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Different perspectives regarding quality of life in chronically ill and healthy individuals

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Abstract

Purpose: The areas that were suggested as most important with regard to quality of life were examined in groups of individuals who were healthy, and those with a chronic condition.

Methods: An electronic survey was completed by 892 participants (261 healthy and 631 with a chronic condition). They answered three questions relating to quality of life: what is most important to you; what areas most impact your quality of life; and an open question what does quality of life mean to you.

Results: Across the three questions both groups highlighted physical functioning, independence and mobility as key areas for quality of life. However, the group with a chronic condition tended to find issues of functioning such as pain, fatigue, and sleep as more important to their quality of life than the healthy participants. In contrast, the healthy participants tended to note the importance of relationships and family as more important than the group with a chronic condition.

Conclusions: That there were such differences between the groups might suggest that different aspects of quality of life could be rated as more important when examining this issue with samples with a chronic condition and those without such a condition.

Keywords: quality of life, perspectives, chronic condition, healthy individuals, mixed methodology.

Quality of life is an increasingly important concept in medical and health care research and evaluation [1,2]. The measurement of an individual's quality of life is recommended to be part of any investigation of a medical or health-care intervention [3,4]. This is true when studying the effect of an intervention for an acute condition, such as cardiac arrest [5], or in the management of chronic conditions [1,6]. In fact, in the evaluation of the outcome effectiveness of interventions and treatments for many chronic conditions, quality of life is one of the few metrics that may be expected to show change [6,7].

Despite its increasing importance in the field of health care, there are still a number of problems connected both with the conceptualization of quality of life, and, partly as a consequence, the factors that influence people's perception of quality of life are still not well understood. For example, there is a clear need to differentiate patient reports concerning their health status, from their reports about how their health status impacts on their daily lives [8,9]. It is not always apparent whether the scales that are taken to reflect quality of life clearly differentiate between these two conceptions [9]. Additionally, it is clear that the issues that impact on quality of life may vary as a function of particular conditions [7], which may impact on individuals in ways not typically measured by generic quality of life tools. As a consequence, there are many condition-specific tools that have been developed to overcome any such omissions [11,12].

However, it is also becoming apparent that individuals' perspectives regarding quality of life can alter over time [6,13]. This latter aspect of the change in people's perspectives regarding their quality of life can both be related to the individual becoming older [14], and to the progression of their condition [6]. In particular, there are documented changes in the issues taken to be important in the assessment of

quality of life as a function of a person's maturation, and also as a function of their adaptation to the condition [6]. These latter aspects may have a greater influence over the measurement of quality of life in chronic conditions, compared to acute conditions, which individuals may experience over a short period of time and which do not necessarily have lasting effects, but exploration of any differences between these types of condition has been relatively sparse.

Given all of the above, it is essential that any instrument that attempts to measure quality of life covers a wide enough spectrum of potential areas of importance to allow this concept to be properly reported by the patient. Many commonly-used instruments [15-17] do cover a range of aspects of functioning, and they display a degree of similarity with one another. For example, the EQ-5D [15] contains questions relating to mobility, self-care, usual activities, pain, and anxiety/depression. The SF-36 [16] has sub-domains that cover physical functioning, role-physical, pain, general health, vitality, social functioning, role-emotional, and mental health. The WHOQoL-BREF [17] measures physical health, psychological health, social relationships, and environment.

Although each of these instruments cover a reasonable range of domains, these domains differ between the instruments, and there are areas that individuals with a chronic condition suggest as important to their quality of life that are not covered by these tools which have often been developed with reference to populations without a chronic illness. For example, several investigators [18,19] have noted that many individuals with a long-term condition, when given a free choice about which areas of their life to monitor and report to their medical professionals, choose areas such as financial independence to comment on, which is often not directly assessed in quality of life tools. Moreover, when people with a chronic condition state what quality of

life means to them, some of the most commonly expressed areas of importance are their ability to participate in daily activities and their independence [6]. These areas may not necessarily be referenced by individuals without a debilitating chronic condition. Thus, the most important areas for assessing quality of life, and whether the importance of these areas is differentially assessed by those with and without a chronic condition, remain unclear.

As many of the generic quality of life questionnaires are designed to be administered to both those with and without a chronic condition, it is important to explore any differences between these groups in terms of their perspectives regarding quality of life. The current investigation was designed to elicit the key areas related to quality of life from groups of individuals with a wide variety of chronic conditions, and to compare these areas to those suggested as important by people without a chronic condition. These data will allow assessment of whether the typically-used quality of life questionnaires cover the areas important to both groups of individuals, and to investigate whether there are any key areas related to quality of life in the key group of individuals with chronic conditions that are not well covered in such questionnaires.

In order to obtain these data, participants were asked three separate questions relating to the most important aspects for their quality of life. The first question asked for a rating regarding the most important aspects for their quality of life, the second question asked about the areas that, if they deteriorated, would have the most impact on their lives, and the third was an open response to a question about what quality of life means to an individual. It was hoped that if any differences emerged between the groups, that these would be reflected across all three questions, and some degree of triangulation about the critical quality of life aspects could be obtained.

Method

Participants and Recruitment

Eight hundred and ninety-two participants were sampled. These participants had responded to an electronic survey. In total, 261 people with no chronic condition responded. In this group there were 17.2% (45) males, and 82.8% (216) females. There ages were: < 20 years – 0% (0); 21-30 years – 8.1% (21); 31-40 years – 25.7% (67); 41-50 years – 32.2% (84); 51-60 years – 28.7% (75); and > 60 years – 5.4% (14). There were 631 people with a chronic condition. In this group there were 19.3% (122) males, and 80.7% (509) females. There ages were: < 20 years – 1.9% (12); 21-30 years – 6.5% (41); 31-40 years – 13.2% (83); 41-50 years – 25.0% (158); 51-60 years – 32.5% (205); and > 60 years – 20.9% (132). These individuals had been diagnosed with a chronic condition for a variety of time periods: <1 year - 12.2% (77); 1-4 years – 29.2% (184); 5-9 years – 20.1% (127); 10-19 years – 18.4% (116); and > 20 years – 20.1% (127). These participants had a range of condition: Arthritis; Diabetes; Parkinson's Disease; Osteoporosis; Epilepsy; Cancer; Asthma; Multiple Sclerosis; Spina Bifida; and Myalgic Encephalopathy.

Materials and Data Collection Procedure

In order to elicit responses regarding the opinions of participants concerning what quality of life meant to them, along with background demographic information, participants responded to an electronic survey (using the Survey Monkey tool; see www.surveymonkey.com).

The first question relating to quality of life asked about areas that were thought to be most important by the participants, and gave them a set of options of

areas relating to quality of life that were based on areas contained in previously validated tools (e.g., pain, independence). The question asked: “Please rate how important the following are to you, where 1 is the least important and 11 is the most important. You cannot give the same rating to two or more items, e.g. it is not possible for you to score 11 for ‘Feeling calm’, and ‘Being pain free’, for the purposes of this survey we would like you to prioritize ‘feeling calm’ or ‘being pain free’.

There were 11 response options were: ‘Being calm’, ‘In a good mood’, ‘Pain free’, ‘Able to have a good night’s sleep’, ‘Able to have relationships (with friends and/or family)’, ‘Financially secure’, ‘Able to function physically (e.g. get up and walk around, move arms/legs easily, go to the toilet with relative ease)’, ‘Independent (not reliant on others)’, ‘Able to complete domestic tasks’, ‘Able to have a social life/hobbies, and ‘Able to have a working life’.

The second question asked about the areas that would most critically impact on the person’s life should they worsen, and gave a series of areas to rate, drawn from those mentioned in previously validated quality of life instruments: “Please indicate to what extent you believe the following would or does negatively affect your quality of life”. The participants were then asked to rate as having ‘no affect’, mild affect’, moderate affect, or severe effect, the following areas: ‘Feeling angry and/or frustrated’, ‘Feeling anxious and/or depressed’, ‘Suffering from fatigue/low energy levels’, ‘Lack of sleep’, ‘Pain’, ‘Lack of mobility and/or physical function’, ‘Deterioration in financial situation’, ‘Deterioration in independence’, ‘Inability to complete domestic tasks’ ‘Deterioration in social life/ carrying out hobbies’, ‘Deterioration in working life’ and ‘Deterioration in relationships’.

The final question gave the participants the opportunity to comment on any areas of life that they thought were important for quality of life. ‘In no more than 30

words please describe what ‘quality of life’ means to you.’ As a large amount of data was generated these data were analysed using a ‘word cloud’ technique [20,21]. This tool visualises the frequencies of words employed into ‘word clouds’. According to the number of times a word is used, the ‘word cloud’ shows that word larger or smaller in size.

Results

Table 1 about here

The percentage of individuals in both the healthy and chronic-condition groups (and the actual numbers) who rated each of the 11 statements to the question: “Please rate how important the following are to you?” as the most important (i.e. as 11), are shown in Table 1. Inspection of these data shows that, while there were some similarities between the groups, there were also some striking differences. In order to verify that these responses were different across the groups, a chi-squared analysis was conducted on these data (actual numbers), and revealed a statistically significant difference between the groups, $X^2(9) = 36.85, p < .0001$.

Inspection of these data shows that the three aspects that were most often rated as important to quality of life for the healthy group were: ‘relationships’, ‘physical functioning’, and ‘independence’. The group with a chronic condition most often rated ‘physical functioning’, pain, and ‘independence’ as most important. To determine if any of these areas seemed to be differentially important to the groups comparison between percentages of individuals rating an aspect as most important was conducted. To this end, any differences of 10% or more between the areas were

highlighted, which revealed that the healthy group more often rated relationships as most important compared to the chronically-ill group. In contrast, the group with a chronic condition more often rated pain as the most important quality of life factor, compared to the healthy group.

Table 2 about here

Table 2 shows the percentages (and numbers) of individuals in the healthy and chronically-ill groups who rated potential deteriorations in each of the aspects of quality of life as having ‘no’, ‘mild’, ‘moderate’, or ‘severe’ impact on their lives. These responses were generated to the question: “*Please indicate to what extent you believe the following would or does negatively affect your quality of life.*” Inspection of these data, again, shows differences between the groups in their ratings, which were analyzed by (2x4) chi-square tests, conducted on the actual numbers of individuals in each group rating the impact of deteriorations in each area as important. As a number of such analyses were conducted, these were adjusted using a Bonferroni correction. These analyses are shown in Table 2, and reveal that the healthy group rated deteriorations in their relationships as having more of an impact on their quality of lives than the group with a chronic condition. In contrast, the chronically ill group tended to rate deteriorations in levels of fatigue, sleep, and working life, as having more of an impact on their lives than the healthy group.

Figures 1 and 2 about here

Figure 1 shows a word cloud displaying the most commonly used words in response to the question: “In no more than 30 words please describe what ‘quality of life’ means to you.” for the healthy group, and Figure 2 shows the same for the group with a chronic condition. The size of the words indicates their relative frequency for the two groups. For the healthy group the most commonly used words were “able”, “life” “family”, happy”, and work”. For the chronically ill group, the most commonly used words were: “able”, “ability”, “life”, “pain”, and enjoy”. The use of these words in the context of what quality of life meant showed a degree of similarity across the two groups. However, there was an exception to this in that the healthy group more often mentioned ‘family’ than the chronically ill group, who more often mentioned ‘pain’. Thus, these qualitative analyses broadly corresponded to the ratings given in response to the first and second two questions.

Discussion

The current investigation explored whether there were any differences between individuals with a chronic condition, and those who are healthy, regarding their views of quality of life. Potential differences between different groups of individuals in terms of what they regard as important for their quality of life have been noted by a number of investigators [6,13,14]. To this end, the participants were asked a range of questions regarding the importance of various aspects of their lives, the aspects of life that would impact most strongly on their quality of life, and also were given the opportunity to say what quality of life meant to them in an open-response question. It was hoped that by using such a range of questions it may highlight any consistent differences in areas regarded as important in quality of life between these groups [18,19].

There were many agreements about the factors that are important for quality of life between the two groups, which were seen across all of the questions. For example, both groups noted the importance of physical functioning, and independence in terms of the key areas relating to quality of life (question 1), and they both noted independence and mobility as the key areas that would impact on their quality of life should they deteriorate (question 2). In response to the open question (question 3), the key words that emerged were connected to their abilities to function. To the extent that physical functioning and mobility are noted in many generic quality of life tools [15-17], then they can be regarded as covering these key areas. However, that independence was noted is consistent with previous findings [6]. That it is not directly measured on all of these tools suggests that some caution need to be taken in interpreting the results from such quality of life tools.

However, there were differences between the two groups [6,13]. The findings that consistently emerged regarding the differences between the groups over the three questions were that the group with a chronic condition tended to find issues of functioning such as pain, fatigue, and sleep as more important to their quality of life than the healthy participants. In contrast, the healthy participants tended to note the importance of relationships and family as more important than the group with a chronic condition. That there were such differences between the groups might suggest that different aspects of quality of life could be rated as more important when examining this issue with samples with a chronic condition and those without such a condition.

By inviting people without a chronic condition to take part, it was hoped to highlight that, when such healthy people are discussing issues around living with a long-term and chronic condition, they do not necessarily appreciate the full

significance that problems like fatigue and pain, for instance, can have on a person's quality of life, because they have not experienced these debilitating difficulties and symptoms, long-term and chronically. This consideration also applies to health professionals who may be managing patients with chronic conditions. There is a danger that health professionals may not totally be able to empathise with their patients, if they are not fully aware of the wide-ranging impacts on quality of life. Hence, comparing healthy people with those living with a long-term and chronic condition was thought to be useful in this context.

In summary, this investigation pointed to the importance of several areas of a person's life, such as independence, that may need more attention on many generic quality of life measures. Moreover, there were differences between the areas identified by those with a chronic condition and those who were healthy (e.g., pain and family relationships). Consideration of these differences will also need to be given in measuring quality of life.

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Figure Captions

Figure 1: ‘TagCrowd’ word cloud of the 40 most commonly used words (and their frequencies) in the responses to the question, “In no more than 30 words please describe what ‘quality of life’ means to you” from the healthy group.

Figure 2: ‘TagCrowd’ word cloud of the 40 most commonly used words (and their frequencies) in the responses to the question, “In no more than 30 words please describe what ‘quality of life’ means to you” from the chronically-ill group.

Table 1: Percentages (and numbers) of individuals rating each of the aspects of quality of life as the most important to them in response to the question: “Please rate how important the following are to you?”.

	Healthy	Chronic
Calmness	3.1 (8)	4.1 (26)
Mood	5.0 (13)	4.1 (26)
Pain	11.5 (30)	22.0 (139)
Sleep	5.0 (13)	9.4 (59)
Relationships	27.6 (72)	14.7 (93)
Finance	3.8 (10)	5.5 (35)
Physical Functioning	23.0 (60)	26.1 (165)
Independence	13.0 (34)	14.9 (94)
Domestic	2.7 (7)	1.4 (9)
Social Life	1.5 (4)	2.2 (14)
Work Life	3.8 (10)	6.2 (39)

Table 2: Percentages (and numbers) of individuals in the healthy and chronically-ill groups who rated each of the domains as having no, mild, moderate, or severe, impacts on their lives, in response to the question: “Please indicate to what extent you believe the following would or does negatively affect your quality of life.”

		None	Mild	Moderate	Severe	Chi-square
Angry	Healthy	3.8 (10)	25.3 (66)	48.7 (127)	22.2 (58)	3.57
	Chronic	4.0 (25)	22.7 (142)	42.5 (268)	27.1 (171)	
Anxious	Healthy	2.7 (7)	15.7 (41)	46.7 (121)	34.9 (91)	3.05
	Chronic	3.2 (20)	17.3 (109)	37.7 (238)	37.1 (233)	
Fatigue	Healthy	3.1 (8)	18.8 (49)	54.8 (143)	23.4 (61)	89.41**
	Chronic	1.3 (8)	7.4 (47)	33.3 (210)	56.6 (356)	
Sleep	Healthy	2.7 (7)	25.3 (66)	43.7 (114)	28.4 (74)	24.03**
	Chronic	4.6 (29)	14.6 (92)	36.8 (232)	41.7 (262)	
Pain	Healthy	2.7 (7)	13.0 (34)	37.9 (99)	46.4 (121)	3.43
	Chronic	4.3 (27)	10.3 (65)	32.8 (206)	47.5 (300)	
Mobility	Healthy	3.4 (9)	6.9 (18)	28.4 (74)	61.3 (160)	4.82
	Chronic	3.3 (20)	10.9 (69)	25.4 (160)	52.9 (334)	
Finance	Healthy	2.7 (7)	20.7 (54)	52.9 (138)	23.8 (62)	31.82**
	Chronic	8.9 (56)	16.0 (100)	32.3 (204)	31.9 (196)	
Independence	Healthy	1.5 (4)	13.4 (35)	37.5 (98)	47.5 (124)	13.79
	Chronic	5.2 (32)	9.7 (61)	27.3 (172)	51.2 (323)	
Domestic	Healthy	11.5 (30)	34.9 (91)	39.1 (102)	14.6 (38)	14.77
	Chronic	7.1 (44)	26.1 (165)	38.8 (245)	22.8 (144)	
Social	Healthy	3.4 (9)	24.5 (64)	49 (128)	23.0 (60)	16.64*
	Chronic	6.0 (38)	16.0 (101)	42.0 (264)	32.3 (204)	
Working	Healthy	5.0 (13)	20.7 (54)	51.0 (133)	23.4 (61)	51.86**
	Chronic	9.5 (60)	13.9 (88)	22.0 (138)	33.0 (208)	
Relationship	Healthy	1.5 (4)	3.4 (9)	28.0 (73)	67.0 (175)	46.25**
	Chronic	9.4 (59)	12.2 (77)	26.1 (164)	44.7 (282)	

* $p < 0.001$, ** $p < 0.0001$

Figure 1



Figure 2



