

**Origins of the concept of quality of life in health care:
a rhetorical solution to a political problem**

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Abstract:

The concept of quality of life emerged in the 1970s as an important new outcome for health care. This paper identifies three independent arenas in which quality of life served as a powerful rhetorical device which was invoked for ‘solving’ major social and medical problems and dilemmas. In the following years, practical quality of life tools were increasingly developed but, it is argued, the perceived value of measuring quality of life was created and sustained by its role as a ‘rhetorical solution’ to an independent set of policy problems.

Over the last two decades the measurement of health-related quality of life has had a major impact on the evaluation of health care and medical interventions. Papers concerned with quality of life measurement are now accumulating in Medline at the rate of over 5000 every year as new measures are tested and refined and old ones applied to more and more clinical situations. The main justification for this widespread use of quality of life measurement is that it gives a much needed voice to the patient's perspective in the face of the traditional dominance of 'biological' and medico-centric outcomes in health care (Bowling 2001; Garratt et al 2002). Yet curiously the origins of quality of life measurement in medicine do not lie with health researchers searching for new and better ways of incorporating the patient's perspective into evaluation research but rather a wider political agenda concerned with more general societal problems. The question addressed by this paper is how the idea of quality of life managed to achieve a form of stability during the 1970s independent of the measurement process. Using contemporary socio-medical literature, this paper identifies several different 'socio-medical' problems of the 1970s and earlier for which the concept of 'quality of life' - whatever it meant - provided the common point of reference.

1 Dilemmas of social progress

During the second half of the 20th century social scientists began to explore the use of 'social indicators' as means of measuring social change. New health care and social welfare programmes promised a 'Great Society' and social indicators such as educational attainment, housing completions, health care use, crime, etc, (Gitter and Mostofsky 1973; Andrews and Withey 1976) enabled the monitoring of progress towards this goal. This vision of social achievement, however, was accompanied by parallel concerns with social crisis. Despite

economic improvements, there also appeared to be an increase in crime, drug use and fragmented families, in sum, a 'rise in social and public alienation' (Campbell 1976:117). An editorial in the Journal of the American Osteopathic Association described the mood of social malaise in terms of 'a growing despair across the nation ...' (Editorial 1970: 13) as past social referents seemed to be disappearing and a new crude materialism emerging.

In examining 'the picture of impending crisis', Watts (1970: 55) claimed that the fundamental problem was the two-edged sword of 'technology' that was responsible both for 'the quality of life which is now becoming possible, but also for the population growth and environmental pollution which make this quality of life and living quite impossible' (1970: 55). Over –population and pollution provided the two key points of articulation for the new socio-medical critique. For some medical commentators such as Flowers (1970) the solution to the first problem was a quasi-eugenic policy of eliminating unwanted pregnancies and the liberal use of sterilization that would lead to an improved quality of life. This eugenic theme was echoed by Abrams, Daugherty, Abrams et al (1971) who viewed the national situation as 'serious' due to the effects of poverty on 'prenatal and paranatal abnormalities, low birth-weight babies, increased infections, neurologic deficits, apathy, emotional immaturity, lack of self-esteem, negative self-image, reduced social mobility, identity confusion, high infant mortality, (and) environmental and cultural deprivation' (1971: 412). Again the solution was seen as massive political programs to improve 'the quality of life'. Improved quality of life was therefore the goal of the liberal abortionist (Lebensohn 1972) but it was also the aspiration of those such as Cardinal Cooke who used quality of life as a justification for supporting the dignity and right to life (Cooke 1972).

Environmental pollution and over-population were only tangentially related to clinical work but this did not prevent the wider goals of health care from being enmeshed in these debates. More directly, health education provided a forum for the engagement of medicine with quality of life as the ultimate measure through which real progress could be assessed. Instead of specific health goals, health education re-oriented itself towards a 'better' society in which high quality of life could flourish (McKay 1972). In effect, health education sought an alliance with political action that would make quality of life an ideological position that stressed the importance of quality over quantity (Galli 1976). Quality of life implied choice and individual responsibility for health as well as new skills and roles for health educators (Dallas 1972).

In summary, quality of life provided a concept that could mediate between ideas of social progress and those of social and moral crisis. Social change could be construed as a force for good or ill but it was appeals to the importance of quality of life that underpinned the debate. In part, it was the very vagueness of quality of life that allowed it to be invoked as a common goal often across very different political programs; in part it offered an apparently agreed criteria by which progress or decline could be determined. A better quality of life therefore became the common measures of social optimists and pessimists, a consensus criterion on which this wider political debate could be usefully articulated.

2 The outcome of technological success

According to le Fanu (1999), the 1950s and 1960s witnessed a remarkable explosion in medical advances such as renal dialysis, renal transplantation, new forms of cancer therapy

and intensive care for neonates. Artificial kidneys, for example, were developed and were in general use by the early 1970s with dramatic effects for patients with renal failure. Whereas before they simply died, now they could survive with regular hospital visits to remove blood impurities artificially.

Yet mirroring the wider debates about social change, medicine too began to recognize disadvantages in apparent technological successes. New technology-based treatments were ‘two-edged weapons’ (Elkinton 1966: 711). Gruenberg (1977) described their negative consequences as ‘failures of success’, pointing to the many health problems, particularly disabilities and chronic diseases, that medical technological triumphs left in their wake. There was, he thought, a need to recognize that ‘our life saving technology of the past four decades has outstripped our health preserving technology and that the net effect has been to worsen people’s health’ (p.22). In particular, it was in the earlier ‘experimental’ years of a technology’s development that many patients paid a heavy price for their enhanced survival.

There were a number of specific areas of technological ‘advance’ that drew the attention of critics, perhaps the most significant of which was renal dialysis. It was soon realized that renal dialysis for children may sustain life but ‘only at considerable sacrifice to the quality of life’ (Crawford 1971). In a review of the brief history of renal dialysis, Kolodner, McCuan and Levenson (1976) concluded that ‘medical advancements have outstripped the ability of the treatment team to insure the quality of life for these long-term patients’ (p. 32); the choice was either ‘To live for the benefits of treatment or to live with the benefits of treatment’ (p.33). When Beard (1971) described the case histories of five patients before and after their renal transplantation he found only two achieved an ‘acceptable level of

quality of life' while the others were plagued by 'fear-ridden, limited, unfulfilling' lives (1971: 30).

The second area of technological 'success' that elicited criticism was survival of congenitally malformed infants. In a review of the history of management of myelomeningocele, Lorber (1975) identified a phase from the late 1950s to the early 1970s characterized by the aggressive treatment of most children. But the results of this policy, he concluded, were deaths and severe physical and mental handicap. Would the results have been worse with no treatment?, he asked.

Then there were the costs of cancer treatment. New treatment agents had emerged in the years after World War II but, as Dempster, Balson and Whalen (1976) noted, the cost of the gains from chemotherapy for malignancies over the previous decade as 'a heavy price in terms of physical discomfort, significant risks of sometimes irreversible or even fatal physiological changes, and long periods of semi-hospitalization' (p. 1). Equally in reviewing progress in the treatment of childhood leukemia, a BMJ editorial could point to the price in terms of the child's growth and development (Editorial 1978).

The notion of quality of life gradually emerged as a counterpoint to the dream of a technological future, an accepted currency in which to express the human costs of technological interventions. Longer survival had to be tempered against the costs for patients' well-being of developing and using the new technology. In cancer rehabilitation it should not just be eradication of the disease but 'quality survival' (Mayer 1975); in surgery it was relatively easy to keep the patient alive, especially on the operating room table but the

real goal was to improve the life of the patient (Dent 1975); in cardiology, the success of a pacemaker implant was not to be assessed through years of survival but through improved quality of life following the patient's restored independence (Amikan, Lemer Roguin et al 1976).

A sub-set of the 'technological success but human cost' debate of the early 1970s was a parallel exploration of the ethical position with regard extending the quantity of life at the expense of the quality of that life. In Brody's 1976 summary of the key issues in medical ethics, quality of life joined the doctor-patient relationship, informed consent and the right to participate in decision-making. This meant that better quality of life became not only a treatment benefit but an ethical one too. It was, for example, an ethical benefit in the selective treatment of spina bifida (Working Party Report 1975; Jonsen and Garland 1975). And at the end of life, debates on euthanasia were framed by discussion of quality of life issues whether in arguing that medicine had placed too much emphasis on quantity and not enough on quality (Nicholson 1975) or in the place of the cognitive, sapient state as the basis for quality of life as in the celebrated Quinlan case (Editorial 1976).

For a variety of clinical situations, then, quality of life provided the foundation for an ethical perspective that was rapidly gaining a strong position in the evaluation of clinical care. A moral medical position became one that attended to the patient's quality of life (Keyserlingk 1979) whether it was in life and death decisions for the neurologically impaired (Beresford 1978) or in ethical actions to lower infant mortality (Chinn 1979).

In summary, ambivalence towards technological progress provided the crucible for

quality of life to be forged. Simple survival data were no longer enough (Jones, Breckman and Hendry 1980). The stage was set for quality of life to extend its remit, from tempering medical enthusiasm for achieving good survival to arbitrating between different technological solutions whether it was renal dialysis against transplant (Kaplan et al 1980), or the value of ileostomy or ileal anastomosis for ulcerative colitis (Jones, Bevan and Hawley 1978). Quality of life moved towards being the new common currency of medical outcome that would allow more meaningful comparison of surgical rates (Bunker 1973) or the explanation of medical care variation (Martini, Allan, Davison et al 1977).

The very need to reaffirm the more traditional measures of clinical success ('subjective responses should not be allowed to replace the objective criteria such as tumor regression and improvement in body metabolism' (Patterson 1975:281)) demonstrated the challenge of this new outcome criterion. Quality of life filled a void created by the perceived narrow successes of high technology medicine. A better quality of life, moreover, became both a legitimate clinical goal and an ethical right. Clinicians might still not have known exactly how to measure quality of life but its introduction into medical discourse allowed a new more patient-centered emphasis to develop in clinical practice to set against the dubious successes of technological medicine.

3 Chronic illness and the quality of care

During the second half of the 20th century the number of patients with chronic illness rose sharply, in part as a consequence of medical 'success'. Patients who might have died survived but with serious disabilities and those with serious disabilities had lengthening life

spans. In addition, the numbers of elderly in the population was increasing, as a result of both medical intervention and fertility patterns earlier in the century. For patients with chronic illness and the health problems that accompanied aging survival was a poor measure of medical achievement. The alternative was quality of life that could provide a new goal for a range of patients' problems for which biological criteria, in particular mortality, were inappropriate. From the impact of new housing (Carp 1975), through the effect on patients' lives of cystic fibrosis (Shwachman, Kowalski and Khaw 1977) or spina bifida (Zachary 1977), to care of the elderly (Chisholm 1977), quality of life provided a key index of success. Not only had medicine a major part to play in the emergence of these problems, it also had major responsibilities for its solution given that, particularly for the elderly, quality of life was increasingly dominated by health related issues (Elwood 1972). As Polliack and Bialik (1975) observed: 'Modern medical care has lengthened life expectancy and encouraged the 'survival of the unfittest', and it is only by accepting the challenge that we can hope to achieve the scope and quality of medical care that our society should provide for the elderly' (p.2196).

Quality of life also provided a solution to a related problem, namely how to assess the quality of care given to those patients, especially the elderly, for whom traditional goals such as cure were mostly inappropriate (Bavin 1970). Callahan, the assistant editor of Nursing Outlook pointed to the success of modern medicine in improving life expectancy but its failure to engage with making those extra years 'satisfying' (1970: 19). This was a particular problem for older people in institutional care; indeed, at the time there were nine Congressional panels investigating the quality of care in nursing homes.

Health care providers looked to the new quality of life paradigm to inform their approaches. In the US, the Veteran's Administration set up a committee to see how health care could be enhanced by addressing the goal of quality of life (Engquist, David and Bryce 1979). For many elderly an institutional living often imposed a 'foreign lifestyle' that had to be ameliorated by improving functional health and thereby enhancing quality of life (Wolk 1975). Attention to quality of life meant providing mobility aids for paraplegic children to increase their self-esteem as well as participation in group activities with greater independence (Letts, Fulford, End et al 1976). A goal of quality of life stressed independence and autonomy (Dresen 1978) and the management of mental impairment (Gunn 1977). Rudd (1974) advocated organizational changes such as educational initiatives, lessening of pressure from routine ward duties and improvements in buildings as means of improving quality of life in hospitals. Barney (1974) thought that opening up nursing homes to outside 'visits' would ensure good quality of care and correspondingly good quality of life for patients.

Quality of life also provided the evaluative framework for the rehabilitation programs (Abrahams, Wallach and Divens 1979) that were emerging to replace the traditional logic of 'cure'. The quality of life of handicapped people could be enhanced through a programs of rehabilitation that could bring 'more beauty into (their) lives' (Jackson and Engstrom 1971); quality of life could be assessed over time for those undergoing rehabilitation for spinal cord injuries (Crewe 1980) and it could be used as a yardstick of recovery from brain damage (Newcombe et al 1980).

Although the demand for improvement to patients' quality of life emerged out of the problems of targeting care on those receiving long term support it can be read as a response

to yet another crisis, this time one located in the health care (particularly nursing) arena. Thus, like the social and ecological crises of the world in general, a more focused problem in health care elicited the same response: quality of life provided the goal and point of articulation, the common currency, through which these various problems could be dissected and a way forward secured.

Discussion

From the advent of ‘modern medicine’ in the late eighteenth century clinical outcomes have been expressed through medically defined criteria, the most important of which was death. In addition, physiological measures such as temperature, swelling, tenderness, etc, dominated attempts to assess recovery and, when the laboratory added its more precise assessments of the ‘milieu interieur’ from the late 19th century, medicine came to rely even more on biological assessments of health status. During the late 20th century, however, a new measure of the success of medical intervention emerged. ‘Health-related quality of life’, and related subjective health measures, began to be recognized as legitimate outcome assessment tools for health care during the final decades of the twentieth century and by the new millennium had become a standard means of health care evaluation.

The field of quality of life measurement is characterized by broad agreement on the importance of the concept as an evaluative criteria for medical intervention, though unlike the formalization and consensus around much biological measurement in medicine, the operationalization of quality of life remains contested as illustrated by the existence of several hundred different instruments (Garratt et al 2002). This is a curious pattern; more

usually it is agreement on measurement that ‘stabilizes’ a concept. Without such stabilization the utility of a concept can easily be called into question and, moreover, different ways of operationalizing the concept can fragment the field, possibly leading to more stable ‘sub-concepts’ as agreement on instrumentation emerges. Yet despite being a contested field for over three decades, quality of life remains an important and essentially unitary concept. The reason for this, as argued above, is that the concept of quality of life underpins a series of major socio-political debates of the last few decades.

The idea of quality of life emerged as part of the ‘solution’ to the debates about social progress and social crisis that beset the 1960s and 1970s. Despite the various social and political positions taken in these arguments, all were agreed that quality of life was the goal and potential arbiter of the debate. Was social progress being made? Were crises such as pollution and over-population having the dire effects that their critics argued? Quality of life, seemingly, could provide the answer.

Equally, quality of life provided the over-arching framework for examining the conflicts inherent in medical technological progress. A new drug, a new machine, a new service, might provide improvements for the biological patient but what was the human cost? The concept of quality of life took the debate out of the technological arena and into the social. Alongside the ‘ethical’ treatment based on moral philosophy, the criterion of quality of life enabled success and failure to be grounded in one important measure, albeit one that had yet to be properly operationalized.

And finally, quality of life provided the point of articulation for the goals of health

care when ‘cure’ was unrealistic (as in the problems of the aged and in chronic illness).

Improved quality of life could provide the goal of health care whatever the age, incapacity or illness of the individual patient and at the same time better quality of life offered a potential new measure of medical success. So again, the concept of quality of life provided an important ‘solution’ to a vexing medical problem.

In summary, three independent debates in the 1970s discovered the concept of quality of life as their common ground or point of articulation. At the level of rhetoric, quality of life allowed these debates to be settled; the progressive could agree with the doom-monger, the technologist with the humanist, the common good could be reconciled with unintentional social harms. Quality of life at once defined the limits of technological excess and provided the counterpoint to medical success. Quality of life asserted the very meaning of life against the non-human forces that social change had unleashed.

Some of these three key 1970s’ debates have since become more muted but others, such as the use of quality of life as the key referent for judging medical success (especially in clinical trials) has continued. Quality of life has now, of course, become empirically grounded in standardized instruments that try and capture the true voice of the patient but this emphasis on quality of life as the definitive patient-assessed outcome suggests that it is the need to hear the patient that underpins the rise of quality of life as a vital medical measuring tool. But, eliciting patients’ views is only one – and a more recent – way of thinking about quality of life and one that equates its measurement procedures with its purpose. The alternative is to see the concept as being grounded in an important socio-political rhetoric that enables an appeal to quality of life as the arbiter of medical goals and clinical success. It is

this rhetorical function that continues to underpin the significance of quality of life and it is this historical position that has made the concept an essential part of medical thought and health policy in the early twenty-first century.

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