Debate

Quality of life — a response to K C Calman

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Author's abstract

There is no technical language with which to speak of patients' quality of life, there are no standard measures and no authority to validate criteria of measurement. It is well known that 'professionals' tend, often for institutional reasons, to play down or undervalue factors which are not defined by their particular expertise. It is fortunate that, despite this tendency, there is a growing interest in broadening the evaluation of medical care, but there is still a need to clarify what is at issue in considerations of quality of life. This article examines the strengths and weaknesses of one approach to assessing quality of life, and sketches out the implications for anyone concerned to establish a framework within which both medical and non-medical objectives of care can be taken into account.

Part One – Calman's hypothesis

In a recent issue of this journal Professor Calman seeks to 'stimulate discussion in the theoretical basis of measuring and defining quality of life' (1), and proposes a definition, and a measure, of quality of life which relates to the gap between an individual's aspirations and actual experience. 'A good quality of life can be said to be present when the hopes of an individual are matched and fulfilled by experience'. This topic is so vast, and the specific objectives are so challenging that these comments can only be regarded as a limited and tentative response.

MORAL AND PRACTICAL IMPORTANCE

The evaluation of quality of life is one issue with immediate practical consequences for medical ethics. Firstly, the evaluation of quality of life is necessary to illuminate the real efficacy of treatments, because it declares the importance of a broader range of criteria than mere survival rates, or physical side-effects. Secondly it enables a continuing re-assessment of the nature and scope of appropriate treatment or rehabilitation. It would simply be a mistake to believe

that the medical community were unaware of the psychosocial factors in their choice of treatment and care of patients. It would be impossible to provide care and not be aware of these factors. However there is, in certain circumstances, a need for (A) a more systematic reminder of, and guide to, the consideration of factors relating to quality of life, and (B) a means of taking these factors into account when making comparative policy judgements about alternative methods of treatment.

This is why Calman's clear and bold 'opening' hypothesis is of such value. However, it seems to me that his comments have a number of shortcomings which derive from the sheer range and complexity of his aims. His account is particularly useful only in connection with objective (A), and has features which seem to make it particularly unsuitable for meeting objective (B).

DEFINING, MEASURING OR MODELLING

It is important to distinguish between giving a definition of something and devising a method for measuring or assessing it. To take an extreme case we can all 'measure' time without being able to give an account of it. The case of quality of life is less mysterious; we have some intuitive sense of what it means and many people could attempt a characterisation of it using terms like 'contentment', 'fulfilment' and 'flourishing'. It is alongside these involved accounts, rather than a simple definition, that we judge the reasonableness and reliability of a hypothetical 'measure'. Otherwise we are in danger of adopting a stipulated meaning, and a narrow yardstick. There are two pitfalls for social research measures – either producing a rich model which is too complicated to employ, or producing a clearly defined set of criteria which is practicable but which fails to capture that which it was designed for. It is better to be clear at the outset about the extent to which we are trying to measure X, and the extent to which we are assessing conditions for, or indicators and components of X.

I would propose that in this instance the realistic objective is to try and formulate valuable and practical indicators and components of 'quality of life', and that this is what Calman undertakes in his paper. His

Key words

Quality of life; patient care.

formulation is to regard quality of life in terms of the 'potential for improvement' perceived as desirable by the individual; where improvement might refer to intellectual or emotional growth as well as to increases in comfort, physical capacity or skills. The greater the desired improvement the lower the quality of life, and vice-versa. Roughly speaking it equates quality of life with the degree to which an individual is satisfied with his or her lot, or with the range of what welfare theorists call 'felt needs'. The strength of this formulation is that it directs attention to the scope for enhancing the patient's quality of life. Its principal weakness, at least in its explicit statement, is that it is too subjective to be of value in making any comparative judgements.

SUBJECTIVITY VERSUS OBJECTIVITY

Calman states that quality of life 'can only be assessed and described by the individual', and he repeatedly emphasises the importance of the assessment being derived from the patient's perspective. This seems to be right, it takes account of the fact that quality of life is judged to vary between individuals in equivalent objective circumstances, and the dangers of imposing an assessment either from a different value perspective, or from what is inevitably a position of relative ignorance. However, it is possible to overstate this subjectivism. If we depend upon Calman's stark definition alone then it is possible for people's quality of life to diminish even whilst they are continually extending and achieving their aims in life, simply by them setting increasingly ambitious goals. Similarly someone whose mental and physical capacities were utilised to a high degree could be judged to have a lower quality of life than an individual with restricted experience and even more confined ambitions. To the degree that these examples are counter-intuitive, they indicate that there is also an objective dimension to quality of life. This dimension is implicitly acknowledged by Calman's condition that the individual's 'goals must be realistic', and by his statement that 'The patient is encouraged to develop appropriate goals'.

Calman uses a number of similar terms to convey the area of improvement (for example 'hopes', 'ambitions', 'goals') but he also uses the expression 'patient needs'. This concept of need, together with the recognition that an individual's aspirations can be inappropriate, highlights the objective dimension of quality of life. In contrast to the simple appearance of his definition, on Calman's full account the scope for improvement is a matter of 'negotiation' between the individual and the caring team. Thus his measure of the quality of life is necessarily indeterminate. When Calman says that 'discussion with the patient is the only way to assess patient needs', he is surely right, but this does not imply that the patient is the only source from which needs can be properly identified. His other comments point to the role of the caring team using their experience to assess and anticipate needs which

may be hidden from the patient's perspective. Here there is clearly the possibility of a counselling or educational role for health professionals, faced by individuals who in certain situations of stress, trauma, or specific ignorance may be unable to recognise the realistic challenges and limitations which face them.

OTHER PROBLEMS

There are two other weaknesses with Calman's definition of quality of life. Firstly it emphasises purely individual goals: 'It must be related to individual aims and goals'. Again this may simply be a feature of its explicit formulation. However, both an individual's hopes and his or her quality of life are tied up with factors which do not constitute 'goals' for that individual. A broad range of factors from social circumstances and support to the economic context, the possibility of war, or the climate are not irrelevant to quality of life, however subjectivist or objectivist our theory.

The second, more crucial, weakness is manifest in Calman's example of the terminally ill: 'In terminally ill patients for example it may be unrealistic in some patients to continue to pretend that things will improve. For others the denial of this may be critical in maintaining the quality of life'. But this is to admit that the size of the perceived gap between aspirations and experience is not in itself a measure of the quality of life. For certain patients, indeed for many individuals, the existence of a wide gap may be an intrinsic part of a higher quality of life. Furthermore the extent to which this gap is regarded as a component of a good quality of life varies from case to case. Some of us are only 'satisfied' by having aspirations which are not satisfied, and some of us more than others.

THE LESSONS OF CALMAN'S HYPOTHESIS

These weaknesses of formulation all stem from Calman's desire to develop 'a pragmatic approach to the definition of quality of life', which is 'task-oriented', in which 'measurement and action need to be linked'. This is an approach geared to improving care: responding to the concerns of patients and being self-conscious about the extent to which the caring team can, and is, meeting these concerns. In this sense an attempt to assess quality of life involves seeing patients as autonomous persons, and as individuals, and is therefore of fundamental moral significance. Yet at the same time Calman's emphasis on the individual, and his or her 'felt needs', gives assessments which are too subjective either to be regarded as a measure of the quality of life, or to provide a sufficient means of making important comparative judgements. Both the analysis of our uses of 'quality of life', and Calman's actual exposition, make it clear that there is a place for looking at more 'objective' indicators or components of quality of life. 'Objective' carries a number of

connotations here, including those characteristics which may lie outside the patient's perspective, those characteristics which lie outside the patient's volition, and those characteristics which are most generalisable.

Part Two – The conditions for reasonable assessment

In outline I would suggest that a 'measure' of the quality of life should: (a) acknowledge the broad range of relevant criteria, (b) be recognised, and stated, as providing assessments or indicators only, (c) be designed for specific purposes (ie why do we want to know?), (d) be adaptable to the subjects under investigation and their circumstances.

DIMENSIONS OF INTEREST

In working towards a more comprehensive picture of assessing quality of life it is essential to achieve a balance between taking account of the individual's potential and problems, and more common or characteristic problems. Equally essential is a balance between relying upon the client's subjective perspective and voice (a phenomenological approach), and a more objective, formalised framework for analysis. These are two distinct dimensions and the caring or research community needs to use a standpoint which shifts along these two dimensions, and which settles in a certain place according to the goals being pursued. Insights drawn from these different perspectives complement and draw from one another; but we must be clear about the connection between the kind of interest we have in quality of life, and the appropriate manner of trying to assess it. Calman's interest, in life enhancement as part of care, makes his use of the 'aspirations-reality gap' a most appropriate indicator. Here it is vital not only to focus on the individual, but to concentrate on the individual voice, in general orientation and in detailed utterance. Complementary approaches are needed for other purposes, such as research into the effects of illness, disability or methods of treatment, where there may be value in using more generalisable or comparable indicators.

THE RANGE OF DETERMINANTS

There are many determinants of quality of life, and hence a broad range of possible indicators. I will discuss these briefly by looking at some points on a map which, roughly speaking, moves from the public to the personal. (i) 'Quality of lifestyle': the most public and generalisable determinants of quality of life relate to the patients' capacities and restrictions in their work, social and home life. This can also encompass such things as changes in social contacts, competences, hobbies or sleep problems. These factors are the most easily quantified and compared, but although they are

clearly relevant to quality of life, they are too blunt to provide good assessments in individual cases. (ii) 'Mental health': this can refer to unstructured subjective reports of changes in disposition, anxiety, aimlessness, irritability etc, the common-sense language of emotional well-being; or to the more standardised diagnostic procedures for illness or risk developed by psychological medicine. (iii) 'Sense of life': the only way fully to take into account the individual's perspective is to start from a phenomenological account of what an illness or treatment means to the patient, and the ways in which it transforms his or her sense of other aspects of life. Although comparison and quantification is possible here, (for example counting the use of certain key concepts or categories), its chief value is to uncover the complex web in which specific events and conditions are enmeshed – including the ways in which these events are interpreted through fears, beliefs and commitments from the most mundane to the most profound. No unqualified judgement of an individual's quality of life could be made without this level of analysis, but a fixed focus on it would obstruct comparative work.

MAKING COMPARISONS AND CHOICES

All judgements are ultimately comparative and we must not pretend that attempts to use more objective criteria as indicators are worthless. It is necessary to be modest in our claims for, and use of, such methods which will certainly be less penetrating with regard to the individual patient. In order to make these blunt assessments most reliable and useful they must be responsive to the circumstances. A range of specific criteria should be chosen according to the groups and issues under question, and like should be compared with like. For example in order to compare alternative treatments more generalisable criteria can be drawn from three sources: 1—Those aspects of life which are characteristically disrupted by the problem and which it is hoped the treatments will improve; 2—Those aspects of life which are characteristically but not wilfully affected by the treatments; and 3—Those areas of life about which patients tend to express concern, whether or not they are commonly affected. What is 'characteristic' has to be continuously defined, and the first-person reports of patients on their 'aspirations' will generate useful criteria.

At the policy or planning level there are very difficult choices to be made in which, for example, life prolongation, disfigurement, physical symptoms, and emotional risks may pull against one another, and somehow have to be balanced together. There is no sense in attaching a single kind of weighting to these incommensurable factors, yet it is surely better to be able systematically to take them into account. There are some relatively clear medical objectives which always will be considered, and it is a particular folly to over-value such things as survival or pain relief by

default. At the individual level the possibility of referring to some more general comparisons helps to inform specific deliberations about these choices.

MORAL RISKS

Is the systematic consideration of quality of life an unalloyed good? It can be used to recognise the autonomy of patients and their role in care, including their participation in making informed decisions about their own care. This is a way in which concern about quality of life can itself actually improve the quality of life. However, I want to draw attention to three kinds of risk.

Firstly, health professionals disagree about the degree to which it is broadly a good thing to involve certain patients in their choice of care. In situations where patients are often very frightened or withdrawn, or putting up a front, this proper caution must extend not only to choosing care, but also to pursuing certain kinds of discussion about quality of life.

Secondly, carefully made assessments of quality of life can only ever be an additional resource for, and never a replacement for, the making of practical interpretative judgements founded on experience. It is vital that this is seen clearly, and that we avoid any trap of mistaking a model for a full picture.

Thirdly, we should hesitate before helping to justify decisions about the distribution of health care resources according to 'measures' which are very imprecise. Above all the quality of a life must not be confused with the worth of a life, which is a completely separate consideration.

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References

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