

Original Paper

Quality of Life: Perception of Lung Cancer Patients

A. Montazeri,^{1,*} R. Milroy,² C.R. Gillis³ and J. McEwen¹

¹Department of Public Health, University of Glasgow, 2 Lilybank Gardens, Glasgow G12 8RZ; ²Department of Respiratory Medicine, Stobhill Hospital, Glasgow; and ³West of Scotland Cancer Surveillance Unit, Ruchill Hospital, Glasgow, U.K.

An investigation was carried out to examine what quality of life means to lung cancer patients. 200 patients with either lung cancer (108) or chronic respiratory disease (92) were interviewed using a short open-ended questionnaire. They were asked to define quality of life in general, identify what they considered to be a good quality of life for themselves and to rank the relative importance attached to each nominated item. A content analysis was carried out and patients' responses were categorised into eight items. These were: ability to do what one wants to do/work, enjoyment of life, family life, financial security, happiness, health, living longer and social life/leisure activities. Of these, health (42%), enjoyment of life (25%) and family life (24%) were the three most nominated items as definition of quality of life in general. Patients perceived a good quality of life for themselves differently. Family life (58%), health (51%) and social life (43%) were found to be the most nominated components of a good quality of life for the patients. Overall, patients ranked family life and health as the first or second most important factors. There were no significant differences between cases and controls. The study results are challenging and serve to remind us that the term quality of life is misused in many studies. Most existing measures do not encompass the wider aspects of quality of life identified here, but rather concentrate on the "health-related" aspects of quality of life. To achieve this, the research into the best ways of measuring and assessing quality of life must continue to seek individual values and preferences and how these can be applied in a simple way in clinical studies. Copyright © 1996 Elsevier Science Ltd

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INTRODUCTION

STUDYING QUALITY of life, especially in patients with a life-threatening disease, such as cancer, is becoming increasingly important. This is due to several factors including understanding patients' experiences of the impact of the disease and its treatments. It is argued that such understanding may help to deliver effective and efficient healthcare.

As many researchers seek to include quality of life measurements in their investigations, the initial question is: what should be assessed? Quality of life is a multidimen-

sional construct and should, therefore, be measured with multidimensional instruments, since unidimensional instruments are insufficient measures of health-related quality of life. Such unidimensional instruments should, in fact, not be called quality of life measures [1].

However, to identify the component parts of quality of life, and their value and importance in every day life of cancer patients, becomes complex. Should one measure quality of life solely in terms of physical, social and mental well-being? Should it be measured in relation to disease symptoms and its treatment side-effects? Should social context be taken into account when measuring quality of life? More importantly, how should it be measured and who should define quality of life—professionals or lay people? It is argued that most quality of life measures impose an exter-

Correspondence to A. Montazeri.

* Present address: P.O. Box 13185-1488, Tehran, Iran.

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nal value system on patients, using standardised instruments and weightings of individual components of quality of life, which are usually derived from grouped data [2].

Using systematic group judgements or a consensus method (Delphi process), Dallkey and his colleagues [3] carried out a series of investigations to find out what quality of life is. They produced an extensive list of different areas and activities affecting the life and its quality, ranging from anxiety to social acceptance and popularity. One of the earliest studies on identifying lay definitions of quality of life found that a high proportion of respondents did not have specific ideas and that they considered quality of life to be happiness and contentment [4]. Such investigations have been criticised for their inability to provide an explicit definition of quality of life. It has been argued that, in this approach, quality of life can be defined in as many ways as individual personalities vary [5], and that this general concept of quality of life has limited empirical value in normal clinical studies.

To overcome the problems inherent in such investigations, there have, in the past, been several attempts to clarify the issue more explicitly, and give more insight into the component parts of lay-defined quality of life as opposed to a professionally defined concept. For example, in a study [6] with a limited sample of 18 Indian cancer patients, 20 of their relatives and 12 professionals, overall items considered to be very important for quality of life were found to be: peace of mind (66%), spiritual satisfaction (62%), satisfaction with religious tasks (60%), and happiness with family relations and social network (60%). These are quite abstract and, therefore, very difficult to measure. In addition, the cultural influence of the research setting on the findings is obvious.

Recently, there have been interesting attempts to identify the components of quality of life as perceived by individuals. Two examples of these are the Schedule for the Evaluation of Individual Quality of Life (SEIQoL), and the Patient Generated Index (PGI). The SEIQoL was developed using the judgement analysis technique in a semistructured interview form and provides a list of five areas that individuals judge to be the most important to their quality of life. It also indicates the relative weights of importance attached to the components of quality of life nominated by the individuals [2, 7, 8]. The PGI was developed using the priority evaluator method (to take account of the preferences), and designed as a self-completed questionnaire. It is very similar to the SEIQoL, and allows patients to define quality of life and to value the relative importance of improvement in their chosen areas of life [9, 10]. A similar method was previously used by Guyatt and associates [11], when they developed a questionnaire that asks patients to specify the five most important areas of their lives affected by their condition, or to choose the five most important from a list of 20 items.

Using the SEIQoL, in a limited sample of healthy individuals (42), it was found that a variety of areas of life were rated as being important to their overall quality of life. Considerable variability was also found in the relative importance attached by participants to the various aspects of their quality of life. For example, those who nominated health as an important factor, weighted health varying from 3 to 59 out of a possible score of 100. A similar study with

a sample of 40 patients indicated that leisure, family and work were significantly more important components of quality of life for the patients than for the healthy controls while fewer patients referred to health than did members of the healthy group [7]. Although this method has been reported to be valid, the bias of introducing life domains by show-cards to those who have no idea about nominated areas remains to be resolved.

Two recent publications by Farquhar [12] and Bowling [13] are representations of a variety of similar and the most advanced in these series of investigations. While the former aimed to identify lay definitions of quality of life among people aged 65 years and over living in three different areas (204 subjects), the latter aimed to provide population norms on the dimensions of life that people perceive to be important in relation to their quality of life based on a large sample (2033) of the general public. The former study [12], using a set of simple questions, highlights how quality of life varies among different age groups of the elderly population living in different geographical areas. Early conclusions also indicate that social contacts appear to be as valued components of a good quality of life as health status. The latter study [13], which used a method very similar to the SEIQoL, found that relationships with family or relatives, the respondents' own health, the health of someone close, and finances (good or bad) were the most important aspects in respondents' lives.

To explore these issues further, an investigation was carried out to examine what quality of life means to lung cancer patients. Life, for this group of patients, is very short, most dying within a year, and the disease and its treatment have major effects on their quality of life. This paper presents the findings of this investigation, and discusses its implications for the development of quality of life measures. It is hoped that the results would provide more insight into ways of promoting the quality of life in cancer patients.

PATIENTS AND METHODS

Design

An interview-based investigation was carried out to measure quality of life in lung cancer patients attending a chest clinic at Stobhill Hospital, Glasgow from 1 January 1995 to 31 December 1995. Quality of life was assessed by means of a series of interviews using standard questionnaires (the Nottingham Health Profile, and the European Organization of Research and Treatment for Cancer Quality of Life Questionnaire). Although the complete data are yet to be analysed, preliminary findings of the study have been reported elsewhere [14, 15]. In addition, at baseline assessments, patients were interviewed by means of an open-ended questionnaire to find out what quality of life means to them. Patients were asked what quality of life is. They did not receive any special instruction and were given freedom to mention as many areas or factors as they wanted. They were then asked what a good quality of life is for them and to rank nominated factors in order of importance.

Patients

A consecutive sample of lung cancer patients attending a chest clinic, regardless of their sex, age, performance status, histological types and stage of disease, were entered into the

study. To ensure validity, it was decided to include a consecutive sample of patients with chronic respiratory disease as controls. The controls were selected if they presented with acute symptoms very similar to lung cancer. To avoid selection bias, patients were not matched for sex, age, performance status and other demographic variables. These variables were recorded by asking patients about their level of education, marital status and employment status. Their socio-economic status was measured using Carstairs and Morris Deprivation Index [16] ranging from 1 (affluent) to 7 (most deprived). These variables were included because of their potential to act as confounding variables, and the consequent implications on an observed relationship between cases and controls.

Analysis

A content analysis of the responses was performed. To designate the units to be coded, the 'theme' of each response was characterised by placing it in a given category [17]. All responses fitted into eight categories and there was no additional coding of responses. Data were analysed descriptively followed by statistical tests (Chi-squared test, Fisher's exact test and *t*-test, odd ratios, and 95% confidence intervals, where necessary) using Epi-Info Version 6. This is a multipurpose computer program designed for epidemiological researchers and jointly produced by the Centres for Disease Control, Atlanta, Georgia, U.S.A. and the World Health Organisation, Geneva, Switzerland [18].

RESULTS

Patients' characteristics

200 patients were interviewed. Of these, 108 were lung cancer patients (cases) and 92 chronic respiratory disease patients (controls). Of the patients, 56% (112) were male and 44% (88) female. The mean age of cases was 66.9

years (S.D. = 9.2) ranging from 40 to 87, while for the controls this was 64.1 years (S.D. = 10) ranging from 38 to 83. Table 1 summarises patients' characteristics. There were no significant differences between cases and controls in socio-demographic characteristics.

'What is quality of life?'

When patients were asked to define quality of life, contrary to expectations, they identified a limited number of areas of life. In total, eight areas of life were extracted from patients' responses. All patients identified at least one aspect of life, 87% two dimensions of life, 59% mentioned three areas, while only 21% nominated four dimensions of life as definition of the quality of life. The highest proportion of respondents (42%) mentioned 'health' as a definition of quality of life, while only 5% of patients indicated that 'living longer' means quality of life. There was no significant difference between cases and controls in most dimensions except in financial security. Significantly more controls than cases considered financial security as one of the components of quality of life (Table 2).

'What is a good quality of life for you?'

Respondents were asked to identify what they considered to be a good quality of life for themselves. The most common choice was 'family life', mentioned by 58% of the respondents as an area that makes life good for them, followed by their 'own health', nominated by 51% and 'social life' by 43%. Although there was no significant difference between cases and controls, cases mentioned health more often than controls. It is worth noting that, when cases were asked to define quality of life in general, they mentioned family life less than controls (Table 2), but when they described their own quality of life, they considered family life as important as their own health (Table 3).

Table 1. Patients' socio-economic characteristics

	Cases (<i>n</i> = 108) <i>n</i> (%)	Controls (<i>n</i> = 92) <i>n</i> (%)	Total (<i>n</i> = 200) <i>n</i> (%)
Sex			
Male	63 (58)	49 (53)	112 (56)
Female	45 (42)	43 (47)	88 (44)
Age (years)			
Mean (S.D.)	66.8 (9.3)	64.4 (10.1)	65.7 (9.7)
Range	38–83	40–87	38–87
Marital status			
Married	65 (60)	49 (53)	114 (57)
Single	7 (7)	6 (7)	13 (7)
Widowed	25 (23)	24 (26)	49 (25)
Divorced/separated	11 (10)	13 (14)	24 (12)
Level of education			
Primary education	99 (92)	84 (91)	183 (92)
Higher education	9 (8)	8 (9)	17 (9)
Employment status			
Employed	14 (13)	16 (17)	30 (15)
Unemployed	9 (8)	12 (13)	21 (11)
Housewife	18 (17)	22 (24)	40 (20)
Retired	67 (62)	42 (46)	109 (55)
Deprivation category			
Affluent	17 (16)	13 (14)	30 (15)
Middle	31 (28)	18 (20)	49 (25)
Deprived	60 (56)	61 (66)	121 (61)

Table 2. Definition of quality of life by lung cancer cases and respiratory disease controls

Nominated areas	Cases (n = 108) n (%)	Controls (n = 92) n (%)	Total* (n = 200) n (%)	OR (95% CI)
Ability to do what one wants to do/work	15 (14)	16 (17)	31 (16)	0.77 (0.33–1.76)
Enjoyment of life	24 (22)	25 (27)	49 (25)	0.77 (0.38–1.53)
Family life	20 (19)	27 (29)	47 (24)	0.55 (0.27–1.11)
Financial security	12 (11)	20 (22)	32 (16)	0.45 (0.19–1.04)†
Happiness	24 (22)	17 (18)	41 (21)	1.26 (0.60–2.68)
Health (own health)	49 (45)	35 (38)	84 (42)	1.35 (0.74–2.48)
Living longer	7 (6)	2 (2)	9 (5)	3.12 (0.75–31.4)
Social life/leisure activities	12 (11)	14 (15)	26 (13)	0.70 (0.28–1.71)

* Since some respondents nominated more than one area, the total exceeds 100% and total sample size. † $P < 0.05$.

Table 3. A good quality of life as perceived by lung cancer cases and respiratory disease controls

Items	Cases (n = 108) n (%)	Controls (n = 92) n (%)	Total* (n = 200) n (%)	OR (95% CI)
Ability to do what one wants to do/work	17 (16)	16 (17)	33 (17)	0.89 (0.39–2.00)
Enjoyment of life	37 (34)	31 (34)	68 (34)	1.03 (0.55–1.92)
Family life	59 (55)	56 (61)	115 (58)	0.77 (0.42–1.42)
Financial security	28 (26)	29 (32)	57 (29)	0.76 (0.39–1.47)
Happiness	28 (26)	28 (30)	56 (28)	0.80 (0.41–1.55)
Health (own health)	60 (56)	41 (45)	101 (51)	1.55 (0.86–2.83)
Living longer	10 (9)	6 (7)	16 (8)	1.46 (0.46–5.10)
Social life/leisure activities	45 (42)	40 (43)	85 (43)	0.93 (0.51–1.69)

* Since some respondents nominated more than one area, the total exceeds 100% and total sample size.

Order of importance

Finally, patients were asked to rank nominated items in order of importance. The overall results are shown in Table 4. The highest proportion of patients nominated either family life (27%) or their own health (25%) as the most important factor. Health was considered to be the second most important factor by 21%, followed by family life (18%) and financial security (18%). This clearly suggests that family life and health were the most or second most important factors. As it was described earlier, most patients considered that a good quality of life depends on mainly these two factors. In contrast, only half the patients or less identified third and fourth factors. For example, in relation

to the fourth important factor for a good quality of life, the highest proportion of patients nominated social life (27%), followed by happiness (17%) and enjoyment of life (15%).

The stratified analysis indicated that, in almost all nominated areas, there were no significant differences between cases and controls. 28 cases and 26 controls nominated 'family life' as the most important factor for a good quality of life, followed by their own health (32 cases and 18 controls). Health was ranked second by 22 cases and 14 controls, followed by family life (20 cases and 12 controls) and financial security (15 cases and 17 controls). The results are shown in Table 5.

Table 4. Dimensions of life mentioned as a good quality of life in order of importance (overall results)

Items	Most important (n = 200) n (%)	Second in importance (n = 174) n (%)	Third in importance (n = 118) n (%)	Fourth in importance (n = 41) n (%)
Ability to do what one wants to do/work	11 (6)	8 (5)	9 (8)	5 (12)
Enjoyment of life	28 (14)	19 (11)	15 (13)	6 (15)
Family life	54 (27)	32 (18)	26 (22)	3 (7)
Financial security	6 (3)	32 (18)	16 (14)	3 (7)
Happiness	20 (10)	15 (9)	14 (12)	7 (17)
Health (own health)	50 (25)	36 (21)	13 (11)	4 (10)
Living longer	4 (4)	5 (3)	5 (4)	2 (5)
Social life/leisure activities	27 (14)	27 (16)	20 (17)	11 (27)

Table 5. Dimensions of life mentioned as a good quality of life in order of importance by cases and controls

Items*	Most important (n = 200)		Second in importance (n = 174)		Third in importance (n = 118)		Fourth in importance (n = 41)	
	Cases n (%)	Controls n (%)	Cases n (%)	Controls n (%)	Cases n (%)	Controls n (%)	Cases n (%)	Controls n (%)
Ability to do what one wants to do/work	6 (6)	5 (5)	5 (5)	3 (4)	3 (5)	6 (11)	3 (14)	2 (11)
Enjoyment of life	12 (11)	16 (17)	10 (11)	9 (11)	12 (20)	3 (5)†	3 (14)	3 (16)
Family life	28 (26)	26 (28)	20 (22)	12 (15)	9 (15)	17 (30)	2 (9)	1 (5)
Financial security	1 (1)	5 (5)	15 (16)	17 (21)	11 (18)	5 (9)	1 (5)	2 (11)
Happiness	12 (11)	8 (9)	6 (7)	9 (11)	4 (7)	10 (18)	6 (27)	1 (5)
Health (own health)	32 (30)	18 (20)	22 (24)	14 (17)	6 (10)	7 (12)	0 (0)	4 (21)‡
Living longer	3 (3)	1 (1)	2 (2)	3 (4)	4 (7)	1 (2)	1 (5)	1 (5)
Social life/leisure activities	14 (13)	13 (14)	13 (14)	14 (17)	12 (20)	8 (14)	6 (27)	5 (26)
Total	108 (100)	92 (100)	93 (100)	81 (100)	61 (100)	57 (100)	22 (100)	19 (100)

* The differences between cases and controls were not significant except for those indicated in the Table. † Significant at 5% level, $P = 0.02$ (Fisher exact two-tailed P -value). ‡ Significant at 5% level, $P = 0.04$ (Fisher exact two-tailed P -value).

DISCUSSION

Quality of life is difficult to define and it varies among individuals. To achieve a more 'common language' in assessing quality of life one may argue that the first task should be to define quality of life and identify its components, not only by professionals but also by individuals themselves. Except for the Nottingham Health Profile (NHP), which was developed through public participation [19], a majority of quality of life measures, both generic and disease specific, were, until recently, developed by professionals. They, therefore, carry professional values rather than the values and preferences of the public, including healthy individuals and patients. However, most recent quality of life studies are actually conceptualised within the framework proposed by the EORTC which has its own merit, especially since it is necessary to provide a 'common language' and prevent haphazard developments.

It is argued that, since quality of life is a uniquely personal perception, most measurements of quality of life in the medical literature seem to aim at the wrong target. Reviewing 75 randomly selected original quality of life articles, Gill and Feinstein [20] observed that, in 87% of the articles, patients were allowed to respond only to a list of items previously selected by experts and were not invited to add any individual responses. This is a serious problem which questions the validity of these instruments. Research work, such as the present study, may help to provide information for those interested in the theory and development of quality of life measures.

This study was an attempt to explore the issue and find out how patients with lung cancer define quality of life. This study included two general but simple principles: patients were allowed to identify the items which affect their quality of life, and were invited to rate the relative importance of these items to their quality of life. It has also been recommended that quality of life measures should give patients an opportunity to rate the severity of the identified items [21], but this was not included in this study.

The most important finding in this study was that patients defined quality of life in one way and they perceived a good quality of life for themselves in another way. For example, as demonstrated in Tables 2 and 3, overall, a significant proportion of patients defined quality of life as

health (42%), enjoyment of life (25%) and family life (24%), while the majority of the same individuals stated that a good quality of life for themselves consists of family life (58%), health (51%) and social life and leisure activities (43%). These differences may be worth noting in terms of understanding the complexity of the individual value system and preferences. The recent studies on development of a new instrument, the Subjective Quality of Life Profile (SQLP), confirms that these differences are real, and should be understood on the basis of differences in personal value system of the subjects, which causes the changes in the evaluation of quality of life [22].

However, there are two major problems associated with this and other studies on the subject. First, the problem of change over time and the course of disease, since the perception of patients may change over time. For example, the wish for survival (which was low in our study, 8%) may become more important than other items near the end of life (which was not studied). Second, the problem related to the flexibility of the individual judgement due to fluctuating defence mechanisms. For example, one may argue that the relatively low rating of 'one's own health' as an important domain of quality of life may be an expression of denial of the threat that cancer and its treatment represents to the individual. Denial may fluctuate over the course of disease and a patient may learn to live with the threat. Then, 'one's own health' may become a very important domain. This study and others could rarely capture such a phenomenon.

The main difference in this study from previous work is the fact that we observed a relatively small number of patients who identified more than three areas of life as important components of quality of life or they perceived to be important for their own quality of life. One explanation is that, in this study, patients did not receive any instructions such as showcards or a list of suggested dimensions of life which were often used in other studies. This, however, indicates that showcards may to some extent create biased results.

Compared with controls, cases were more often concerned about their own health. This is not surprising, since the cases in this study were newly diagnosed lung cancer patients. However, they were concerned about family as much as their own health. This finding is similar to previous

and current studies where family has been the most important item rated by either the general public, or patients with different types of diseases including cancer patients [23].

Interesting results in this study relate to the role of family, and importance of social life, leisure activities and financial security in patients' quality of life. These are vital issues and are often neglected in most of the well-known measures of quality of life or have, at best, received little attention. Most of the instruments which have been developed focus on health, concentrate on feelings, functions and problems associated with the ill health, disability or disease. Our study and several recent studies [12, 13, 23] clearly suggest that these instruments should either be reviewed or supplemented with additional items covering family, social life, leisure activities and other areas identified in this study and other studies.

In conclusion, taking account of patients' views in establishing validity of quality of life instruments should be considered an indispensable criterion for ascertaining the strength of such instruments. To achieve this, the research into the best ways of measuring and assessing quality of life must continue to seek individual values and preferences. Measuring quality of life and its relevance to clinical decisions and science is still a matter of research, and further investigations are needed before easy-to-use questionnaires are added to the package of current clinical protocols.

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