concept. His suggestion is based on statistical probability rather than experimental evidence. The term satisfaction is also used synonymously with overall quality of life. Taylor and Bogdan (1996) go so far as to state that "Quality of life refers to one's satisfaction with one's lot in life, an inner sense of contentment or fulfilment with one's experience in the world". Felce and Perry (1995) agree that, because individuals differ in what they find important, satisfaction with life is an essential criterion of quality of life. They note that overall satisfaction may reflect satisfaction in a number of life domains. They warn, however, against using personal satisfaction as a synonym for quality of life, rather it should be considered alongside objective indicators such as living conditions and income.

Satisfaction is often used as an outcome measure, under the assumption that it is dependent on life circumstances and events. Thus, it is often used as a dependent variable in research that evaluates the outcome of life changes or the impact of particular life circumstance. For example, Legault (1992) used three and five point Likert scales to evaluate the satisfaction of sixty-one people with an intellectual disability who lived in circumstances of varying independence, and found a significant inverse relationship with the degree of supervision people received and their satisfaction with their home life. That is, the more independent people were, and the less supervision they received, the more satisfied they were. Muthny et al (1990) used a life satisfaction index to assess the quality of life of cancer sufferers compared with people with other medical conditions, and found no difference between the two groups, both reporting high satisfaction with their quality of life.

The term satisfaction has a very particular use in health care, where it is an essential component of evaluations, and is used to make economic and resource decisions. Fitzpatrick (1997) states that “Patient satisfaction is a summary term that refers to the diverse range of patients' reactions to the experience of health care. (It) is increasingly assessed in surveys of health care settings as a measure of the quality of care”. Despite the fact that he recognises that there has not been much theoretical discussion in the psychology literature about satisfaction as a concept, he further states that it may be seen as the product of discrepancies between patients’ expectations of care and perceptions of what they receive. Satisfaction with health and health care, although an area of study in its own right, is also a key component of quality of life studies, most models encompassing a health domain (e.g.Cummins, 1995b; Felce and Perry,1995).

Well being, happiness and satisfaction are all key concepts in the consideration of subjective aspects of life quality. There is not, however, one consistent definition of any of the terms, and many authors use them interchangeably.

Stability of satisfaction

The remarkable stability of satisfaction over time and individuals is now considered.

Despite the varying definitions, it has been known for many years that satisfaction, or well being scores tend to be consistently high, with most people rating themselves happier than average and that, except under unusual circumstances, there is remarkably little relationship between a person's degree of satisfaction and the material aspects of their life (e.g.Cummins, 1997; Costa et al, 1987). Brickman et al (1978) report on interviews with twenty-nine people severely incapacitated by accidents, twenty-two lottery winners and twenty-two controls who had not been incapacitated nor won the lottery. As part of the interview, they were asked to rate how happy they were on a six-point scale. They found that there was no significant difference in happiness between lottery winners and the controls. The accident victims rated themselves as less happy than controls, but nevertheless, still rated themselves higher than average. Headey and Wearing (1987) state that "…in nearly all countries that have been studied, almost all sections of the community rate their subjective well being above the mid-point of scales".

Cummins (1995a) notes that studies of quality of life rarely use comparable measures He nevertheless points out that some general characteristics of quality of life studies have been identified, most notably that irrespective of the instrument used, people rated themselves above average in happiness, satisfaction and well being. This finding applied to the majority of studies he reviewed except for studies on people with a chronic medical conditions, who displayed great variability of scores, but scored lower on average than other groups. Cummins (1995a) believes this is an internal psychological mechanism, which serves to underpin and maintain a positive perception of self. He bases this hypothesis on the findings in the literature that high scores on subjective quality of life are ubiquitous and that the phenomenon is consistent over a number of studies. Cummins believes that this high level of consistency from one population to another in the absolute level of perceived life satisfaction indicates that a single statistic or "gold standard" could provide a reference point for all empirical studies into life quality. In order to pursue this statistic, he reviewed seven hundred publications of studies of life satisfaction and identified fifteen large studies which measured satisfaction in adults, and which gave sufficient data to make comparisons. Each data set was converted into a common statistic "Percentage of Scale Maximum (%SM)". Thirteen different scales were used over the fifteen studies. Nevertheless, despite this lack of commonality in methodology, the combination of the studies yielded a mean of 74.8% SM with a standard deviation of 2.87. In effect this means that most people rated themselves significantly above average in terms of their happiness. Cummins, like Headey and Wearing (1987) proposes a psychological homeostatic mechanism maintaining life-satisfaction at about 75%SM. This would be a highly adaptive mechanism on a population basis, ensuring that, under relatively stable but diverse living conditions, most people would feel satisfied with their lives. Cummins proposes that this 75%SM with a standard deviation of 2.5%SM be used as the Life Satisfaction gold standard in future research. He recognises that, as scores lie above the mean, ceiling effects might have an effect on sample variance. He tested for this statistically calculating a Spearman Rank Correlation Coefficient between the rank order of population means and the rank order of their variance. The resulting coefficient was significant, supporting his hypothesis.

There is also a growing body of evidence that satisfaction is stable over time. Edgerton (1996) reports on a number of longitudinal studies that indicate that individuals, followed up over a number of years are remarkably stable in their reported well being over time, despite life changes that might have occurred. He states that major life events can bring about changes in expressed life satisfaction and affect, but before long people return to the state of well being they enjoyed before. Good fortune has a similar rebound effect. Costa et al (1987) compared four thousand, nine hundred and forty-two American people with responses they had made ten years earlier on a general well being schedule and reported great stability in the measures over the ten years. Edgerton (1996) points out that Costa et al's research took a global measure of well being, and could have missed domain specific effects of environmental change on well being, particularly in the area of health status. Nevertheless, he proposes that feelings of well being may be more of a reflection of personality or temperament than objective life conditions. Hatton and Emerson (1996) have reported a similar finding with people with intellectual disability who have been resettled into the community from institutions, initially people showed improvements in satisfaction, but these were only short-term.

Reasons for stability

The psychological mechanisms that have been considered to contribute to the stability of satisfaction scores are now examined.

Why is it that people should so consistently rate themselves as happy, and more satisfied than average? Gilbert et al (1998) point out that people make the best of situations, allowing themselves to remain relatively pleased with themselves “despite all good evidence to the contrary”. They state “psychologists from Freud to Festinger have described the artful measures by which the human mind ignores, augments, transforms, and rearranges information in its unending battle against the affective consequences of negative events”. Gilbert et al propose a psychological immune system which is made up of a number of psychological mechanisms, and which maintains the high level of subjective well being. They set up a number of experiments to test how well people can predict how happy or sad they would be after a predicted event, and they were then tested at a later date. One thousand and twenty five people took part in one of six different conditions predicting how happy or sad they would be following particular circumstances such as breaking up with their partner, or gaining or not gaining tenure at University. The participants were assessed again after the event they were considering. Some situations were real life, such as the tenure situation, where assistant professors who were hoping to be appointed were asked in advance, how happy or sad they would be if they gained, or lost the job. Other situations were set up by the researchers, for example, people were asked to make a presentation and were then told they had passed or failed. The general findings were that people overestimated the duration of their affective reactions to both happy and sad events. They, in fact, adjusted back to their previous state within a much shorter time period than they predicted.

Taylor et al (1983) considered victims, people they defined as “being harmed by or made to suffer from an act, circumstance agency or condition". They were particularly interested in people with health problems, and those that were victims of crime. They propose a mechanism, which they call Selective Evaluation. They postulate that victim status is aversive, and people selectively evaluate themselves and their situation in ways that are self-enhancing. They do this by downward comparison, focussing on attributes that make them appear advantaged. For example, they may create hypothetical worse worlds, comparing their own situation with what might have happened, thus, rape victims frequently note that they might have been killed. They may construe benefit, by reconstructing the event so as to highlight its benefits; thus a cancer sufferer might believe that she has become a stronger person as a result of her suffering. They may manufacture normative standards of adjustment which makes their own appear exceptional, the strategy being embodied in the statement, “I’m doing very well under the circumstances”, with the implication that others would not do so well. Taylor et al (1983) state “ the point is, of course, that everyone is better off than someone as long as one picks the right dimension”. They quote many studies of people who have suffered a serious event to support their hypotheses.

Headey and Wearing (1987) note that researchers, in attempting to explain the reported high levels of satisfaction in all groups studied, have chosen various explanations including low levels of aspiration, social pathology and measurement error. Headey and Wearing (1987) propose a psychological mechanism, which they call the sense of relative superiority (SRS). They consider SRS to be an adaptive mechanism and call on attribution theory, adaptation level theory and social comparison theory to explain how it works. They review the literature on these three mechanisms and give examples of how they work. Social comparison theory focuses on comparisons people make between themselves and others, and research in the area, although admittedly focussed on minor roles and attributes, demonstrates that most people think themselves superior to others. Attribution theory considers how people accept explanations that maintain or enhance their self-esteem, thus students who pass an exam will attribute success to their innate abilities, whilst attributing other's success to hard work or luck. Adaption level theory deals with how people adjust to environmental change, and maintain equilibrium; people habituate to change by adjusting their aspiration levels upwards or downwards depending on whether the change is perceived as favourable or adverse.

Thus it can be seen that a number of psychological mechanisms have been postulated to maintain stability of satisfaction over time and over circumstances, and it may be that some act together to this end. Some writers make the case that the mechanisms involved have an adaptive role for both individuals and populations.

Intellectual disability and satisfaction studies

This section considers how satisfaction studies have been used in research with people with intellectual disability.

There is a large body of research into quality of life for people with an intellectual disability, reflecting the increasing recognition of how services have denied people dignity and respect. The need for subjective measures of quality is well recognised (e.g.Taylor and Bogdan, 1996; Felce and Perry, 1995; Edgerton, 1996), but only in the last few years have attempts been made to assess these in people with intellectual disability. Rapley and Lobley (1995) point out that there is a wide array of instruments, none of which had achieved psychometric adequacy or acceptance in the UK. Cummins (1997b) has put together a directory of instruments measuring quality of life, which describes over 2,000 instruments, only 11 of which are specifically designed for use with people with an intellectual disability. Despite the recognised need for assessing subjective factors, particularly satisfaction, few studies have been carried out interviewing people with intellectual disability themselves and those that have, have been undertaken with people who are able to respond to questions. There remains a large group of people with intellectual disability who are unable to do this. Taylor and Bogdan (1996) report on studies where family members state that they can recognise signs of thinking and feeling in their severely disabled relatives, although they do not report any validation data. They state that understanding the subjective experience of people with the most severe disabilities is a methodological challenge: "The issue is not whether people have subjective experience, but how we can learn about that experience".

One solution to the methodological challenge is to rely on reports from carers and relatives. Borthwick-Duffy (1996) notes that for objective items, this poses less of a problem, than it does for indicators of satisfaction. McVilly and Rawlinson (1998) state that there is a dearth of research investigating the validity of proxy responses of satisfaction for people with intellectual disability. They quote only one, a study by Burnett (1989) where residents' satisfaction scores and those predicted by staff were weakly correlated. They then review the literature on proxy response in the health-related literature and draw conclusions from this about how proxy responses should be considered in the intellectually disabled population. They note that in the health-related literature, as questions increase in detail and subjectivity, proxy-subject agreement decreases. Furthermore the complexity, observability and salience of the issue all effect concurrence. They conclude that these factors are important to take into account when considering the use of proxy responses in QOL assessments for people with intellectual disability. In another study Harner and Heal (1993) adapted the Lifestyle Satisfaction scale (Heal et al, 1991) to assess the satisfaction of one hundred and forty people with an intellectual disability with aspects of their life, using a five point scale scored by the interviewer. They concluded that the adapted scale was a reliable and valid instrument to measure satisfaction of individuals with an intellectual disability. Carers were asked to assess the satisfaction of the people in their care, and the results indicated that they did not always accurately predict satisfaction reported by the individuals in their care. Harner and Heal (1993) conclude that service providers should not be solely relied upon to provide data regarding the satisfaction of individuals whom they serve.

Despite these reservations, proxy studies continue to be undertaken. A frequently used measure, the Schalock and Keith (1983) Quality of life Questionnaire, which has four subjective measures, including satisfaction, was developed to be used with proxies when individuals cannot respond. The results are designed to be used as if they were those of the individuals reported on. Other studies have accepted without comment proxies’ evaluations (e.g. Spellar, 1996) or reported them as if they were they were actual evaluations by people with intellectual disability themselves. Stanley and Roy (1988) identified eleven life domains that were important to a local community and rated the satisfaction of members of that community with each domain. They used these domains to assess satisfaction for people with an intellectual disability, some of whom were to be resettled in that community, under the assumption that those domains would be socially valued. To obtain comparative satisfaction data for two groups of people with intellectual disability, they interviewed staff who knew the individuals concerned, and found that people with an intellectual disability living in a hospital were less satisfied than those living in the community. It is difficult to place weight on these findings, when studies of proxy responding consistently show little correlation between carer and client responses.

There are, however, methodological difficulties encountered when interviewing people with intellectual disabilities themselves. Heal and Sigelman (1996) have reviewed studies looking at these difficulties. They considered responsiveness, reliability, consistency and external verification. The studies they reviewed showed that responsiveness increased with IQ, and that yes-no questions were easier to answer than either-or or multiple choice questions. They found that interview test-retest reliability was high when yes-no questions were asked. This was due to respondents being more likely on each occasion to acquiesce, that is say “yes”, rather than “no” regardless of the content of the question. Consistency of response to multiple choice questions was much lower. With either-or or questions such as “are you usually happy or sad”, there seemed to be a recency bias, with respondents choosing the second option regardless of which order the question was asked. Open-ended questions were associated with underreporting. Comparison of responses with those of parents or carers reflected the tendency to acquiesce and underreport. Heal and Sigelman (1996) note that to obtain meaningful results from people with limited verbal skills requires interview techniques that take account of the response biases. They believe that assessment of quality of life should involve multiple methodologies, which have been demonstrated to be reliable and valid. Interviews with people with an intellectual disability could be one of these methodologies, but should not be used on their own without other measures such as direct observation and factual records. Heal and Chadsey-Ruch (1985) used a statistical correction for response bias in their Lifestyle satisfaction scale. They included an acquiescence sub-scale with paired questions, for which responding yes to both would indicate acquiescence. Life style satisfaction scores were then downgraded statistically according to the respondents' tendency to acquiesce.

Gudjonssen and Haward (1998) describe a test of acquiescence used extensively in forensic practice, which consists of twelve logically opposite pairs of statements. On this test he found that acquiescence was negatively correlated with intelligence. Gudjonssen (1997) has developed a set of scales for suggestibility, which considers other aspects of response bias, in particular "interrogative suggestibility". Interrogative suggestibility comprises the tendency to be led by leading questions, and the tendency to change initial answers in response to interrogative pressure. The scales can also be used to measure confabulation. A study by Clare and Gudjonson (1993) compared people with intellectual disability with members of the general public and found that people with an intellectual disability were more likely to confabulate, acquiesce and yield to leading questions. However they did not differ in their susceptibility to give in to interrogative pressure.

Rapley and Antaki (1996) challenge the view that people with intellectual disability have a tendency to acquiesce in interviews as conceptually cloudy and empirically unproven. They criticise the work carried out by Sigelman and colleagues from the 1980's onwards, looking at:

> *The questions.* They suggest that Sigelman et al confound inconsistency with acquiescence and that inconsistency is not necessarily motivated acquiescence. They also point out that some of the questions were odd, for example asking people living in an institution whether they could fly an aeroplane.
>
> *The context.* They note that Sigelman et al pay little attention to the social context of the interview situation, particularly the power differential between interviewer and interviewee.
>
> *The language.* They note that none of the studies report what was actually said. They suspect that there is something about the actual delivery of question and answer that is "glossed" over in the literature, and which needs further analysis

In order to pursue their concerns, Rapley and Anataki (1996) used conversation analysis, an empirically driven approach derived from phenomenology and sociology, to examine transcripts of eight interviews where experienced interviewers administered the Schalock and Keith (1993) Quality of Life Questionnaire. They present a transcript of parts of interviews, analysing pauses and non-speech utterances as well as speech. Their analysis indicates that interviewees orientated to the interview as if it were a test with the implication that there would be right and wrong answers. The interviewers also appeared to be “shepherding” the interviewees to acceptable answers, by reformulating and re-asking questions, and echoing back answers. Rapley and Anataki also report on the interviewees’ resistance to changing their responses, not acquiescing, but holding onto their viewpoint. The interviewees demonstrated competent conversational management, in the face of the interviewer's reformulation of their answers and shepherding them to the “correct answer”. This was a small study, using a technique not often employed in intellectual disability research, but it raises serious concerns about assumptions of acquiescence in people with intellectual disability.

While there are few instruments that measure subjective satisfaction by interviewing people with an intellectual disability, there are even fewer that have been specifically developed to be used with both a disabled and non-disabled population. Agar (1990) has developed the Life Experiences Checklist, which can be used with any population, to compare the range and extent of life experiences against a normative population. Although the checklist can be used with people with an intellectual disability, it is a list of activities such as visiting friends, travelling by public transport, and so on, with a measure of frequency. The checklist does not directly ask about satisfaction with activities, rather it assumes that experiences undertaken are valued. The ComQol (Cummins et al, 1997) asks direct questions about subjective factors, including satisfaction. The authors point out that previously no scales existed that could be given to both populations, allowing a measure of quality of life that could be used in the context of normative comparisons. They feel this normative comparison is particularly important in the area of intellectual disability as most definitions of quality of life for people with intellectual disability, cover fewer dimensions than those for the general population. Cummins et al (1997) report on an initial evaluation of their scale developed to measure objective and subjective quality of life, subjective factors being reported satisfaction and importance, which has a parallel version for use with people with intellectual disability. In an initial evaluation the scale was administered to fifty-nine people with an intellectual disability, and sixty-nine university students. Cummins et al (1997) do not report directly on the satisfaction scores, but combine them with importance scores to give an overall subjective quality of life score. They report that this quality of life score was not significantly different between the two groups.

Few studies of people with intellectual disability take account of the research findings that satisfaction is remarkably stable over time, and is consistently reported as high. Data reported in studies of people with an intellectual disability tends to be reported in a way that makes it difficult to assess the level of satisfaction. Thus Crocker (1989) compared two different ways of measuring satisfaction in services. He interviewed twenty-nine people with intellectual disability on two separate occasions. On the first occasion, he used an open-ended interview, the interviewer then rating satisfaction on a five-point scale according to how many negative and how many positive statements were made. On the other occasion, he presented the interviewee with a choice of two adjectives e.g. good or bad, and then with a choice of the next two degrees of the chosen adjective e.g. very good or somewhat good. If the person did not choose an adjective, their response was counted as neutral. Thus a five-point scale was achieved. Crocker found low test-retest correlations, and low inter-rater correlation. He only presents the correlation data, but discusses the fact that data from the second procedure was skewed and suggests that the high scores obtained with this second procedure is a ceiling effect. Raphael et al (1996) developed an instrument for distinguishing what they call quality of care from quality of life. The latter they consider to be related to perceptions of life along four dimensions, importance, enjoyment, control and opportunities. They interviewed forty-one people with an intellectual disability. They found that their mean scores for all their domains were above average when the participant self-rated, and that these scores where higher than those of proxies. The authors suggest that this might be due to the participants having little experience of being asked if they are satisfied with life or having a narrow experience of life. Sands et al (1991) interviewed two hundred and forty people with intellectual disability about their satisfaction with work, education, care, health services, and other services on a scale of one to five. They found that satisfaction ranged from 64% to 100%. They consider that this high level of satisfaction might be due to the low expectations of the participants. Flyn and Saleem (1986) interviewed twelve adults with intellectual disability about their satisfaction with their lives using open ended questions which were then rated on a five-point scale according to how many negative and positive statements were made. They also asked whether people would wish to change anything in their lives. Despite the fact the majority of those interviewed wished to change some aspect of their lives, a further analysis of the satisfaction data indicates that 84% of the satisfaction ratings were at the mid-point or above of the five-point scale.

This section has demonstrated that that there are significant methodological difficulties in assessing subjective experiences of people with intellectual disability. Some of these difficulties relate to the difficulty of interviewing people with restricted language. Some studies have looked at acquiescence, but have not taken in account the settings in which acquiescence is elicited. There are no studies comparing interview responses in disabled and non-disabled groups, which would clarify whether people with an intellectual disability acquiesce more than a non-disabled population. Nevertheless, interview studies of satisfaction in people with intellectual disability tend to show the same high levels that have been reported in the non-disabled population. These high levels, however, have not been attributed to similar psychological mechanisms that exist in the general population, rather they have been explained in terms of lack of expectation or experience on behalf of the individual concerned.

Should measures of satisfaction be used with people with intellectual disability?

The studies of satisfaction and measurement reviewed earlier in this paper throw doubt on the use of satisfaction as a measure of change, or a reflection of material circumstances. Results from studies using satisfaction as a measure should be interpreted cautiously in all populations. Hatton (1998) believes that adopting a quality of life agenda which depends on assessing subjective satisfaction, effectively disenfranchises people with severe intellectual disability and little or no communication, particularly as there are currently no reliable and valid methods to ascertain how satisfied this group of people is with their lives. When people have sufficient language to be interviewed, he notes that they may be bringing an entirely different set of expectations to the interview than the interviewer, which will have a profound influence on their responses. He also notes that the expectations of the interviewers will affect what response they will accept. Some of these problems may be to do with acquiescence (Sigelman et al, 1981), although Rapley and Antaki (1996) present evidence that acquiescence may very well be a function of the interviewer's expectations, and that the people in their study used strategies taken from the normal repertoire of conversational management. One of the implications of this is that acquiescence may not differ in the disabled and non-disabled populations.

Edgerton (1996), in reviewing the literature, argues that features of a person's environment are less important in bringing about a sense of well being than are aspects of that person's personality or temperament. He bases this argument on the evidence of the remarkable stability of subjective well being in individuals, over time. Any change tends to be short-term, as a result of an adaption process (Headey and Wearing, 1989) or homeostatic mechanism (Cummins, 1995a). Hatton (1998) suggests that these findings have profound implications for the use of subjective well being as an indicator of quality of life and service quality. He is particularly concerned that the research on de-institutionalisation of people with intellectual disability often shows short-term improvements in satisfaction but little long-term change (Hatton and Emerson, 1996) and this can lead to misleading conclusions about service quality. Felce (1997) also has concerns about the use of satisfaction as a measure of quality of life, stating that "far from being the subtle indicator of quality of life that is often assumed to be, satisfaction may be an unresponsive indicator, sensitive only to gross and immediate changes in life conditions". He believes that at an aggregate level, subjective factors, such as satisfaction could be used to compare different groups of people, but that objective measures are perhaps better when determining social equity.

It is clear that satisfaction as used in research into subjective experiences, remains stable over time and conditions, people rating themselves consistently higher than average. It could be argued therefore, that it is not an appropriate measure to use to assess outcomes, and to judge quality of life. In addition, assessing the subjective experiences of people who have difficulties in the use of language is fraught with difficulties, and any conclusions based on those assessments needs to be interpreted with caution.

Conclusions

Quality of life is a fairly recent concept developed to judge the well being of the population, and to make decisions about service delivery. (Andrews and Withey, 1976; Hatton, 1998). As such it is a social construct, which might explain why, despite over thirty years of research, there is no agreed definition. Decisions about resource allocation are nevertheless often made on the basis of quality measures. Parmenter (1992) suggests that the use of quality measures should be abandoned because of the danger of them becoming a justification for the denial of rights to people with disabilities.

In recognition of the fact that only an individual can legitimately judge their own life, recent research has focussed on subjective measures, and in particular satisfaction. Satisfaction appears to be a stable psychological function possibly related to disposition, which is maintained at a high level by a homeostatic or adaptive mechanism. It's use as a measure of change, or to make judgements about quality of life should therefore be undertaken with caution, if at all. The assessment of subjective quality of life in people with an intellectual disability is complicated by difficulties in communication, including verbal ability and possible acquiescence. Studies that have been done indicate, however, that satisfaction levels in this population are as high as in the non-disabled population. The use of satisfaction to measure quality of life in people with an intellectual disability could therefore be argued, as Hatton (1998) does, to be untenable.

Ways forward

Decisions made on the basis of research into quality of life should be taken cautiously, and should be at a population rather than an individual level. The stability of satisfaction indicates that it should not be used as a basis for decisions about quality of life or resource allocation. This is particularly true for people with an intellectual disability, who already have difficulty in asserting their needs. Research is needed into the best way to represent their needs and aspirations, and whether these needs and aspirations mediate their satisfaction with aspects of their life. Research is also needed into whether people with an intellectual disability in fact acquiesce in interviews any more than do non-disabled people. The remarkable stability of satisfaction suggests that investigation of circumstances where satisfaction is particularly high or low may throw further light on human “happiness”.

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Title:

Subjective judgements of Quality of Life: a comparison study between people with an intellectual disability and those without a disability

Running title:

Subjective QOL

Key words:

Intellectual disability, satisfaction, quality, importance, health

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Subjective judgements of Quality of Life: a comparison study between people with an intellectual disability and those without a disability

Abstract

This study investigated the relationship between objective and subjective measures of quality of life, and in particular health status and primary care services. Thirty-one people with an intellectual disability were interviewed using Cummins (1993a) quality of life questionnaire. Thirty-one matched controls from the general population filled in a parallel questionnaire. The results in both groups support the findings of many researchers that satisfaction with aspects of life is generally high, at around 75% of maximum possible satisfaction. The study also confirms previous findings that satisfaction with aspects of life does not correlate with objective circumstances in either group. The importance that people attach to aspects of their lives did not correlate with their objective circumstances or their satisfaction with life. People with intellectual disability, however, attached greater importance to all aspects of their lives than did people without a disability. This may be linked to their aspirations, preferences, and opportunities for choice, which may, therefore, be a more meaningful way of considering their life quality. These findings call into question the use of satisfaction as a general measure of quality of life, and also indicate that the use of importance as a mediating variable in understanding satisfaction may not be a solution. People with an intellectual disability had poorer health than the controls, and were significantly less satisfied with their health. Contrary to other findings (e.g. Kerr et al, 1996) they reported that they had received more health checks than had the controls over the previous year. Half of these checks had been carried out by "special" services rather than primary care services.

Introduction

Primary Care

The UK Government's policy in the late twentieth century, to close long stay hospitals, as embodied in the NHS and Community Care Act (1990), has led to a focus on community support for people with intellectual disability. Emerson et al (1996) state "that a high quality of life is one in which people receive individually tailored support to become full participants in the life of the community, develop skills and independence, be given appropriate choice and control over their lives, be treated with respect in a safe and secure environment". Emerson et al's (1996) extensive review of the research literature indicates that the quality of life for people with learning disabilities tends to be low according to these criteria.

A key area where these aspirations are not met, is primary health care. A Government publication, A strategy for People with Learning Disabilities (DOH, 1995), stresses the central role of the general practitioner in ensuring health promotion, health surveillance and health care. There are a number of studies that show that people with learning disabilities have a higher health morbidity, but significantly different quality of primary health care than the non-disabled population. Kerr et al (1996) in a major review of primary care for people with intellectual disability, noted that, although people with an intellectual disability have a higher level of specific illness, such as epilepsy, cerebral palsy, and sensory impairment than the general population, this morbidity is often not diagnosed and treated. Beange et al (1995) studied two hundred and two adults with intellectual disability living in Sydney, Australia, and found that they had an average of 5.4 medical disorders per person, half of which had not been previously detected. Kerr et al (1996) reported that people with an intellectual disability also have fewer health checks, and experience fewer health promotion procedures than the general population. Whitfield et al (1996) compared seventy-eight adults with intellectual disability with seventy-eight non-disabled adults matched for age and gender and found that although the people with intellectual disability consulted their general practitioners at an equivalent rate to the controls, they had significantly less preventative care.

Few studies have been carried out on how satisfied people with intellectual disability are with the services they receive from their general practitioner. Those that have indicate that, as in the general population (Fitzpatrick 1993), satisfaction levels are high. Singh (1997) conducted a study looking at the role of general practitioners in the provision of primary care for people with an intellectual disability. He examined the attitudes and experiences of people with an intellectual disability, their carers and GPs. Questionnaires were completed by eight hundred and twenty-one people with an intellectual disability, and a further twenty-five were interviewed. 94% of those people were generally happy with the treatment they had received from their GP. Martin et al (1997) set up a screening programme for people with an intellectual disability. They found that after the screening, 81% (forty-three) of them said they were satisfied with their doctor.

In attempting to explain these high levels of satisfaction, various mechanisms have been suggested. Martin et al (1997) suggest that it may be because the service users rarely have the opportunity to spend time on their own with a professional who is solely concerned with them. Singh (1997) considered that it might be due to low levels of expectation and a reluctance to complain. Cummins (1995a) attributes the high levels of satisfaction to a hypothesised homeostatic mechanism, which leads to an average satisfaction level of 75%. (See later).

Services, particularly health services, are often evaluated in terms of satisfaction expressed by users (Fitzpatrick, 1993). Resource decisions are regularly made on the basis of these evaluations. It is important to note that reported levels of satisfaction may not necessarily accurately reflect the quality of services delivered.

Measuring satisfaction

The measures of quality of life that have been developed for people with intellectual disability have for the most part, focused on objective criteria, such as type of residential provision, income, and so on. Wolfensberger's (1972) principle of normalisation was extremely influential in the development of quality tools that looked at measuring the huge disparities between the life conditions of people with learning disabilities and the ordinary population. Wolfensberger and his colleagues (Wolfensberger and Glenn, 1975; Wolfensberger and Thomas, 1983) developed PASS and PASSING as measures of whether normalisation was being achieved in service settings. However, whilst PASS and PASSING measured objective variables, they did not measure subjective psychological variables such as satisfaction and happiness that ordinary people would consider to be an essential component of an assessment of quality of life.

It is now commonly agreed that a satisfactory measure of quality of life has to include both subjective and objective measures (e.g. Raphael, Brown et al, 1996; Emerson, 1985; Borthwick-Duffy, 1992). Hughes and Wang (1996) conducted a literature review of quality of life measures, and listed those that could be classed as subjective psychological measures. These were: satisfaction with aspects of life, feelings, perception of life, personal values and aspirations, self-concept, sense of general well being, happiness and personal dignity.

Satisfaction is frequently used as a measure of quality of life, and as an outcome measure in service evaluation. This is despite the evidence of the remarkable stability of satisfaction across time and individuals. Cummins (1995a) reviewed a number of unrelated studies of satisfaction in different groups, and has found that despite significantly different life conditions, life satisfaction in all the groups comes out at a mean of around 75%. The only group scoring significantly higher, were those with a higher than average income. Cummins hypotheses the existence of a psychological, homeostatic mechanism, maintaining an average level of life satisfaction at around 75%. There is a body of evidence that supports Cummins' hypothesis. It has been known for a number of years that satisfaction scores tend to be consistently high, with most people rating themselves more satisfied than average on all domains of life, and that, except under unusual circumstances, there is a remarkably weak relationship between a person's degree of satisfaction and the material aspects of their lives (e.g. Cummins, 1997; Costa et al, 1987; Brickman et al, 1978). There is also evidence that this judgement can be remarkably stable over time (e.g. Edgerton, 1996; Gilbert et al, 1998).

Studies on the stability of satisfaction have tended to be carried out on the general population (e.g. Andrews and Withey, 1976; Costa et al, 1987). However, studies of satisfaction in the intellectually disabled population over a wide range of life domains show the same trend. The results tend to be explained in terms of low expectations, little choice, or lack of experience (e.g. Sands et al, 1991; Flynn and Saleem, 1986; Raphael et al, 1996). Felce (1996) notes that research with people with intellectual disability living independently has provided a picture consistent with low expectations, in that individuals say they are satisfied despite experiencing many adverse conditions.

Importance

A number of researchers have suggested that the satisfaction a person expresses about an aspect of their life, might be related to the importance they attach to that aspect. Felce and Perry (1995) have proposed a model of quality of life that integrates subjective and objective indicators reflecting a broad range of life domains, through an individual ranking of the relative importance of each domain. These domains are physical well being, material well being, social well being, development and activity, and emotional well being. Felce and Perry argue that the significance of either the objective or subjective assessment of a particular life domain is interpretable only in relation to the importance the individual places on it. Raphael et al (1996) note that people may express high enjoyment of life within an environment of poor quality, and that this may be because they are unaware of other possibilities, or believe that they have to suppress the importance of some possibilities. They argue that the importance a person places on their enjoyment of life serves as a weight for that enjoyment. Cummins (1995a) states that any measure of satisfaction needs to be mediated by a measure of importance, because of the stability of satisfaction. Despite the recognition of the need to consider the salience people attribute to aspects of their life, few studies have done so. Sandhu (1996) asked forty-three people with an intellectual disability to name three things they considered important in life. The three categories with the highest frequency were “having friends”, “going out socially”, and “independence”. She concluded that the variety of responses she received suggest that assumptions should not be made about what people with an intellectual disability find important.

Cummins (1995b) argues that it is of great importance to measure quality of life for people with intellectual disability using the same models of quality as for the ordinary population. He has developed a quality of life scale which can be used with adults with mild and moderate learning disabilities as well as with the general population. This scale includes the domains listed by Felce and Perry (1995), and assesses them in terms of objective facts, and their importance to individuals. It also measures the importance of and satisfaction with those domains. An initial evaluation of this scale (Cummins et al, 1997) reports data collected from fifty-nine people with an intellectual disability, the vicarious responses of their primary caretakers, and sixty-nine university students. The relationship between importance and satisfaction is not directly explored, rather importance and satisfaction are combined to give an overall measure of subjective quality of life.

Aim of the current study

The evidence that measures of satisfaction are stable across time and across groups suggests that satisfaction might not be an appropriate measure to judge quality of life, or of services, on its own. People with intellectual disability tend to have poorer objective quality of life, particularly in health and health services. The research evidence suggests however, that they will nevertheless express high satisfaction with their life and the services they receive. This study aims to explore whether the relationship between objective measures of quality of life, and satisfaction with life is similar in a disabled and non-disabled group. It also aims to explore whether subjective judgement of importance with domains of life is a better predictor of satisfaction than objective measures, as suggested by the literature.

It is hypothesised that

1. The overall objective quality of life, and in particular, health status, will be lower in the intellectually disabled group
2. The satisfaction expressed by both groups with the various domains of their life will not be significantly different
3. The importance attached to each domain of life, and particularly health status, will be a better predictor of satisfaction than objective measures.
4. Both groups will be equally satisfied with the care they receive from their GP
5. The non-disabled control group will have received significantly more health promotion services than the intellectually disabled group.

Method

In this study thirty-one people with an intellectual disability living in the community, were interviewed using a questionnaire about their quality of life. Thirty-one people without a disability filled in a parallel questionnaire.

Participants

In order to identify participants, the author, an experienced qualified clinical psychologist, contacted the managers of all the day services for people with intellectual disability, a local voluntary group, and all the community intellectual disability nurses in the area covered by an NHS Trust, part of a large city conurbation, to ask for help. The nature and purpose of the research was explained to the managers and staff, and to service users in the local service users group. Literature prepared for the staff and service users was given to them to consider[1]. Staff identified forty-two people with an intellectual disability who would be interested in taking part in the research and who were able to communicate verbally. To establish understanding and consent, the procedure was explained to each potential participant in the presence of a member of staff who knew them well. They were then asked questions about what they had heard in order to establish their understanding (Arscott et al, 1998). The questions were:

What will I be talking to you about?
How many times will I want to talk to you?
Are there any good things about talking to me?
Are then any bad things about talking to me?

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[1] See Appendix III

What can you do if you decide you don’t want to talk to me anymore?

People had to respond appropriately to at least three of the questions to be considered able to participate further, and six people were considered to be unable to do so.

The questionnaire used (Com Qol-ID) involves a pre-test protocol on two of its three scales to determine whether the participant is able to understand the use of the scales. Participants are given a pre-test where they are required to rank order two, then three then five bricks according to size, and then relate them to the visual ladder to the cue “I want you to point to the step that matches each brick. Where does this brick go on the step?” They are then asked to identify something that is important to them and where they would put it on the ladder. In this way, the interviewer determines whether the participant can deal with a two, three or five step scale to measure importance. To measure satisfaction a similar procedure is followed using faces representing happiness and sadness. If the participant fails the procedures the interview does not proceed. A further five people were unable to understand the procedures, and were excluded from the study.

The questionnaire was administered to thirty-one people. All thirty-one were on the register of the local community learning disability team. The mean age of the sample was 41 years (SD 13, range 24 to 68 years). Twenty-six attended day centres, and five were resident in the same group home. Each person was interviewed in the day centre or their home.

Controls

Controls were identified from the lists of two large GP practices. They were matched to the participants for year of birth, gender, ethnic origin, and residence in the outer or inner city. Four matched controls were identified for each participant. The resulting one hundred and twenty-four people were sent written information about the nature and purpose of the research, and asked, by letter, if they would participate[2]. Each person that replied was sent a questionnaire (ComQol-A). If more than one questionnaire matching a participant was returned, only the first one received was used. At least one questionnaire was received that matched each of the thirty-one participants with an intellectual disability. Only thirty-one were used in the analysis.

The Measure - The Comprehensive Quality of Life Scale

The Comprehensive Quality of Life Scale has three forms, two of which, ComQol-A for the general adult population, and ComQol-Id for people with an intellectual disability (Cummins 1993a, 1993b) were used in this study. The two scales are considered to be parallel, and only differ in their mode of administration

Each has a measure of objective quality of life across seven domains, and a measure of the importance of and satisfaction with those domains. The domains are: Material well being, health, productivity, intimacy, safety, place in community, and emotional well being. The objective measure consists of three questions for each domain. For example, the health domain questions ask how often the respondent has seen a doctor in the last three months, what illnesses they have, and what medicine do they take. The measure provides a scoring protocol.

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[2] See Appendix IV

Importance and satisfaction are both measured on Likert scales. Com Qol-A for the general population has a five point scale for importance and a seven point scale for satisfaction. ComQol-ID has a visual ladder to measure importance and a series of faces from happy to sad to measure satisfaction. Psychometric data on the test has been reported in four studies on ComQol-ID (Cummins, 1997; Cummins et al, 1997) and seventeen studies on the adult scale (Cummins, 1997)

Other measures

The administration of the ComQol to both people with an intellectual disability and controls included a question on the importance of and satisfaction with their family doctor, framed in the same way as in the ComQol. That is, they were required to rank the importance of and satisfaction with their doctor on a two, three, or five point Lickert scale. Both groups were also asked if they had undergone any of eight possible health promotion checks over the last year, and if so, where. These were: a full health check, blood pressure check, eye test, hearing test, advice on contraception and or sexual activity, and advice on smoking, diet, drinking alcohol and exercise[3].

Results

ComQol

ComQol-A and ComQol-ID raw scores can be converted to a standardised comparison statistic which reflects the extent to which the raw score approximates to the maximum score which could be obtained (Cummins 1993a,1993b). In the case of

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[3] See Appendix IX

the objective scale, each domain has a maximum score of fifteen, the Likert scale for importance, two, three or five, and the Likert scale for satisfaction, two, three, five or seven. Cummins provides a formula to convert the scores, which allows direct comparisons to be made between the three scales of the questionnaire, and between people using different size Likert scales This percentage scale maximum, (%SM) was computed for all scores, according to the procedure laid down in the test manual. The means and standard deviations for the ComQol scores are presented in Table 1. Higher scores reflect reporting of better objective circumstances, greater importance and greater satisfaction respectively. Participants with an intellectual disability are referred to as “participants”, and participants without a disability, as “controls”.

Objective scale

To test the hypothesis that overall objective quality of life, and in particular, health status would be lower in the participants, a multivariate analysis of variance between the two experimental groups and across the seven domains for the objective scale, was carried out.

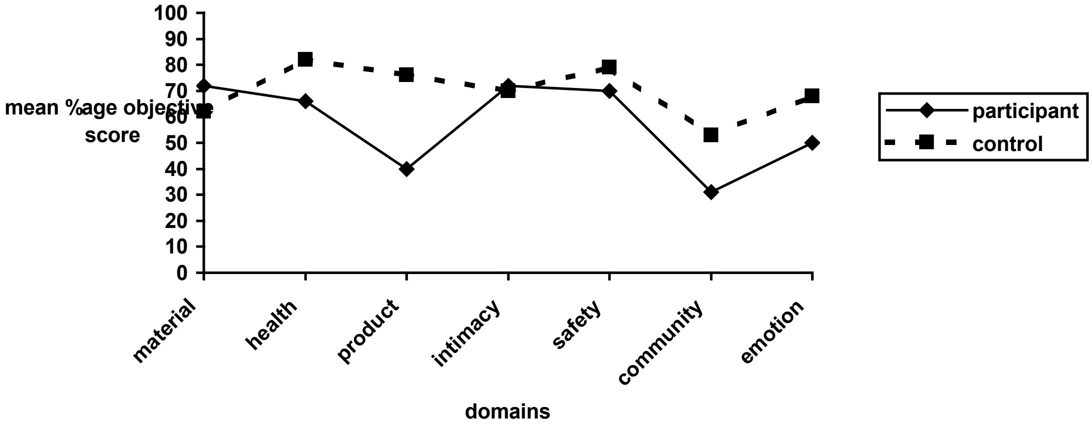
Table 1. Analyses of Variance between participants and controls for the objective scale

Domains		Mean	Standard Deviation	df	Mean Square	F	Sig.
Material	Participant	72.04	31.52	1	1533.378	2.574	0.114
	Control	62.10	14.08				
Health	Participant	66.12	19.72	1	3770.520	10.218	0.002*
	Control	81.72	18.69				
Productivity	Participant	39.78	19.21	1	20413.31	53.624	0.000*
	Control	76.08	19.81				
Intimacy	Participant	72.04	22.52	1	71.685	0.189	0.666
	Control	69.89	15.91				
Safety	Participant	70.16	25.35	1	1146.953	3.028	0.070
	Control	78.76	10.72				
Community	Participant	30.51	18.37	1	7625.336	23.320	0.000*
	Control	52.69	17.79				
Emotion	Participant	50.27	25.41	1	4732.303	9.961	0.003*
	Control	67.74	17.45				

* significant at $p<0.05$

The multivariate analysis of variance was significant (Wilk's Lambda 0.405, $p<0.000$). There were significant differences between the two groups in the domains of health, productivity, community and emotion. In all of these the participants' scores were lower than the controls (see Figure 1), supporting the hypothesis that objective quality of life would be lower for the participants than the controls, in those domains.

Figure 1.Percentage Objective quality across the seven domains



Subjective data – satisfaction

To test the hypotheses that the two experimental groups would not differ in their satisfaction with domains of their life, and in particular their satisfaction with their GP, a multivariate analysis of variance between the two groups and across the seven domains for satisfaction, was carried out.

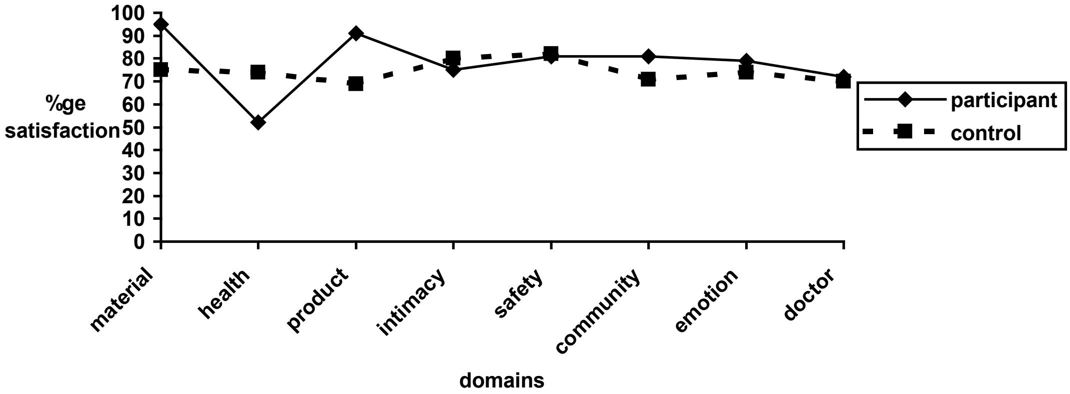
Table 2. Analyses of Variance between participants and controls for the satisfaction scale

Domains		Mean	Standard Deviation	df	Mean Square	F	Sig.
Material	Participant	95.16	15.03	1	6469.534	33.170	0.000*
	Control	74.73	12.82				
Health	Participant	52.42	47.59	1	7348.790	6.006	0.017*
	Control	74.19	13.50				
Productivity	Participant	91.13	22.87	1	323.701	19.679	0.000*
	Control	69.35	14.97				
Intimacy	Participant	75.00	38.19	1	17.921	0.370	0.545
	Control	76.57	17.06				
Safety	Participant	80.65	32.09	1	1451.613	0.031	0.861
	Control	81.72	11.67				
Community	Participant	80.65	35.18	1	448.029	1.916	0.171
	Control	70.97	16.65				
Emotion	Participant	79.03	30.34	1	54.884	0.800	0.800
	Control	73.66	14.13				
Doctor	Participant	71.77	36.94	1		0.067	0.796
	Control	69.89	16.34				

* significant at $p<0.05$

The multivariate analysis of variance was significant (Wilk's Lambda, 0.405, $p<0.000$). There were significant differences between the two groups on three domains. Participants with intellectual disability were more satisfied with their material well-being and productivity than the controls, but less satisfied with their health (see Figure 2). Thus the hypotheses that there would be no difference in satisfaction between the participants and the controls in particular for their GP were supported for five of the eight domains including that for their GP.

Figure 2. Percentage Satisfaction across the seven domains, and for doctor



Subjective data – Importance

In order to consider whether the groups differed in the importance they attributed to the domains of their life, a multivariate analysis of variance between the two groups across the seven domains for importance was carried out.

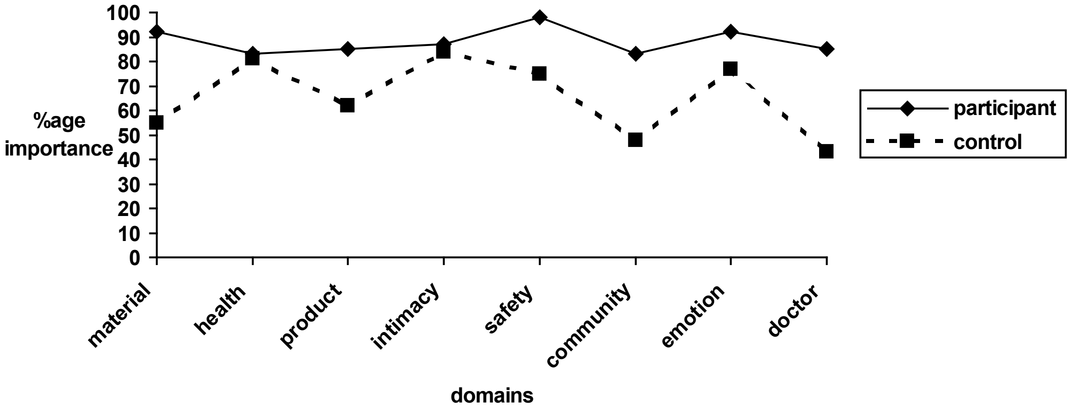
Table 3. Analyses of Variance between participants and controls for the importance scale

Domains		Mean	Standard Deviation	df	Mean Square	F	Sig.
Material	Participant	91.94	22.72	1	21330.65	49.209	0.000*
	Control	54.84	18.73				
Health	Participant	83.06	34.99	1	90.726	0.124	0.726
	Control	63.71	19.19				
Productivity	Participant	85.48	29.42	1	7348.790	11.912	0.001*
	Control	63.71	19.19				
Intimacy	Participant	87.10	25.72	1	161.290	0.331	0.567
	Control	83.87	17.74				
Safety	Participant	97.58	9.91	1	7903.226	30.705	0.000*
	Control	75.00	20.41				
Community	Participant	83.06	33.78	1	18639.11	22.188	0.000*
	Control	48.39	23.22				
Emotion	Participant	91.94	22.72	1	3639.113	8.192	0.000*
	Control	76.61	19.30				
Doctor	Participant	84.68	32.07	1	27258.065	26.772	0.000*
	Control	42.74	31.75				

* significant at $p<0.05$

The multivariate analysis of variance was significant (Wilk's Lambda 0.314, $p< 0.00$). There were significant differences between the two groups on five domains, material well being, productivity, community, safety and emotion, with the participants scoring higher (see Figure 3). Thus participants with an intellectual disability rated five of the eight domains to be more important to them than did the controls.

Figure 3. Percentage Importance across the seven domains, and for doctor



Correlations

In order to test the hypothesis that importance would be a better predictor of satisfaction than would objective measures, correlations were carried out between objective scores and importance and satisfaction scores, and between importance and satisfaction scores for both controls and participants.

a) note on significance levels

There were 23 multiple comparisons in the correlation matrix[4]. Statistical significance levels were calculated, using a Bonforoni adjustment (Clark-Carter, 1997) to take into account the number of analyses conducted, thus using a stricter criterion in probability levels. As a total of 23 were conducted, the significance level is set at 0.002 (p = 0.05/46).

b) relationship between objective data and importance

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[4] see Appendix X

In neither the participant or the control group were there significant Pearson correlations between objective and importance scores.

c) relationship between objective data and satisfaction

In the participant group there were no significant correlations between any of the objective domains and satisfaction with those domains. In the control group, there was a significant positive Pearson correlation between objective and satisfaction scores for emotion ($r=0.607$, $p<0.000$).

d) relationship between importance and satisfaction

There were no significant Pearson correlations between importance and satisfaction scores in either the control or participant group.

The lack of correlation between importance scores and satisfaction and objective scores except in the domain of emotion for the controls, means that importance scores can not be used to predict satisfaction, and therefore the hypothesis is not supported.

Additional measures

In order to test the hypothesis that the control group would have received more health promotion services than the participants, both groups were asked how many of eight ill health preventative measures they had received within the last year. The participants received more measures than the controls (participants mean 4.39, S.D. 1.94, controls mean 2.03, S.D. 1.97). On an unrelated t-test, there was a significant difference in the number of measures received between the two groups ($t= 4.73$, $p<0.000$). However whereas the controls had received the majority of their measures from their GP, the participants with an intellectual disability had received half of their measures from other sources, such as the local specialist hospital, or their day centre

(GP measures for participants, mean 2.00, S.D. 2.13). The hypothesis, therefore, is not supported.

Discussion

In this study, the Comprehensive Quality of Life Scale (Cummins, 1993a,1993b) has been used to compare thirty-one people with an intellectual disability and thirty-one matched controls on their objective and subjective quality of life. Participants with an intellectual disability generally had significantly higher importance scores for all the ComQol domains than did the non-disabled controls, except for health and community involvement. These latter two domains were the only ones that the controls felt were as important to them as did the people with an intellectual disability. Why should people with an intellectual disability attach such high importance to these domains of their life? The people interviewed for this study were very well aware that they were different to other people, and the disadvantages this difference conferred on them. Many of them had aspirations to do better in life, even if that was simply learning to cross the road in order to get on a bus. Perhaps the importance they placed on life was a reflection of their awareness of difference, and their aspirations. Flynn and Saleem (1986) interviewed 12 adults with intellectual disability living with their parents, and reported on their desire to change. The majority had aspirations to change their lives, wishing to take on extra responsibilities at home, and at work and in their social life and interests. Eight of the respondents wished to leave home. Stalker and Harris (1998) in a comprehensive review of the exercise of choice by people with an intellectual disability, note that although methods are available to assess preferences, choice making opportunities are typically limited. The assessment of life aspirations, their potential fulfilment and the opportunities for choice may be a fruitful development in quality of life research.

Felce and Perry (1995), Raphael et al (1996) and Cummins (1995a) all argue that the importance a person places on aspects of their life needs to be taken into account when considering their satisfaction with their life. In this study, the importance both groups placed on domains of their life did not correlate with how satisfied they were. Thus the importance the participants and controls placed on a particular domain of their life was not necessarily related to how satisfied they were with that domain. Judgements of importance did not correlate with objective scores. This study has not provided evidence that the importance a person with an intellectual disability places on any part of their life, is related to their objective circumstances, or correlates with their satisfaction with those circumstances. The study, therefore throws into question the proposal that the importance a person attaches to aspects of their life can be used to enrich the concept of quality of life, and in particular help to explain why people can be highly satisfied with a poor material quality of life. It has, however, highlighted the importance people with an intellectual disability place on all aspects of their lives.

The satisfaction scale in ComQol is based on asking people with an intellectual disability how happy they are, whilst asking people without an intellectual disability, how satisfied they are. Cummins et al (1997) note in their evaluation of the scale that the “happy-sad” scale might be acting as a state rather than a trait, and therefore the use of “happiness” instead of “satisfaction” may not represent response equivalence. Despite these reservations, the satisfaction scores in this study confirm the findings of other researchers, and particularly Cummins (1995a). Both participants and controls had a high average satisfaction score over all domains except health, the controls averaging 74%, and the participants slightly higher at 78%. The participants were, however, significantly less satisfied than the controls with their own health. This reflects statements people made in the interview about how unhappy they were with their health. Participants were more satisfied than the controls with their material well being, and with their productivity. This was despite the fact that their objective scores for productivity were lower than the controls. It is a possibility that the controls may have been less satisfied with their productivity because of the stress of having to earn a living. Satisfaction did not correlate significantly with any objective measures for either of the two groups. This reflects the findings in the literature that satisfaction with life is not necessarily related to objective circumstances e.g. Cummins (1996), Edgerton (1996). Many studies use satisfaction as a way of assessing quality of life and quality of service provision e.g. Singh (1997), Sands et al (1991), Martin et al (1997). These results indicate that the use of satisfaction as a measure of quality on its own should be used with caution in both the general population and with people with an intellectual disability.

Some reservations need to be made about the objective scale. The scale contains items that have a subjective judgement involved. For example, one question asks "how many things do you own compared with other people". This may be a difficult question for someone with an intellectual disability with little experience of ordinary life, to make a judgement about. Interpretation of results on the objective scale needs to take account of the lack of external verification of some of the facts. The results of this study show that people with an intellectual disability scored lower than controls in their reported objective circumstances relating to health, productivity, community and emotional well being. The questions in ComQol in the productivity, community and emotional well being sections are concerned with integration into the community, holding down a job or a voluntary position of some status, having friends to talk to, and doing things outside the home. There was no reported difference in material circumstances between the people with intellectual disability and the controls, both groups living in homes with similar facilities, and both stating that they owned a similar number of possessions. The questions in the ComQol do not differentiate between living in and owning or having control over where you live. Thus, although the participants with intellectual disability may have lived in similar facilities to the controls, they did not necessarily own or have control over them. Participants' reports of their activities indicated they were not participating in community events nor spending as much time with friends as did the controls. This is the challenge faced by services that support people with an intellectual disability living in the community and reflects the findings of other researchers including Kinsella (1993) and Hatton et al (1996). Material well being does not guarantee full community integration.

Both participants with an intellectual disability and the controls were very satisfied with their general practitioner The participants, however attached much more importance to the services of the general practitioner than did the controls. Of the eight health promotion activities on which information was requested, the people with an intellectual disability had received twice as many checks as the controls. Despite the fact that they had received half of these at their day centre or specialist hospital, they had still received more from the general practitioner than did the controls. This is a different finding from other studies, (e.g. Kerr et al, 1996) and perhaps reflects increased awareness by general practitioners of the need to provide services to people with intellectual disability, although it needs to be noted that the participants were not necessarily a representative sample of people with intellectual disability. They were all well known to “special” services, and this might explain the health checks delivered by those services. It may be the case that members of the general population do not receive as many health promotion measures as the Government intended in its Health of the Nation Targets. Despite the positive finding that people with an intellectual disability are having their health checked regularly, this is still being done for the most part by “special” services and not by the primary care services the rest of the population receive. The people with an intellectual disability in this study were much less satisfied with their health than the controls without a disability, even though they were receiving more health checks. They were, however, just as satisfied with their doctor. Studies that look only at satisfaction with health services received may not accurately reflect people’s views on their health status.

It needs to be noted that in this study the people with an intellectual disability were not selected randomly, and had sufficient verbal skills to respond to an interview. Although they were identified by experienced learning disability professionals as people whose responses would be valid and useful, any extrapolation of the findings to people with an intellectual disability who have fewer verbal skills, cannot be made. The participants with intellectual disability were interviewed whereas the controls filled in a postal questionnaire, which might reduce the comparability of results.

Conclusions and Recommendations

This study has indicated that people with an intellectual disability demonstrate the same high levels of satisfaction with life found in the general population. The implication of this finding is that satisfaction may not be the most sensitive or appropriate measure to use to assess quality of life or of service provision.

People with an intellectual disability place more importance on most aspects of their lives than do people without disability. This finding should alert clinicians to be sensitive in their assessment of the needs of people with an intellectual disability. Judgements of importance in the intellectually disabled group and the non-disabled control group had no relationship to reported objective circumstances, or to satisfaction with those circumstances. It cannot therefore be used as an alternative measure to satisfaction or as a predictor of satisfaction. The fact that people with an intellectual disability judged all domains of their life to be very important to them is worthy of further investigation, particularly to consider the relationship between judgements of importance and peoples' aspirations, preferences, and opportunities for choice. These parameters may well be a better reflection of quality of life than the measures currently employed.

This study has confirmed that, in the participants involved, those with an intellectual disability had poorer health than controls, but had more health checks, from both special and primary care services, and more health input from their general practitioner. This is different from previous findings (Kerr et al, 1996) and suggests that perhaps services are beginning to respond better to the health needs of people with intellectual disabilities. Nevertheless, half of the checks were delivered by special services. This marks people out as “different” and runs counter to Government policy of providing ordinary services through primary care and it is important that this is not seen as a reason to reduce primary care services for people with intellectual disabilities. Participants with intellectual disabilities were aware of their health problems and were significantly less satisfied with their health than the controls. This awareness needs to be taken into account when service are planned and delivered.

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Title:

Carer judgements: proxy judgements of the quality of life of people with an intellectual disability

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Carer judgements: proxy judgements of the quality of life of people with an intellectual disability

Abstract

This study compared the responses of sixteen people with an intellectual disability and the proxy responses of their sixteen carers, using a quality of life questionnaire (ComQol., Cummins, 1993). The participants nominated the carers themselves, and all were professional carers except for one relative. The questionnaire had an "objective" scale and two subjective scales measuring importance and satisfaction. On the objective scale the carers' estimates did not differ significantly from the participants in any of the domains. On the two subjective scales, the participants with an intellectual disability scored very highly. Significant differences and significant negative correlations between participants with an intellectual disability and their carers were found for seven of the possible eight importance domains, and two of the possible satisfaction domains. It was considered that this might have been the result of participants with an intellectual disability using a more restricted Lickert scale than their carers', but that further investigation of this negative relationship was warranted. It was concluded that, in studies of proxy responding, the use of Lickert scales of different lengths should be used with caution, if at all. Further research is needed into the validity of proxy responding particularly of subjective experience, and, because of methodological difficulties, what measures other than Lickert scales should be used.

Introduction

Quality of life is a concept that has developed over the latter half of the twentieth century into a complex construct that attempts to take into account environmental and personal factors. Despite the wide range of definitions (Hughes and Wang, 1996) there is general agreement that any comprehensive measure must include an individual's own assessment of their life quality. For example, Felce and Perry (1995) propose a three-component model of quality of life, which encompasses objective life conditions, subjective well being and personal values and aspirations. Other researchers have also proposed similar models (Cummins, 1995; Boyle, 1994; Raphael et al, 1996).

There are particular problems in assessing the subjective experiences of people with intellectual disability. For example, in interviews, people with intellectual disability have been found to be likely to acquiesce, and answer in a socially acceptable way (Heal and Sigelman, 1996; Heal and Chadskey-Rusch, 1985). For those people who have no verbal communication skills, assessing subjective experience is obviously even more difficult. Schalock (1996) suggests a number of strategies to assess subjective experience in people with intellectual disability including behavioural observation, participant observation, correcting statistically for response bias, and using proxy judgements.

Proxy judgements by relatives and carers are used frequently under the assumption that they directly reflect an individual's experience. Taylor and Bogdan (1996) believe that "entering other people's worlds," means getting to know them well enough to make reasonable inferences about their feelings, which may involve many hours of work. Schalock and Keith's (1993) widely used Quality of life questionnaire is constructed on the assumption that carers who know an individual can judge their life quality. Many other researchers also assume proxy responses are a valid representation of an individual's experience (e.g. Atkinson, 1988; Flynn and Saleem, 1986). There are, however, very few studies that investigate the reliability and validity of proxy responses of subjective experience of people with a learning disability (McVilly and Rawlinson, 1998). Those studies that have been done show a weak correlation between proxy responses and responses of individuals with intellectual disability (e.g. Cummins et al, 1997). Cummins et al (1997), as part of the initial evaluation of his quality of life questionnaire- ComQol, interviewed fifty-nine people with an intellectual disability and asked their carers to fill in the questionnaire as if they were the individuals involved. They found very little correlation between the scores, and suggest that vicarious responses by carers relating to the subjective quality of life for people with an intellectual disability should be viewed most cautiously. Harner and Heal (1993) used a lifestyle satisfaction scale to assess personal satisfaction in people with an intellectual disability. For one hundred and twenty-one of the people that they assessed, they asked the primary carer to fill in a caretaker questionnaire, and a quality of life questionnaire. Their results led them to state that professional caretakers do not always accurately predict satisfaction reported by the people in their care, and that they should not be solely relied on to provide data about the satisfaction of those people. McVilly and Rawlinson (1998) reviewed proxy responding in the measurement of quality of life, particularly in the health literature, and found that proxy-respondent concurrence is more problematical for evaluations of emotional experience, than for objective facts. They found that as questions increased in detail and subjectivity, the degree of proxy-respondent agreement decreased. They recommend that when proxies are used for people with intellectual disability, the interpretation of results must be undertaken with great care. They emphasise the importance of this in evaluation of health issues in particular. Coulter (1997) notes that the WHO definition of health is a state of well being. He believes that this means that health related quality of life (HRQOL) must be judged by the person concerned, not a carer or professional, and until or unless this judgement can be made, HRQOL concepts should not be applied to people with intellectual disability.

The aim of this study is to repeat that part of Cummins et al (1997) study investigating the relationship between the responses of people with an intellectual disability and their carers using the ComQol (Cummins, 1993) with additional questions about their subjective judgement of the care they receive from their general practitioner. It is hypothesised that carers will be accurate in assessing objective measures of quality of life, but that there will be little correlation between their assessment of subjective factors, and those of the people with intellectual disability themselves.

Method

This investigation was carried out as part of a larger study (Hensel, this volume). In that study, thirty-one people with an intellectual disability were interviewed using the ComQol. Those people attended one of three day centres in a large city, or lived in one group home. They were identified by staff as being interested and able to take part. Their interest and ability to consent was tested using questions based on those proposed by Arscott et al (1998)[1]. All participants were asked if they would be happy for someone close to them to be interviewed to see "how good they were at knowing what you feel" and if so, whom would they nominate. They were reassured that anything they said would be confidential. Twenty-six of the thirty-one people agreed. They were interviewed either in the day centre, or their group home. Of the carers nominated, sixteen responded to a letter inviting them to participate, and were willing to be interviewed[2]. The other ten (two professional carers and eight relatives) did not respond to the letter of invitation or a follow up prompt letter. Of those carers who did respond, one was a parent, and fifteen were professional carers. They were interviewed by the author, who asked them to answer "as if" they were the person with an intellectual disability.

ComQol-ID (Cummins, 1993) is a questionnaire designed to be used in interview with people with intellectual disability. It has three sections, one relating to factual (objective) information, and the other two sections to subjective information on importance and satisfaction. All three scales relate to seven domains which are, material well being, health, productivity, intimacy, community, safety and emotion. The importance and satisfaction scales are Likert scales, which can have two, three, or five points depending on the individual's ability to understand the procedure. The importance and satisfaction scales involve a pre test of the individuals understanding, if they fail, the interview is discontinued. (For further details of the instrument, see

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[1] see Appendix III
[2] see Appendix V

Cummins et al, 1997). An extra question about the participant's judgement of the importance of and their satisfaction with their general practitioner, was included.

Results

Data for sixteen people with an intellectual disability and their corresponding carer was analysed. The scores for each scale of the ComQol were converted to a standardised comparison statistic, which reflects the extent to which the raw score approximates to the maximum score which could be obtained (Cummins, 1993). Because of the small sample, Mann-Whitney tests were used to compare the differences between the participants and their carers on all the domains for objective, importance and satisfaction scores, and importance of and satisfaction with their general practitioner. For the two subjective scales, importance and satisfaction, the mean ranks of the participants with an intellectual disability, except for health satisfaction, were higher than the carers. The results are presented in Table 1.

There were no statistically significant differences between participants and carers on the objective scale. There were significant differences between the two groups for importance scores in the domains of material well being, health, safety, community and doctor. There were also significant differences between the two groups for satisfaction with material well being and productivity.

Table 1. Mean ranks and Mann-Whitney comparisons for ComQol scores for 16 participants and their carers

		Objective			Importance			Satisfaction		
Domains		Mean Rank	U	Sig.	Mean Rank	U	Sig.	Mean Rank	U	Sig.
Material	Participant	16.97	120.5	0.776	23.19	21.0	0.000*	21.28	51.5	0.001*
	Carer	16.03			9.81			11.72		
Health	Participant	14.94	103.0	0.343	23.03	23.5	0.000*	16.25	124.0	0.877
	Carer	18.06			9.97			16.75		
Productivity	Participant	16.59	126.5	0.955	20.69	61.0	0.007	22.84	26.5	0.000*
	Carer	16.41			12.31			10.16		
Intimacy	Participant	16.38	126.0	0.939	19.72	76.5	0.031	19.44	81.0	0.060
	Carer	16.63			13.28			13.56		
Safety	Participant	16.69	125.0	0.939	22.72	28.5	0.000*	19.25	84.0	0.081
	Carer	16.31			10.28			13.75		
Community	Participant	16.84	122.5	0.834	22.53	31.5	0.000*	20.03	71.5	0.020
	Carer	16.16			10.47			12.99		
Emotion	Participant	11.72	51.5	0.004	21.00	56.0	0.004	18.50	96.0	0.202
	Carer	21.28			12.00			14.50		
Doctor	Participant	---------	--------	-------	21.59	46.5	0.001*	18.50	96.0	0.202
	Carer	---------			11.41			14.50		

*significance<0.002

Note on Significance levels

There were 23 multiple comparisons in the Mann-Whitney tests and also in the correlation matrix. Statistical significance levels were calculated, using a Bonforoni adjustment (Clark-Carter, 1997) to take into account the number of analyses conducted, thus using a stricter criterion in probability levels. As a total of 23 were conducted, the significance level is set at 0.002 (p = 0.05/23).

Spearman rank correlations were also carried out between the participants and their carers for all the domains, for the objective, importance and satisfaction scales (see Table 2). Correlations were also carried out for estimations of importance and satisfaction with the participants' general practitioner.

Table 2. Spearman correlations between 16 participants and their carers for each domain for objective and subjective scores

	Objective		**Importance**		**Satisfaction**	
Domains	correlation	significance	correlation	significance	correlation	significance
Material	0.051	0.781	-0.799	0.000*	-0.602	0.000*
Health	0.170	0.351	-0.761	0.000*	-0.028	0.880
Productivity	0.010	0.956	-0.481	0.005	-0.753	0000*
Intimacy	0.014	0.941	-0.388	0.028	-0.338	0.059
Safety	-0.020	0.912	-0.745	0.000*	-0.314	0.080
Community	-0.038	0.837	-0.694	0.000*	-0.419	0.017
Emotion	0.521	0.002*	-0524	0.002*	-0.229	0.208
Doctor	---------	----------	-0.583	0.000*	-0.229	0.208

* significance<0.002

There was only one statistically significant correlation on the objective scale, and that was a positive correlation for the domain of emotion. For the other domains of the objective scale, there was no relationship between the scores of the participants and those of their carers. The importance scores for all domains, except for productivity and intimacy, were significantly negatively correlated. Satisfaction scores for the domains of material well being and productivity were also significantly negatively correlated.

Discussion

In this study, carers were asked to put themselves in the place of the person with an intellectual disability for whom they cared, in order to answer a questionnaire about quality of life. The participants with an intellectual disability nominated the carers themselves, and all were professional carers except for one relative. The majority of participants nominated their professional carers rather than their relatives, even though some of them still lived at home. Some of them stated that this was because they did not want their life to be discussed with their parents. Eight of the nine relatives contacted did not reply to two letter of invitation. The professional carers interviewed either worked at the day centre or at the participant’s group home. It is not possible to judge whether they knew the participant better than would a relative, but a number of them stated that they did not know all about the participant’s life, particularly the hours spent out of their care.

The questionnaire had an objective scale and two subjective scales measuring importance and satisfaction. On the objective scale, there was no significant difference between the scores of the participants with an intellectual disability and their carers, neither were there any significant correlations. This indicates that there was no clear relationship between the participants' scores, and the judgements of their carers. It is, however, not possible to determine the accuracy of the judgement of either group as no external verification was carried out. The objective scale of the ComQol has a subjective element, for example, respondents are asked to judge how many things they own in comparison with other people. People with an intellectual disability, may find this a difficult judgement, and indeed many in this study considered themselves to be well off, despite none of them being householders or car owners.

There were significant differences between the participants and their carers in five of the possible domains for importance. These five domains were also significantly negatively correlated indicating that the more important a participant thought a domain, the less important their carer considered it to be for them. This is also true for satisfaction with two of the domains. This strengthens the findings of significant differences between the groups despite the methodological difficulties of using a restricted Lickert scale.

The high scores of the participants with an intellectual disability on the two subjective scales may have been the result of using a restricted Lickert scale. A number of the participants responded on a restricted Lickert scale of three points, whereas all the carers responded on a five-point scale. All scores were converted to a percentage of scale maximum, but the use of a three-point scale necessarily restricts the variability of the data in the participant group, and may have led to further skewing of the data towards positive responding. This difficulty was exacerbated by the small sample size in the study. This was not a difficulty with the objective scale, as it was measured in a different way.

It was concluded that proxy responses on behalf of people with an intellectual disability by professional carers should be used with caution if at all, particularly when assessing subjective judgements. In this study, proxy judgements by relatives were hard to obtain, and, for the most part, people with an intellectual disability did not want their relatives to speak on their behalf. Studies of proxy responding should ensure that relatives are not used as proxies without the permission of the person involved, and any respondents used should have a good knowledge of that person. It was also concluded that, in studies of proxy responding, the use of Lickert scales of different lengths should be used with caution, if at all. Further research is needed into the validity of proxy responding particularly of subjective experience, and, because of methodological difficulties, what measures other than Lickert scales should be used. The negative relationship between participants and carers judgements of subjective well being warrants further investigation to determine whether it is a true finding, and if so, why it should occur.

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Appendix I Ethics Committee Approval

Appendix (II)

Instructions for authors

Appendix III

Information for participants with an intellectual disability

A COMPARISON OF QUALITY OF LIFE AND SATISFACTION WITH HEALTH CARE BETWEEN PEOPLE WITH LEARNING DISABILITY AND THOSE WITHOUT

INFORMATION SHEET

Thank you for thinking about taking part in my study. Here is some information about the study to help you decide.

What is the study about?
The study is about the things that make life good for people. I want to see if the things that are good for you, are also good for other people. One of the things I especially want to know about is the help you get from your doctor.

What will you have to do?
You would meet me at a place you choose. I would ask you a number of questions. This would probably take about an hour.

What are the benefits?
At the end of the study I would have information to help make services better.

What are the risks?
There are no risks.

What if you do not want to take part?
If you do not want to take part, just say no. Nothing else will happen.

What happens to the information?
No one else will know what you told me.

Who else is taking part?
120 people from a number of places will be taking part. Your carer will be taking part.

What happens at the end of the study?
At the end of the study, I shall write a report for those who have taken part. I shall also be writng a report for the University of Birmingham.

What if you have more questions, or do not understand?
Ask me , or get someone else to ask me for you.

What happens now if you decide to take part?
If you decide to take part, I shall arrange a time with you, when I can meet you.

What happens if you change your mind during the study?
You can change your mind at any time, just say, and the interview will stop.

Who to contact?
My name is Elizabeth Perkins, and I am a clinical psychologist. My address is:
[redacted]
Tel. [redacted]

Name/number

Presentation

I am interested in what people think about their lives. I am particularly interested in what they think of their doctors. I would like to talk to you about the things that are important to you. Would you like me to go through the information sheet I have given you?

I could see you at your work, in my office, in your home, or anywhere you feel comfortable. I would only need to see you once. The interview would take about an hour. I would not tell anyone else what you said. You could say you wanted to stop at any time if you were not happy with the questions.

Later on I would like to interview your mother/father/carer, but would not tell them what you said. I will only see them if you say I can. When I write my report, your name would not be mentioned. I hope my report will help people make services better.

You do not have to take part at all if you do not wish.

Is there anything you would like to ask?

Please can I check that you are clear about what I have said

1) What will I be talking to you about? score 1 score 0

2) How many times will I want to talk to you? score 1 score 0

3) Are there any good things about talking to me? score 1 score 0

4) Are there any bad things about talking to me? score 1 score 0

5) What can you do if you decide you don't want to talk to me anymore? score 1 score 0

A comparison of quality of life and satisfaction with health care between people with a learning disability and those without (Elizabeth Perkins)

Name

Address

I have had the research explained to me and I understand it . I am happy to take part. I understand that nobody else will be told what I say, and that my name will not be in the report . I understand that I can stop taking part at any time.
I am happy/not happy for …………………………………………….. to be interviewed as well.

Signature

Date

Witness's signature

Date

Appendix IV

Information given to controls

Date

Name
Address

Dear
I am carrying out some research on how people with a learning disability compared with a control group of people without such a disability, feel about their lives. I am particularly interested in their experiences and thoughts about the service they get from their GPs. Dr X has suggested that you might be willing to take part in the study as a member of the control group. If so, I would send you a questionnaire to fill in which should take about half an hour. What you had to say would be confidential, and you would not be able to be identified in the final report. When I have finished the research I will be writing a report to give to the people who have helped me. If you are happy to take part, please could you fill in the attached form and send it back to me in the enclosed stamped addressed envelope. I would then send you the questionnaire. Please do ring me if you have any queries.

Yours sincerely

Elizabeth Perkins
Chartered clinical psychologist

A COMPARISON OF QUALITY OF LIFE AND SATISFACTION WITH HEALTH CARE BETWEEN PEOPLE WITH LEARNING DISABILITY AND THOSE WITHOUT

INFORMATION SHEET

Thank you for thinking about taking part in my study as part of my non-learning disabled control group. Here is some information about the study to help you decide.

What is the study about?
The study looks at quality of life for people and what they feel about their life. I am particularly interested in what services people get from their GP. I want to see if there is any difference between people with a learning disability and those, like you, without.

What will you have to do?
You would need to fill in questionnaire, and return it to me in a post-paid envelope. This would take you about half an hour.

What are the benefits?
At the end of the study, I will have information about whether there is any difference in how satisfied people are with their life, and if there is any difference between people with learning disabilities and those without that need to be addressed.

What are the risks?
There are no risks.

What if you do not want to take part?
If you do not want to take part, just say no. Nothing else will happen.

What happens to the information?
Your answers will be confidential. The results will be grouped together and analysed statistically.

Who will be taking part?
120 people will be taking part.

What happens at the end of the study?
At the end of the study, I shall write a report for those who have taken part, as well as a report for the University of Birmingham.

What if you have more questions or do not understand?
If you have any questions, please ring me or write to me.

What happens if you decide to take part?
If you decide to take part, your doctor will give you a questionnaire, and a pre-paid envelope to return it to me.

What happens if you change your mind during the study?

You can change your mind at any time, just stop filling in the questionnaire. If you do decide to stop, it would help me if you were to let me know, using the pre-paid envelope, so that I can ask someone else, but you do not have to do this.

Who to contact?

My name is Elizabeth Perkins, and I am a clinical psychologist. My address is:

[redacted]

control number

A comparison of quality of life and satisfaction with health care between people with learning disability and those without (Elizabeth Perkins)

Name

Address

Yes I am happy/No I am not happy (delete as appropriate)
to take part in the research by filling in a questionnaire. I understand that what I write will be confidential and no names will be put in the report. I have read and understood the leaflet explaining the research. I understand that I can withdraw from the study at any time.

Signature

Date

Witness's name

Witness's signature

Appendix V

Information given to carers

Date

Name
address

Dear,

I am carrying out some research into how people feel about their lives. I am interested in whether people with a learning disability have similar concerns about their lives as do people who do not have a learning disability. I am particularly interested in their experiences and thoughts about the service they get from their GP. I have already spoken to your *son/daughter/person* you care for at *y location* and *he/she* has agreed that I can contact you. I would welcome the opportunity to come and talk to you about *x* and *his/her* experiences. I would come and visit you in your own home, or see you in my office if that is more convenient to you. The interview would take about an hour. What you had to say would be confidential, and I would write my report in such a way that you and *x* could not be identified. When I have finished the research I will be writing a report to give to the people who have helped me.

If you are happy to take part, please could you fill in the form attached, and send it back to me in enclosed stamped addressed envelope, and I will then contact you to make an appointment to see you. If you have any questions, please do not hesitate to ring me.

Yours sincerely

Elizabeth Perkins
Chartered clinical psychologist

A comparison of Quality of life and satisfaction with health care between people with a learning disability and those without (Elizabeth Perkins)

Name ....

Address..

....

....

Tel. no...

Yes I am happy/ No I am not happy (delete as appropriate)
for you to come an interview me about and his/her experiences of life. I understand that what I say will be confidential, and that no names will put in the report. I have read and understood the leaflet explaining the research. I understand that I can withdraw from the study at any time.

Signature

Date

Witness's signature

Date

A COMPARISON OF QUALITY OF LIFE AND SATISFACTION WITH HEALTH CARE BETWEEN PEOPLE WITH lEARNING DISABILITY AND THOSE WITHOUT

INFORMATION SHEET

Thank you for considering taking part in my study. Here is some information to help you decide.

What is the study about?
The study looks at quality of life for people, and what they feel about their life. I am particularly interested in what services people get from their GP. I want to see if there is any difference between people with a learning disability, and those without.

What will you have to do?
I would arrange to meet you at a place convenient for you. I would then ask you questions about your son/daughter/the person you care for, and their life. This will take about an hour.

What are the benefits?
At the end of the study, I hope to have information about how services for people with learning disabilities can be improved.

What are the risks?
There are no risks.

What if you do not want to take part?
If you do not want to take part, just say no. Nothing else will happen.

What happens to the information?
Anything you tell me will be confidential. The results from everyone will be grouped together and analysed statistically.

Who else is taking part?
120 people will be taking part, including your son/daughter.

What happens at the end of the study?
At the end of the study I shall write a report for those who have taken part, as well as a report for the University of Birmingham.

What if you have more questions, or do not understand?
Please ask me if you have any questions, or get someone to ask me on your behalf.

What happens now if you decide to take part?
If you decide to take part, I shall arrange a time with you, when I can meet you.

What happens if you change your mind during the study?

You can change your mind at any time, just say, and the interview will stop.

Who to contact?

My name is Elizabeth Perkins, and I am a clinical psychologist. My address is:
[redacted]

Tel. [redacted]

Appendix VI Questionnaire given to participants with an intellectual disability

COMPREHENSIVE QUALITY OF LIFE SCALE

FOURTH EDITION
(ComQol-ID4)

Robert A. Cummins

ComQol-ID4

“I am going to ask you some questions about your life. Is that alright?”

“If you do not understand a question, just let me know.”

Your name --

Date of Birth -----------------/----------------/---------------------
Day Month Year

Sex (circle one) male female

SECTION 1: This section asks for information about various aspects of your life

1 a) **What is your personal or household (whichever is most relevant to you) gross annual income before tax?**

Less than £6,999

£7,000 - £14,999

£15,000 -£24999

£25,000 - £31 999

More than £32,000

b) **Where do you live?**

A house or flat of:

- high quality

- medium quality

- low quality

or a hostel

Which best describes who you live with?

- alone, family, close friend

- 1 or 2 acquaintance(s)

- 3 or more acquaintances

c) **How many personal possessions do you have compared with other people?**

More than almost anyone

More than most people

About average

Less than most people

Less than almost anyone

2 a) **How many times have you been to your doctor (GP) over the past three months?**

Number of times --

b) **Do you have any physical disabilities or medical conditions? (e.g. visual, hearing, physical health, etc.).**

yes no

If “yes” please specify:

Name of disability or medical condition	**Extent of disability or medical condition**
e.g. visual diabetes	e.g. require glasses for reading, require daily injections
-------------------------------	--------------------------------------
-------------------------------	--------------------------------------
--------------------------------	--------------------------------------

c) **What regular medication do you take <u>each day?</u>**

none

<u>OR</u>

Name(s) of medication

----

3 a) **How many hours paid work, formal education, or unpaid child care do you do <u>each week?</u> (Average over three months)**

Hours paid work -------------------- Hours formal education ---------------------

Hours unpaid child care ------------------------

b) **In your spare time, how often do you have nothing much to do?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **<u>Over the past week,</u> list the most productive things you have done. These can include anything you have <u>made, collected, performed, created, mended,</u> or any <u>voluntary work.</u>**

None

<u>OR</u>

Description	**Over how many days in the week did this happen?**

4 a) **How often do you talk with a close friend?**

Daily	Several times a week	Once a week	Once a month	Less than once a month

b) **If you are feeling sad or depressed, how often does someone show they care for you?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **If you want to do something, how often does someone else want to do it with you?**

Almost always	Usually	Sometimes	Not usually	Almost never

5 a) **How often do you sleep well?**

Almost always	Usually	Sometimes	Not usually	Almost never

b) **How often do you feel safe at home?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **How often do you feel anxious or worried during the day?**

Almost Always	Usually	Sometimes	Not usually	Almost never

6 a) **Below is a list of activities. Indicate how often in an <u>average month</u> you take part in or attend each one?**

Activity **Number of times per month**

(1) Clubs/groups/societies
(please provide the name <u>as well as</u> the number
of times you attend each month) --

----

(2) Go to hotel/bar/pub --

(3) Watch live sporting events (not TV) --

(4) Go to church --

(5) Chat with neighbours --

(7) Go to the pictures --

(8) Other (describe) --

----

b) **Do you hold a position of responsibility in relation to any club, group or society?**

Yes No

If yes, please describe

----

c) **How often do people <u>outside your household</u> ask for your help or advice?**

Almost every day	Quite often	Sometimes	Not often	Almost never

7 a) **How often can you do things you really want to do?**

Almost always	Usually	Sometimes	Not usually	Almost never

b) **When you wake up in the morning, how often do you wish you could stay in bed <u>all day?</u>**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **How often do you have wishes that cannot come true?**

Almost always[5]	Usually	Sometimes	Not usually	Almost never

Testing procedure

Ask the client to name some possession which he/she regards as highly important. This will be used in the third phase of testing.

Item of importance ---

2.2.1. Order of magnitude test

Record of success(+)
or failure (-)

a) Present client with two blocks of extreme different sizes

Q: Please point to the BIGGEST block

Q: Please point to the SMALLEST block

b) Present 3 blocks of differing size arranged, small, large, middle

Q: Please point to the BIGGEST block

Q: Please point to the MIDDLE SIZED block

Q: Please point to the SMALLEST block

Note: If the client makes an error with b), repeat with a) asking in reverse order to the first trial, i.e. smallest, largest.

c) Present 5 blocks of different sizes arranged second smallest, largest, smallest, middle sized,, second largest.

Q: Please point to the SMALLEST block

Q: Please point to the SMALLEST block

Q: Please point to the MIDDLE SIZED block

Q: Please point to the SECOND BIGGEST block

Q: Please point to the SECOND SMALLEST block

2.2.2. Scale with a concrete reference

1. Procedure Present a 2-point ladder scale. Explain that the top is BIG and the bottom is SMALL. Point to each block when asking the questions.

Record of success (+)
or failure (-)

a) Present 2 blocks of extreme size difference

Q: Where does the big block go on the ladder?

Q: Where does the small block go on the ladder?

b) Present 3 blocks in order of size

Q: Where does the middle sized block go on the ladder?

2. Procedure Present a 5 - point scale and explain each point.

c) Present 5 blocks in order of size. Point to them in the sequence indicated, asking "where does this block go on the ladder?"

The biggest block

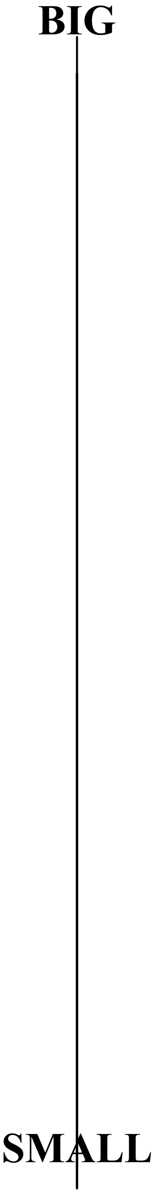
The middle sized block

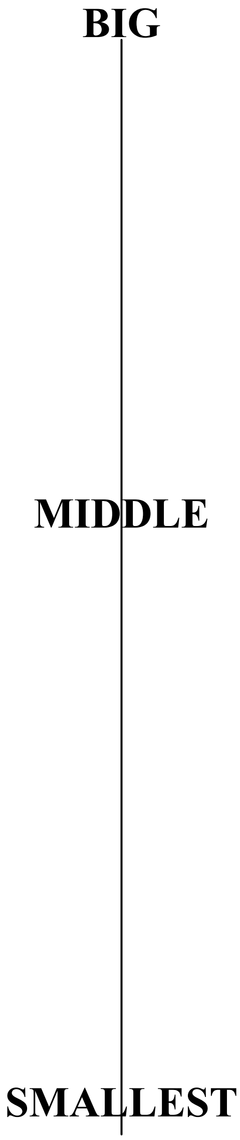
The second biggest block

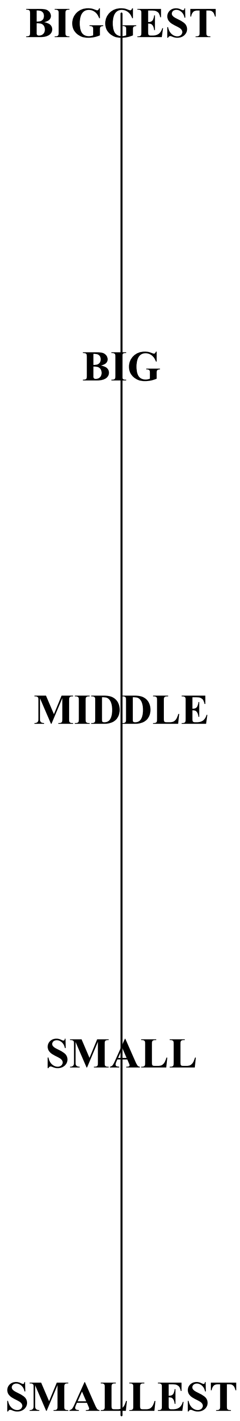
The second smallest block

The smallest block

Correct response: pointing, or placing block on scale


BIG
SMALL


BIG
MIDDLE
SMALLEST


BIGGEST
BIG
MIDDLE
SMALL
SMALLEST

2.2.3 Scale with an abstract scale of reference

Record of success (+)
or failure (-)

a) Present a 2 - point ladder of importance.

- explain the divisions

- recall the personal possession that is important to the client, then ask them to place it on this scale, asking:
  " Is -------------- very important to you?"
  " Where would you put it on this ladder?"

- ask "If something was not important to you, where would you put it on the ladder?"

b) Present a 3 - point ladder of importance

- explain the divisions

Q: If something was very important, where would you put it on the ladder?

Q: If something was not important to you, where would you put it on the ladder?

Q: I something was somewhat important to you, where would you put it on the ladder?

c) Present a 5 - point ladder of importance

-explain the divisions

Q: If something was most important in the world where would you point?

Q: If something was not important , where would you point?

Q: If something was somewhat important, where would you point?

Q: If something was slightly important, where would you point?

Q: If something was very important, where would you point?

VERY IMPORTANT

NOT IMPORTANT

VERY IMPORTANT

SOMEWHAT IMPORTANT

NOT IMPORTANT

MOST IMPORTANT IN THE WORLD

VERY IMPORTANT

SOMEWHAT IMPORTANT

SLIGHTLY IMPORTANT

NOT IMPORTANT

2.3 Testing of domain importance

Use the 2, 3 or 5 point importance scale determined in 2.23

Record which one is used 2 3 5

Explain that you are going to ask how important some things are to her/him, using the importance ladder.

Response

1. How important to you are the things you have, like the money you have and the things you own?
2. How important to you is your health, whether you are ill or not?
3. How important to you are the things you make, or the things you learn?
4. How important to you is having a close friend or family?
5. How important to you is how safe you feel?
6. How important to you is doing things with people outside your home?
7. How important to you is your own happiness?
8. How important to you is your family doctor (GP)?

2.4.2. Testing of domain satisfaction

Say, " now I want you to do a different task. It's another pointing task, but this time, there are two faces"

Present the 2 - face scale

Record of success (+) or failure (-)

a) Say, whilst pointing. "one is a happy face, one is a sad face"

"What makes you happy?"

After the participant has replied, say " So if I said how happy are you about X, which face would you point to?"

"What makes you sad?"

After the participant has replied, say "So, if I said how sad are you about Y, which face would you point to?"

After establishing that the participant is able to use the faces appropriately, proceed to the 3 - face scale

b) Present the 3 - face scale, and explain very happy, very sad and a face that is neither happy nor sad

Q: If you felt very happy about X, which face would you point to?

Q: If you felt very sad about Y, which face would you point to?

Q: If you felt neither happy nor sad, which face would you point to?

Proceed to the 5 - face scale

c) Explain the scale

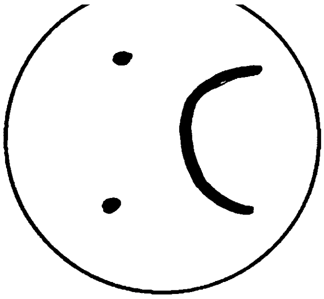
Q: If you felt very happy about X, which face would you point to?

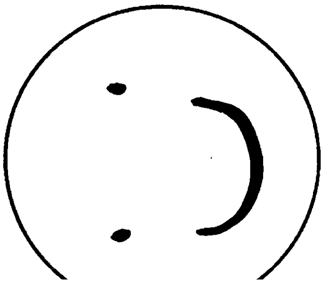
Q: If you felt a bit happy about X, which face would you point to?

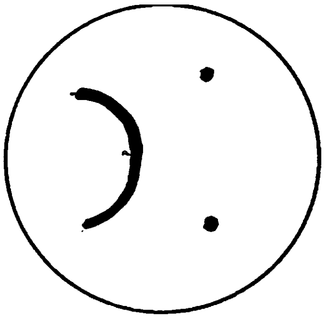
Q: If you felt very sad about Y, which face would you point to?

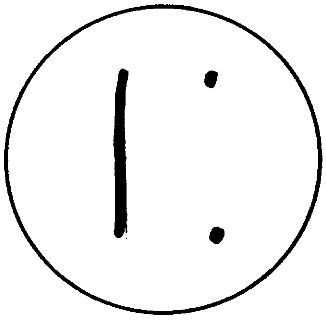
Q: If you felt a bit sad about Y, which face would you point to?

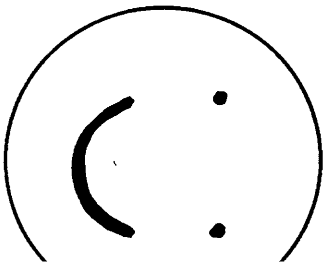
Q: If you felt neither happy nor sad, which face would you point to?

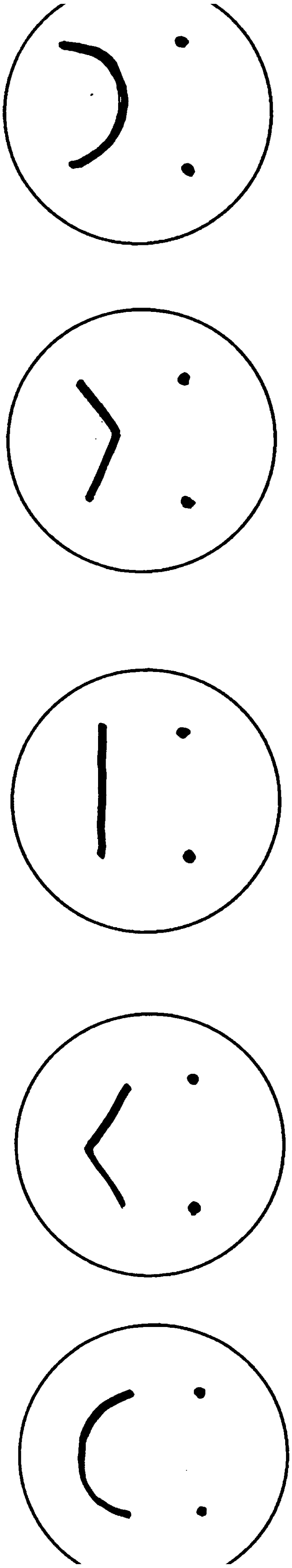












Testing of domain satisfaction

Use the 2,3 or 5 point scale determined in 2.4.2

Scale used 2 3 5

Explain that you are going to ask how happy the participant is with things by using the face scale.

Response

1. How happy or sad do you feel about the things you have, like the money you have, and the things you own
2. How happy or sad are you about your health, whether you are ill or not?
3. How happy or sad are you about the things you make, or the things you learn?
4. How happy or sad are you about your friends and family?
5. How happy or sad are you about how safe you feel?
6. How happy or sad are you about doing thins outside your home?
7. How happy or sad are you about yourself?
8. How happy or sad are you about your family doctor (GP)?

Appendix VII Questionnaire given to controls

COMPREHENSIVE QUALITY OF LIFE SCALE

FOURTH EDITION
(ComQol-4)

1

Robert A. Cummins

ComQol-4

This scale has three sections, the first will ask for some factual information. The second and third will ask you how you feel about various aspects of your life.

To answer each question please circle the most appropriate statement.

Please try to answer all the questions, and do not spend too much time on any one item.

Number --

Date of Birth -----------------/----------------/---------------------
Day Month Year

Sex (circle one) male female

SECTION 1: This section asks for information about various aspects of your life. Please circle the statement that most accurately describes your situation.

1 a) **What is your personal or household (whichever is most relevant to you) gross annual income before tax?**

Less than £6,999	£25,000 - £31,999
£7,000 - £14,999	More than £32,000
£15,000 -£24,999	

b) **Where do you live?**

A house or flat of:	Which best describes who you live with?
- high quality	- alone, family, close friend
- medium quality	- 1 or 2 acquaintance(s)
- low quality	- 3 or more acquaintances
or a hostel	

c) **How many personal possessions do you have compared with other people?**

More than almost anyone	More than most people	About average	Less than most people	Less than almost anyon2

a) **How many times have you been to your doctor (GP) over the past three months?**

Number of times ---

b) **Do you have any physical disabilities or medical conditions? (e.g. visual, hearing, physical health, etc.).**

yes no

If "yes" please specify:

Name of disability or medical condition	**Extent of disability or medical condition**
e.g. visual	e.g. require glasses for reading,
diabetes	require daily injections
-------------------------------	-------------------------------------
-------------------------------	-------------------------------------
--------------------------------	-------------------------------------

c) **What regular medication do you take __each day?__**

none

<u>OR</u>

Name(s) of medication

----

a) **How many hours paid work, formal education, or unpaid child care do you do __each week?__ (Average over three months)**

Hours paid work -------------------

Hours formal education ---------------------

Hours unpaid child care ------------------------

b) **In your spare time, how often do you have nothing much to do?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **<u>Over the past week,</u> list the most productive things you have done. These can include anything you have <u>made, collected, performed, created, mended,</u> or any <u>voluntary work.</u>**

None

<u>OR</u>

Description	**Over how many days in the week did this happen?**
--	--
--	--
--	--
--	--
--	--

4 a) **How often do you talk with a close friend?**

Daily	Several times a week	Once a week	Once a month	Less than once a month

b) **If you are feeling sad or depressed, how often does someone show they care for you?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **If you want to do something, how often does someone else want to do it with you?**

Almost always	Usually	Sometimes	Not usually	Almost never

5 a) **How often do you sleep well?**

Almost always	Usually	Sometimes	Not usually	Almost never

b) **Is your home a safe place to be?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **How often do you feel anxious or worried during the day?**

Almost Always	Usually	Sometimes	Not usually	Almost never

6 a) **Below is a list of activities. Indicate how often in an <u>average month</u> you take part in or attend each one?**

Activity **Number of times per month**

(1) Clubs/groups/societies
(please provide the name <u>as well as</u> the number of times you attend each month) --

----

----

(2) Go to hotel/bar/pub --

(3) Watch live sporting events (not TV) --

(4) Go to church --

(5) Chat with neighbours --

(7) Go to the pictures --

(8) Other (describe) --

----

b) **Do you hold a position of responsibility in relation to any club, group or society?**

Yes	No

If yes, please describe

----

c) **How often do people <u>outside your household</u> ask for your help or advice?**

Almost every day	Quite often	Sometimes	Not often	Almost never

7 a) **How often can you do things you really want to do?**

Almost always	Usually	Sometimes	Not usually	Almost never

b) **When you wake up in the morning, how often do you wish you could stay in bed <u>all day?</u>**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **How often do you have wishes that cannot come true?**

Almost always[6]	Usually	Sometimes	Not usually	Almost never

Section 2: How IMPORTANT are each of the following life areas to you?

Please answer by placing a circle round the statement that best fits your situation.

There are no right or wrong answers. Please choose the statement that best describes how **important** each area is to you. Do not spend too much time on any one question.

1. How IMPORTANT to you are the things you own?

could not be more important	very important	somewhat important	slightly important	not important at all

2. How IMPORTANT to you is your health?

could not be more important	very important	somewhat important	slightly important	not important at all

3. How IMPORTANT to you is what you achieve in life?

could not be more important	very important	somewhat important	slightly important	not important at all

4. How IMPORTANT to you are close relationships with your family or friends?

could not be more important	very important	somewhat important	slightly important	not important at all

5. How IMPORTANT to you is how safe you feel?

could not be more important	very important	somewhat important	slightly important	not important at all

6. How IMPORTANT to you is doing thing with people outside your home?

could not be more important	very important	somewhat important	slightly important	not important at all

7. How IMPORTANT to you is your own happiness?

could not be more important	very important	somewhat important	slightly important	not important at all

8. How IMPORTANT to you is your family doctor (GP) ?

could not be more important	very important	somewhat important	slightly important	not important at all

Section 3. How SATISFIED are you with each of the following life areas?

There are no right or wrong answers. Please circle the statement that best describes how SATISFIED you are with each area.

1. How SATISFIED are you with the things you own?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

2. How SATISFIED are you with your health?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

3. How SATISFIED are you with what you achieve in life?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

4. How SATISFIED are you with your close relationships with family or friends?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

5. How SATISFIED are you with how safe you feel?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

6. How SATISFIED are you with doing things with people outside your home?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

7. How SATISFIED are you with your own happiness?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

8. How SATISFIED are you with your family doctor?

delighted	pleased	mostly satisfied	mixed	mostly dissatisfied	unhappy	terrible

Appendix VIII Questionnaire given to carers

COMPREHENSIVE QUALITY OF LIFE SCALE

FOURTH EDITION
(ComQol Ca)

1

Robert A. Cummins

ComQolCa

This questionnaire asks about the person you care for (N).

This scale has three sections, the first will ask for some factual information. the second and third will ask you how you believe N feels aout various aspects of his/her ife.

To answer each question please circle the statement that most accurately describes N's situation.

Please try to answer all the questions, and do not spend too much time on any one item.

Your name --

The name of the person you care for (N) ---

N's date of Birth -----------------/----------------/---------------------
Day Month Year

N's Sex (circle one) male female

SECTION 1: This section asks for information about various aspects of N's life. Please circle the statement that most accurately describes N's situation.

1 a) **What is N's personal or household (whichever is most relevant) gross annual income before tax?**

Less than £6,999	£25,000 - £31,999
£7,000 - £14,999	More than £32,000
£15,000 -£24,999	

b) **Where does N live?**

A house or flat of:	Which best describes who N lives with?
- high quality	- alone, family, close friend
- medium quality	- 1 or 2 acquaintance(s)
- low quality	- 3 or more acquaintances
or a hostel	

c) **How many personal possessions does N have compared with other people?**

More than almost anyone	More than most people	About average	Less than most people	Less than almost anyone

2 a) **How many times has N been to the doctor (GP) over the past three months?**

Number of times --

b) **Does N have any physical disabilities or medical conditions? (e.g. visual, hearing, physical health, etc.).**

yes no

If "yes" please specify:

Name of disability or medical condition	**Extent of disability or medical condition**
e.g. visual	e.g. require glasses for reading,
diabetes	require daily injections
------------------------------	-------------------------------------
------------------------------	-------------------------------------
-------------------------------	-------------------------------------

c) **What regular medication does N take <u>each day?</u>**

none

<u>OR</u>

Name(s) of medication

----

3 a) **How many hours paid work, formal education, or unpaid child care does N do <u>each week?</u> (Average over three months)**

Hours paid work -------------------- Hours formal education ---------------------

Hours unpaid child care ------------------------

b) **In N's spare time, how often does he/she have nothing much to do?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **Over the past week, list the most productive things N has done. These can include anything he/she made, collected, performed, created, mended, or any voluntary work.**

None

OR

Description	**Over how many days in the week did this happen?**
--	--
--	--
--	--
--	--
--	--

4 a) **How often does N talk with a close friend?**

Daily	Several times a week	Once a week	Once a month	Less than once a month

b) **If N is feeling sad or depressed, how often does someone show they care for him/her?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **If N wants to do something, how often does someone else want to do it with him/her?**

Almost always	Usually	Sometimes	Not usually	Almost never

5 a) **How often does N sleep well?**

Almost always	Usually	Sometimes	Not usually	Almost never

b) **Is N's home a safe place to be?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **How often does N feel anxious or worried during the day?**

Almost Always	Usually	Sometimes	Not usually	Almost never

6 a) **Below is a list of activities. Indicate how often in an <u>average month</u> N takes part in or attend each one?**

Activity	**Number of times per month**
(1) Clubs/groups/societies (please provide the name <u>as well as</u> the number of times N attends each month)	-- -- -- --
(2) Go to hotel/bar/pub	--
(3) Watch live sporting events (not TV)	--
(4) Go to church	--

(5) Chat with neighbours --

(7) Go to the pictures --

(8) Other (describe) --

----

b) **Does N hold a position of responsibility in relation to any club, group or society?**

Yes No

If yes, please describe

----

c) **How often do people outside his/her household ask N for help or advice?**

Almost every day	Quite often	Sometimes	Not often	Almost never

7 a) **How often can N do things he/she really wants to do?**

Almost always	Usually	Sometimes	Not usually	Almost never

b) **When N wakes up in the morning, how often does he/she wish he/she could stay in bed all day?**

Almost always	Usually	Sometimes	Not usually	Almost never

c) **How often does N have wishes that cannot come true?**

Almost always	Usually	Sometimes	Not usually	Almost never

Section 2: How IMPORTANT are each of the following life areas to N?

“ I am going to ask you how IMPORTANT you think some aspects of life are to N. To do this I want you to answer as though you are N. That is the answers you give should be the answers you think N would give.” Show scale.

“So now I am going to name some aspects of life and you will tell me how IMPORTANT each one is for N".

1. How IMPORTANT to N is the things he/she owns?

could not be more important	very important	somewhat important	slightly important	not important at all

2. How IMPORTANT to N is his/her health?

could not be more important	very important	somewhat important	slightly important	not important at all

3. How IMPORTANT to N is what he/ her achieves in life?

could not be more important	very important	somewhat important	slightly important	not important at all

4. How IMPORTANT to N is close relationships with his/her family or friends?

could not be more important	very important	somewhat important	slightly important	not important at all

5. How IMPORTANT to N is how safe he/her feels?

could not be more important	very important	somewhat important	slightly important	not important at all

6. How IMPORTANT to N is doing things with people outside his/her home?

could not be more important	very important	somewhat important	slightly important	not important at all

7. How IMPORTANT to N is his/her own happiness?

could not be more important	very important	somewhat important	slightly important	not important at all

8. How IMPORTANT to N is his/her family doctor (GP) ?

could not be more important	very important	somewhat important	slightly important	not important at all

COULD NOT BE MORE IMPORTANT

VERY IMPORTANT

SOMEWHAT IMPORTANT

SLIGHTLY IMPORTANT

NOT AT ALL IMPORTANT

Section 3. How SATISFIED is N with each of the following life areas?

“Now I want to ask youa different set of questions. This time I will ask you how SATISFIED you think N is with each of the life areas. I still want you to answer as if you were N”. Show the scale.

“So now I am going to name the same areas of life as before and you will tell me how satisfied N is with each one”

1. **How SATISFIED is N with the things he/she owns?**

delighted pleased mixed unhappy terrible

2. **How SATISFIED is N with his/her health?**

delighted pleased mixed unhappy terrible

3. **How SATISFIED is N with what he/she achieves in life?**

delighted pleased mixed unhappy terrible

4. **How SATISFIED is N with his/her close relationships with family or friends?**

delighted pleased mixed unhappy terrible

5. **How SATISFIED is N with how safe he/she feels?**

delighted pleased mixed unhappy terrible

6. **How SATISFIED is N with doing things with people outside his/her home?**

delighted pleased mixed unhappy terrible

7. **How SATISFIED is N with his/her own happiness?**

delighted pleased mixed unhappy terrible

8. **How SATISFIED is N with his/her family doctor (GP)?**

delighted pleased mixed unhappy terrible

Appendix IX

Health questionnaire

name/number *date*

Health Questionnaire

1. How many times have you been to your GP in the last year?

2. Why did you go?

3. In the past year has anyone done the following?

	at your GP's practice	***elsewhere (please list where)***
• given you a health check?	Y/N	Y/N
• taken your blood pressure?	Y/N	Y/N
• given you advice on smoking?	Y/N	Y/N
• given you advice on diet?	Y/N	Y/N
• given you advice on drinking?	Y/N	Y/N
• given you advice on exercise?	Y/N	Y/N
• checked your eyesight?	Y/N	Y/N
• checked your hearing?	Y/N	Y/N
• given you contraceptive advice and/or advice about safe sex?	Y/N	Y/N
• (women only) taken a cervical smear?	Y/N	Y/N

Is there anything else you would like to tell us about your GP?

Appendix X Pearson correlations between objective and subjective scores for participants and controls

		Objective/Satisfaction		**Objective/Importance**		**Importance/Satisfaction**	
Domains		correlation	significance	correlation	significance	correlation	significance
Material	**Participant**	-0.031	0.868	-0.403	0.025	-0.118	0.527
	Control	0.006	0.975	-0.098	0.601	0.237	0.199
Health	**Participant**	0.305	0.096	0,188	0.312	0.100	0.591
	Control	0.398	0.026	-0.401	0.025	0.123	0.511
Productivity	**Participant**	0.182	0.327	-0.247	0.181	0.050	0.790
	Control	0.130	0.484	0.143	0.444	0.206	0.266
Intimacy	**Participant**	-0.105	0.574	-0.164	0.378	-0.085	0.650
	Control	0.234	0.205	-0.147	0.767	0.022	0.906
Safety	**Participant**	0,265	0.149	0.062	0.739	-0.087	0.643
	Control	0.235	0.203	-0.127	0.496	0.466	0.008
Community	**Participant**	0.117	0.531	-0.147	0.431	-.118	0.527
	Control	0.429	0.016	0.364	0.044	0.414	0.021
Emotion	**Participant**	0.323	0.077	-0.381	0.034	-0.253	0.169
	Control	0.607	0.000*	-0.88	0.638	0.059	0.752
Doctor	**Participant**	……….	……….	………..	………..	0.397	0.027
	Control	---------	----------	……….	……….	0.207	0.263

* significance p<0.001