Pergamon

European Journal of Cancer Vol. 32A, No. 5, pp. 753–754, 1996
Copyright © 1996 Elsevier Science Ltd. All rights reserved
Printed in Great Britain
0959–8049/96 $15.00+0.00

S0959-8049(96)00043-3

Editorial

Defining Quality of Life

S.R. Cohen,[1] B.M. Mount[1] and N. MacDonald[2]

[1]Division of Palliative Care, Department of Oncology, McGill University, Royal Victoria Hospital, Ross 6.10, 687 Pine Avenue West, Montreal, Quebec, Canada H3A 1A1; and [2]Center for Bioethics, Clinical Research Institute of Montreal, 110 Pine Avenue West, Montreal, Quebec, Canada H2W 1R7

People engage the health care system when they recognise that they have an illness and are suffering. Too often a patient's distress is then narrowly defined by the health care system and their illness is described in terms of the biology of disease. Treatment is solely aimed at eradicating or controlling the patient's disease while the associated suffering of the patient is ignored. The growing recognition of a need to redress this imbalance and refocus attention on the person who is suffering has led to a research field devoted to measuring quality of life. "Quality of life studies and measurements serve to prevent a devastating separation of a patient's body from a patient's biography during delivery of care" [1].

There is an increasing consensus that quality of life is a subjective evaluation rather than an objective reality and so can only be assessed with reliability by the person whose quality of life is being evaluated [2–5]. We have come to accept that pain is what the person says it is. So too, quality of life is what the individual experiences it to be. The subjective nature of quality of life is illustrated by the comment of an insightful participant in our ongoing study of the quality of life of women with advanced breast cancer undergoing experimental high dose chemotherapy. She indicated that her quality of life had greatly improved over the preceding week, explaining, "Nothing that is happening to me has improved. In fact, physically I am feeling worse. What is different *is how I am taking it*". Clearly, the subjective nature of quality of life means that it will vary greatly from person to person and even for a given individual over time in the same objective circumstances.

We define quality of life as subjective well-being. A single global question asking a person to rate his/her overall quality of life is perhaps the most valid measure, in that it most closely represents what that individual means by quality of life, but such a scale fails to identify the factors contributing to the assessment. To provide the best care possible, health care providers would need to know what contributed to the person's decision to rate his/her quality of life as high or low.

Unfortunately, many investigators claim to measure quality of life when they are in fact measuring something else, such as physical functioning. For example, in a 1990 *Lancet* article [6], the authors stress the importance of measuring quality of life when assessing the true benefit of anticancer therapy, and conclude that their treatment prolongs survival while maintaining a good quality of life. What was measured in assessing quality of life in this study, however, was performance status and the number of patient days of normal activity lost. No direct input from the patient was considered. We would suggest that the study did not assess quality of life at all. Others have chosen to measure 'health-related quality of life' using the definition of health in the preamble of the World Health Organisation constitution, rather than that of the patients whose quality of life is being measured [2, 5, 7, 8]. The World Health Organisation defines health as physical, psychological and social well-being [9]. People with a life-threatening illness, however, define health as a sense of personal integrity and wholeness [10] encompassing physical, mental/emotional and spiritual domains [11]. Cassel's comments regarding the suffering of persons [12, 13] are relevant to this latter definition of health.

> Our intactness as persons, our coherence and integrity, come not from intactness of the body, but from the wholeness of the web of relationships with self and others [12].
>
> Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner [13].
>
> Meaning and transcendence offer two additional ways by which the suffering associated with destruction of a part of personhood is ameliorated [14].

Existential concerns are of great importance to people with a life-threatening illness [11, 15–19] but this domain is not included in most quality of life measures. The existential domain includes concerns regarding death (existential obliteration); freedom (the absence of external structure); isolation (the unbridgeable gap separating self from all else); and the question of meaning (the dilemma of meaning-seeking creatures who recognise the possibility of a cosmos without

---

Correspondence to N. MacDonald.

Received 15 Jan. 1996; accepted 25 Jan. 1996.

meaning) [20]. If our quality of life measures are to account for important determinants of quality of life such as "how I am taking it", we will need to include measures relating to coping and existential well-being, which place the person's interpretation of his/her objective circumstances in the context of his/her world view. This is precisely what Salmon and colleagues begin to do with their Life Evaluation Questionnaire in their article published in this issue (pp. 755–760).

We believe [4, 21, 22] and others [23] concur that it is premature to conclude that we have a clear and complete working understanding of what constitutes quality of life. We need more studies, such as that of Salmon and colleagues, which ask those cared for to define the domains which need to be included in assessing their quality of life. Once the important domains are well-defined and we have established acceptable, valid and reliable means of measuring them, we must learn how to integrate the measures of these different domains so that we achieve an accurate representation of overall quality of life as experienced by the whole person. The resultant instruments must be practical, allowing ready application in clinics outside the research setting. There is challenging work ahead.

This does not mean that clinicians should refrain from using simple symptom control scales (which are not measuring quality of life but are important) and existing quality of life instruments, imperfect as they are, until this work is completed. Interpretation of quality of life results should, however, consider the limitations of current instruments. In fact, clinicians must work together with the researchers to further develop and refine quality of life instruments. It is only in the use of quality of life instruments that we come to appreciate their strengths and weaknesses.

---

1. Roy DJ. Measurement in the service of compassion. *J Palliat Care* 1992, **8**, 4.
2. Aaronson NK. Quality of life research in cancer clinical trials: a need for common rules and language. *Oncology* 1990, **4**, 59–66.
3. Campbell A. Subjective measures of well-being. *Am Psychol* 1976, **31**, 117–124.
4. Cohen SR, Mount B. Quality of life assessment in terminal illness: defining and measuring subjective well-being in the dying. *J Palliat Care* 1992, **8**, 40–45.
5. Guyatt GH, Feeny DH, Patrick DL. Measuring health-related quality of life. *Basic Sci Rev* 1993, **118**, 622–629.
6. Osband ME, Levin PT, Babayan RK, *et al.* Effect of autolymphocyte therapy on survival and quality of life in patients with metastatic renal cell carcinoma. *Lancet* 1990, **335**, 994–998.
7. Schipper H. Guidelines and caveats for quality of life measurement in clinical practice and research. *Oncology* 1990, **4**, 51–57.
8. Cella DF. Quality of life: concepts and definition. *J Pain Symptom Manage* 1994, **9**, 186–192.
9. World Health Organisation. Preamble of Constitution of the WHO. Geneva, World Health Organization, 1946.
10. Kagawa-Singer M. Redefining health: living with cancer. *Soc Sci Med* 1993, **37**, 295–304.
11. Fryback PB. Health for people with a terminal diagnosis. *Nurs Sci Q* 1993, **6**, 147–159.
12. Cassell EJ. *The Nature of Suffering and the Goals of Medicine.* New York, Oxford University Press, 1991, 40.
13. Cassell EJ. The nature of suffering and the goals of medicine. *N Engl J Med* 1982, **306**, 640.
14. Cassell J. The nature of suffering and the goals of medicine. *N Engl J Med* 1982, **306**, 644.
15. Belcher AE, Dettmore D, Holzemer SP. Spirituality and sense of well-being in persons with AIDS. *Holistic Nurs Practice* 1989, **3**, 16–25.
16. Ferrell B, Grant M, Schmidt GM, *et al.* The meaning of quality of life for bone marrow transplant survivors. Part 1. The impact of bone marrow transplant on quality of life. *Cancer Nurs* 1992, **15**, 153–160.
17. McCorkle R, Quint-Benoliel J. Symptom distress current concerns and mood disturbance after diagnosis of life-threatening disease. *Soc Sci Med* 1983, **17**, 431–438.
18. O'Connor AP, Wicker CA, Germino BB. Understanding the cancer patient's search for meaning. *Cancer Nurs* 1990, **13**, 167–175.
19. Reed PG. Spirituality and well-being in terminally ill hospitalized adults. *Res Nurs Health* 1987, **10**, 335–344.
20. Yalom ID. *Existential Psychotherapy.* New York, Basic Books, 1980.
21. Mount BM, Cohen SR. Quality of life in the face of life-threatening illness: what should we be measuring? *Curr Oncol* 1995, **2**, 121–125.
22. Cohen SR, Mount BM, Strobel MG, Bui F. The McGill Quality of Life Questionnaire: a measure of quality of life appropriate for people with advanced disease. A preliminary study of validity and acceptability. *Palliat Med* 1995, **9**, 207–219.
23. Gill TM, Feinstein AR. A critical appraisal of the quality of quality-of-life measurements. *JAMA* 1994, **272**, 619–631.

Acknowledgements—S.R. Cohen is a Research Fellow of the National Cancer Institute of Canada, supported with funds provided by the Canadian Cancer Society.