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30. Plat. *Lg.* VII. 805d-806b. Le fonti sulla militanza delle Spartane sono state eccellentemente discusse da NAPOLITANO M.L., *Le donne spartane e la guerra: problemi di tradizione*. Annali dell'Istituto Orientale di Napoli 1987; IX: 127-144.
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32. Plat. *Resp.* V 466d.
33. Plat. *Lg.* VIII. 840d.
34. Cfr. Plat. *Pol.* 262a-263a con ERNOULT N., op. cit. nota 25, in corso di stampa.
35. *Avanzato* perché scandalosamente libertino: cfr. Ibyc. *PLG III*² 252 F 61 = F 58 Page; Soph. F 788 Nauck² = 872 Radt; Eur.*Andr.* 597 ss.; Arist. *Pol.* II.1270a6 ss., II.1296b 12ss.; Plut. *Comp.Lyc.-Num.* III.5ss. con PARADISO A., *Femmes libertines et belles infidèles*. In: BAYLE P., *Sparta nel Dizionario*. A cura di PARADISO A., con una nota di CANFORA L., Palermo, Sellerio, 1992, pp.21-49.
36. Plut. *Thes.* 27.
37. Ephoros *FGrHist* 70 F 160a Γυναικοκρατούμενοι.
38. Diod. III.53, in cui confluiscono Ippocrate ed Eforo.
39. Plut., *Lyc.* XIV.2. Cfr. Id., *Comp.Lyc.-Num.* III.5ss.
40. Plut., *Lyc.* XIV.2.
41. Plut., *Lyc* XIV.8.

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Articoli/Articles

THE CONCEPT OF QUALITY OF LIFE
IN RELATION TO HEALTH

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SUMMARY

This paper will discuss the broadening of the concept of health to include social and psychological concepts, as well as physical health, and the movement away from narrow conceptions of health and disease. In Europe and in USA, some specialties, particularly in psychiatry and cancer, have made considerable progress in the development of broader measurements of outcome in relation to health related quality of life. Others, such as cardiology and rheumatology have been more limited (concentrating on role functioning or return to work at most). Across all specialties, however, there has been an increasing interest in measuring outcome of health care in relation to the patient's quality of life.

Background

Success in the West is usually determined by economic achievement and occupational status. In the developed world, with the emphasis on affluence and with the increasing longevity of populations, there is a general interest in knowledge about how to find the *goodness* of life, sometimes called life satisfaction or quality of life. Quality of life research spans a range of topics, from quality of life in the last year of life to quality of life in urban environments. The concept of quality of life has a usage across many disciplines - in geography, literature, philosophy, health economics, advertising, health promotion and the medical and social sciences.

Key words: Quality of life - Health

There is an increasing interest in defining and measuring quality of life. Social science has a long tradition of research and theoretical analysis regarding what is quality of life, although until recently this expertise was concentrated among philosophers, theologians and social scientists, particularly in relation to the achievement of *satisfaction with life* and *the good life*, and what has been generally termed *social indicators research*¹.

Social gerontologists were also involved with the empirical work in this field during the 1960s, selected medical specialties (eg oncology) have been attempting to measure various domains of quality of life since the 1940s, and economists have long been concerned with utility analysis (*preferences*). Today, research on quality of life and *the social temperature* encompasses many concerns, including sociology, psychology, geography, economics, history, medicine, pharmaceuticals, education, criminology, architecture, transport, the arts, income, employment, community and environmental issues, and the marketing departments of commercial enterprises. Despite all this activity, there is no consensus on what is quality of life.

Psychologists, sociologists and social gerontologists carried out most of the early empirical social research on quality of life in studies in the USA which attempted to estimate wellbeing, satisfaction or happiness, and what people meant by *the good life*. Andrews argued that quality of life is the extent to which pleasure and satisfaction have been obtained². Lawton first proposed a theoretical model of quality of life as *the good life*, defined as psychological well-being, perceived quality of life, behavioural competence and the *objective* environment³. The gerontological literature on the topics of *successful ageing*, *positive ageing* and *quality of older age* has focused largely on life satisfaction and morale, and, more recently, on feelings of control and motivation. Ultimately, however, the question of what is quality of life ultimately remains philosophical.

Overlapping with this research, is the long history of the exploration of happiness dating from the work of early Greek philosophers to present day philosophy and social science. In the twentieth century, researchers are moving away from

negative indicators of disease and illness and are looking for more positive indicators of mental and physical well-being to supplement the latter. For example, quality of life research in gerontology and research on positive ageing increasingly centres around feelings of control and coping. In social indicators research it encompasses all circumstances of life, for example, housing, leisure activities, work, the environment, income. Some have argued that human needs are the foundations for quality of life and that quality of life is the degree of satisfaction of those needs - for - example, physical, psychological, social, activity, marital and structural.

Alternatively, phenomenologists would argue that quality of life is dependent upon the interpretation, and perceptions, of the individual. Rosenberg has argued that the psychometric translation of quality of life into components such as emotional status, social interaction, economic status, health status and physical capacity, while incorporating the multidisciplinary nature of human beings, does not capture their subjectivity⁴. He argued that hermeneutic thinking should be introduced into modern medicine, so that a naturalistic concept of mankind is presented along with a concept of the human being as a self reflective individual responsible for his or her own actions.

Health and quality of life

The measurement of health outcome, and appropriateness, of clinical interventions has become a cornerstone of health services research and public health. The emphasis is on measuring the outcomes of health care - purchasers of health services are asking what health gain treatments provide. The emphasis is positive. So, purchasing debates in health care have been focusing on health care costs in relation to broader *health gains* or *benefits* (ie. health related quality of life) from the treatments and interventions that are being contracted for. In public health and in social services, quality of life is increasingly incorporated into criteria for the assessment of people's needs for effective services. The emphasis of research and audit is on the

measurement of health outcomes in its broadest sense. Treatment and care need to be evaluated in terms of whether they are more likely to lead to an outcome of a life worth living in social, psychological and physical terms. A wide range of generic and disease specific scales has been developed in response to this. The assessment of quality of life as a supplement to toxicity and adverse affects, biochemical markers and survival rates is given more urgency in the light of information that some surgical procedures are inappropriate or ineffective, and relatively few have been subjected to rigorous, multi-centre randomised controlled trials.

A concept of health related quality of life needs to be derived from a concept of health, the most commonly cited definition of which is the broad WHO⁵ utopian definition of health as a state of complete social physical and psychological well-being. An emphasis on the positive side of health is also necessary when studying samples of the general population - while most people have some symptoms much of the time, according to morbidity surveys, they tend to be minor and would not show up on most morbidity scales or indicators. Therefore, most disease indicators - or even scales of everyday functioning - tell us little about the state of well-being and health of the majority of the population.

Health status is often referred to as quality of life, and, in order to narrow down its operationalisation in research studies, quality of life is increasingly referred to as health related quality of life. Health related quality of life is a subjective concept, and essentially relates to the perceived effects of health status on the ability to live a fulfilling life. The literature on, and purported measurement scales of, health related quality of life rarely include any attempt at a definition of the concept and covers a range of components: functional ability including role functioning (eg. domestic, return to work), the degree and quality of social and community interaction, psychological well-being, somatic sensation (eg. pain), symptoms, adjustment, coping and life satisfaction. From a health care perspective, quality of life can be said to refer to the social, emotional and physical wellbeing of patients following treatment, thus mirroring the

WHO's definition of health - a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The WHO has since added *autonomy* to this list. More precisely, health related quality of life, then, is the achievement of optimum levels of mental, physical, role (eg work, parent, carer etc.) and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being. It should also include some assessment of the patient's level of satisfaction with treatment, outcome and health status and with future prospects.

The World Health Organisation has a working party on quality of life under its umbrella, which is undertaking a ten country study of health related quality of life. The World Health Organisation Quality of Life Group (WHOQOL Group, 1993)⁶ has provided a definition of quality of life which also takes individual perception and relationship to the environment into account:

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

This definition underpins the WHOQOL - this is an instrument being developed for measuring quality of life, that can be used in a variety of cultural settings. It is being developed as a core instrument, and modules are being planned which will be specific to certain population groups (eg. cancer patients, elderly people etc). Extensive piloting of the instrument is currently underway. The WHOQOL is designed to be self-administered, and it contains five broad domains: physical health (bodily states and functions); psychological health; level of independence; social relationships; and environment. Each domain contains several facets (eg physical health includes pain and discomfort, vitality and fatigue and sensory functions). Care is being taken to make the questions sensitive to individual cultures, while measuring the same domains across cultures.

Indicators of quality of life and health related quality of life

As with the concept, the potential range of dimensions of health related quality of life which could be measured includes functional ability, health status, symptoms and somatic state, psychological well-being, social support and life satisfaction, morale, independence, control over life, coping and adjustment abilities. On the whole they have been applied to *quality of life* research without any theoretical underpinnings and with little understanding of how the public, or patients, define or value the different components of life. The measurement of quality of life is imprecise in the current state of methodological development, partly because of its nebulous conceptualisation, in turn due to lack of empirical research. It can be measured using proxy data based on assumptions of what its constituents are.

Promising research on health related quality of life has involved the application of the techniques of human judgement analysis to assess health related quality of life, which is a novel method of measuring this concept from the perspective of the individual (with this technique respondents are asked to list the five areas of life (*cues*) that they judge to be the most important to their overall quality of life (the technique is known as the schedule for the evaluation of quality of life SEIQoL). Open ended questions are used to elicit the relevant cues. Then subjects rate their current status against a vertical visual analogue scale, labelled at each extremity *as good as could possibly be* and *as bad as could possibly be*. Respondents are then asked to rate their global quality of life on a similarly labelled horizontal visual analogue scale. Relative weights of importance are then attached to the items. Thus this instrument provides a means by which individuality can be assessed scientifically (O'Boyle et al.⁷⁻⁹). Their research has been concentrated on patients, although the instrument was piloted on small samples of the general population, and shows that priorities are different among different groups of people.

A similarly hermeneutic approach to measuring disease specific quality of life was adopted by Guyatt and his colleagues¹⁰⁻¹², in their development of quality of life scales for people with

bowel disorders, respiratory disease and heart disease. With their scales, respondents are asked to list activities that are affected by their condition, and then specify which are the most important in their day to day lives.

The study

The research presented here aimed to begin to build up a theoretically useful body of knowledge, based on population norms, for use in health services research on health related quality of life (ie in the evaluation of health outcomes of treatments). In particular, the research aimed to address the following question: are we measuring all of the relevant life domains in health related quality of life scales?

Aims and methods

The aims of the research were to provide population norms on the dimensions of life that people perceive to be important, in relation to quality of life and health related quality of life, through a national survey based on a large random sample of 2,000 members of the public in Great Britain taken by the Office of Population Censuses and Surveys (OPCS) for their Omnibus Survey. The OPCS Omnibus Survey is a monthly survey of a target 2,000 randomly selected people (using postcode sectors and addresses) in Great Britain. It offers the opportunity for other researchers to buy into the survey with their own questions. The response rate was 77% (2031). The details of the methodology have been described in Bowling¹³.

Questionnaire design

Given the lack of agreement about the components and definition of quality of life, the approach taken in this research was hermeneutic, and the aim was to ask respondents themselves

simply about what was important in their lives (positive and negative domains). Respondents could mention as many items as they wished, but only up to five were coded. Respondents selected the code from a showcard to represent the items mentioned, and both their free responses (which were compared with their coded responses by the researcher, to check consistency) and selected codes were recorded. The items on the showcard were chosen after analysis of the items mentioned by O'Boyle et al's respondents, and responses to other surveys of quality of life. Items which did not fit the pre-codes were listed and coded by the interviewers under *other*; these were analysed by the researcher and an extension to the coding frame was designed to enable the *other* codes to be re-coded later by OPCS coders. Respondents were then asked to place the items mentioned in rank order of importance. Both respondents' selected codes of life areas, and their free responses (which were later coded back in the office) were analysed and compared. Then subjects were asked to rate their current status for each item mentioned against a categorical scale, labelled at each extremity *as good as could possibly be* and *as bad as could possibly be*. Respondents were then asked to rate their overall life on a similarly labelled categorical scale. Respondents who reported any limiting longstanding illness, disability or infirmity were next also asked to define and rate the most important effects of this on their lives using the same techniques.

Results

The characteristics of respondents were similar to the characteristics of respondents to the OPCS General Household Survey.

The most important things in life in priority order

Respondents were most likely to prioritise relationships with either family or relatives as the first most important thing in their lives (31%), followed by their own health (23%) and the health of

another person (close other/dependent other) (20%), and finances/standard of living/housing (10%). In relation to the second, third and fourth most important things in their lives, respondents were most likely to select finances/standard of living/housing (selected by between 25-29%), and social life/leisure activities was most likely to be selected as the fifth most important item (20%). When the replies coded as *other* were analysed, this showed that the largest new category created was *happiness/satisfaction/wellbeing*, which was chosen by just <1-2% of respondents as the five priority choices. Other areas mentioned by smaller proportions of people included politics (national, as well as local government politics) and crime, and pets (eg cat, dog, horse).

All most frequently mentioned areas of life (ranks 1-5 combined)

The most frequently mentioned things, across priority ranks, were finances/standard of living/housing (60%), followed by relationships with family or relatives (54%), own health (43%), health of other people (close) (35%), and social life/leisure (20%).

In relation to the frequency with which things were mentioned, males were more likely to mention finances/standard of living/housing as the most frequent thing, followed by relationships with family or relatives, and women were more likely to mention relationships with family or relatives as the most frequent thing, followed by finances/standard of living/housing. Finances/standard of living/housing were most frequently mentioned by respondents aged under 54, followed by relationships with family or relatives, and own health was more likely to be the most frequently mentioned item by respondents aged 55 and over (and, in particular, by those aged 65 and over), followed by relationships with family or relatives.

Health status and longstanding illness conditions

Respondents were asked the standard OPCS question: *Do you have any longstanding illness, disability or infirmity? By longstanding*

I mean anything that has troubled you over a period of time or that is likely to affect you over a period of time? Respondents who said yes were asked what the condition was (and later about the condition that had most affected their life as a whole, over the last 12 months, if more than one was reported), and whether it limits your activities in any way? A relatively high proportion, 40%, reported a longstanding illness, disability or infirmity, and 60% of these reported that it limited their activities in some way. The proportion who reported a longstanding illness was similar to the proportions reported in the 1991 and 1992 OPCS Health Survey.

First most important area affected by longstanding illness condition, and all areas mentioned as important

The most commonly freely mentioned *first* most important effects of the longstanding illness on their lives were (in order of frequency) *ability to get out and about/stand/walk/ go out shopping* (mentioned as first most important by 25%), *being able to work/find a job* (14%) and *effects on social life/leisure activities* (13%), and *physical effects and symptoms* (9%).

When respondents selected codes from a *showcard* in relation to health effects, however (prior to the office recoding), there were some discrepancies with their (office coded) verbatim replies. The *showcard* apparently had the effect of prompting them to code areas of life that they had not previously mentioned to the interviewer. Consequently, the most commonly mentioned *first* most important effects of the longstanding illness on their lives (when coded from the *showcard* by respondents) were (in order of frequency) *pain* (20%), *tiredness/lack of energy/ lethargy* (16%), *social life/leisure activities* (14%), and *availability of work/ability to work* (10%).

When priority ranks 1-5 are combined, the most frequently mentioned (free responses) area of life affected was *ability to get out and about/stand/walk/go out shopping* (36%), followed by *social life/leisure activities* (28%), *availability of work/ability to work* (19%), *other specific physical effects/symptoms* (these included, having to carry tablets around, being out of breath, embarrassment of scars, bladder control affected by

medication) (18%), *ability to do housework/clean home/carry shopping/gardening/other similar activities* (13%), *depression/worry/anxiety/unhappiness* (12%), and *other restrictions on activities* (these included *swimming, football, other sports, dancing, playing with/carrying children, driving, reading and playing with pets*) (11%). Other areas were mentioned by between 1 and 7% of respondents (full tables available from the author).

Thus, different methods of analysis and different methods of recording respondents' choices can produce slightly different results, illustrating the complexity of this area and cautioning against reported content validity on existing health related quality of life measurement scales. Further analyses reported elsewhere illustrate that different medical conditions affected lives in quite different ways, as would be expected (Bowling, in press), and several domains mentioned by respondents were absent in most generic scales. These findings lend support to the development of disease specific health related quality of life measurement scales, rather than reliance on generic scales.

Conclusions

The research presented here highlights the need for more sensitive measurement of health related quality of life, and also supports the current trend to develop disease specific health related quality of life questionnaires, rather than use generic scales. It is common for investigators to use traditional health status measurement scales to measure health related quality of life, on the basis of the usually unquestioned assumption that the concepts are interchangeable. The construct validity of scales is called into question by this interchange. None of the health status scales have been rigorously assessed for their content validity as measures of health related quality of life, and none are based on the public's (healthy or unhealthy) definitions of the important areas of measurement in relation to health related quality of life. Most scales were developed on the basis of reviews of existing scales, or surveys of the public's perceptions of the effects of illness

on behaviour or functioning. The public, and specific groups of patients, are the best judges of how medical conditions adversely affect their quality of lives. However, the relevant dimensions of health related quality of life which should be included in measurement scales is still the subject of vigorous debate and disagreement, partly because few scales have been developed and rigorously tested using sufficiently large enough samples of people¹⁴⁻¹⁵.

Attention is now being paid to disease specific measures of quality of life, which attempt to tap domains that are relevant to people with specific conditions. Generic scales can be criticised for containing items that may be irrelevant to people with the condition under study, and for omitting others that are pertinent. Few disease specific or generic instruments have been based on a model of quality of life, few scale developers have attempted to define this concept, and few have been adequately patient based in their development, with most being based on health professionals' and scale developers' perceptions of the relevant domains for inclusion.

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