

10. The Elderly Patient and Quality of Life Judgements

Anthony Fiorini

Quality of life and the elderly.

How does one define quality of life in the elderly age group? Is it their health status; their functional status; whether they are still living in their own homes; their financial means, whether their favourite football team is winning? Since I have been asked to discuss patients, I'll stick to health.

Health-related quality of life - definitions.

There are definitions on health-related quality of life in the elderly. The ideal, or preferred definition, must reflect the multiple and inter-related dimensions that are characteristic features in health of the elderly. Functional, mental and social aspects commonly complicate the physical problems and all have to, and can, be objectively assessed and measured. At the same time, subjective parameters such as "morale", "self-esteem", "life-satisfaction", "dignity" "autonomy" also need to be addressed. Therefore, the formulation of a definition is not an easy task and threatens to be incomplete.

Also, once health is influenced by health care, quality of life is controlled by the quality of care given. Therefore, any measure of an individual's quality of life must take into consideration that individual's surroundings, i.e. whether the elderly person is living at home, or is in a hospital ward, or resides in a long-stay institution. For example, in a very recent article in the British Medical Journal, it was stated that the dignity and autonomy of older persons were being undermined in health care settings in the United Kingdom (1).

Health-related quality of life - a goal to aim for?

Health care professionals and learned societies agree, and recommend, that health-related quality of life is a goal to aim for.

For example, in 1994, and then in 1996, Roberts et al (2) (3) asked health care workers and managers to rank 14 separate measures in order of importance to reflect their goals and priorities, and hence their performance indicators, in providing care for the elderly. The results obtained indicated that geriatricians, general practitioners, nurse managers, physiotherapy and occupational therapy managers and even general managers all put “improving quality of life” in the number one slot.

Similarly, in 1992, the Royal College of Physicians of London together with the British Geriatrics Society (4), recommended that the assessment of all elderly patients should be standardised and, besides their medical problems, information should be routinely obtained, and documented, on such aspects as functional abilities, cognitive function, the presence of depression and their quality of life.

The Royal College of Physicians of London together with the British Geriatrics Society, also published in 1992 (5), and then again in 1998 (6), documents to “enhance the quality of health care of older people in long-term care that have an obvious link to quality of life”. In these documents the College recommended the routine assessment and measurement of twelve key factors amongst which were included such headings as “preserving autonomy”, “optimising the environment”, “overcoming disability”.

Health-related quality of life - assessment instruments.

A good number of assessment instruments now exist to gauge health-related quality of life in the elderly. The publications of the Royal College of Physicians and the British Geriatrics Society have already been mentioned. Besides these there are others and include:

The Comprehensive Assessment and Referral Evaluation (CARE); The Older Americans Research and Service Center Instrument (OARS); The Nottingham Health Profile; The Sickness Impact Profile; The Southampton Self-esteem Scale; The Life Satisfaction Index; The Philadelphia Geriatric Centre Morale Scale; The Bradburn Affect Balance scale; The Rosser Index of Disability and Distress (7); The Medical Outcomes Study SF 36 (8) and so on. All measure a range of parameters. For example the Medical Outcomes Study looks at physical functioning, role functioning, social functioning, mental health, general health perception and bodily pain.

Quality of life measures for specific diseases are also available, for example the Parkinson's Disease Quality of Life Questionnaire (9), which looks at symptoms, social and emotional functioning.

Health-related quality of life - positive attitudes.

Therefore tools are available to judge quality of life. Most are used for research purposes whilst others are recommended for routine everyday use. These quality of life assessments should be viewed as positive tools. They emphasise the fact that being elderly, although associated with the 'twilight years' does not mean 'end of life'. They also emphasise the fact that a lot can be done to improve problems that may effect the elderly. A sample of elderly people attending a Day Hospital in the United Kingdom were asked what they expected from

health care (1). In their replies they gave greatest importance to improving their quality of life and reducing disability.

And it is also relevant at this stage to remember that not treating on the basis of old age alone should be considered unacceptable, dare I say unethical, even as a mechanism to ration resources. For example, in 1992, it was noted that one fifth of coronary care units in the United Kingdom operated an age-related admission policy whilst two fifths operated an age-related thrombolysis policy (10). In other words, older age groups were being denied medical management known, and shown, to be of benefit to them, even life-saving. Such policies are worrying and have to be discarded.

Health-related quality of life - end of life decisions.

There are situations when a decision to withhold or withdraw treatment is the right one and there are guidelines to help reach such decisions.

The statement that “all patients who are competent to consent to life prolonging treatment are also competent to refuse it ” (11) is also relevant to the elderly. Their wishes have to be listened to. The statement that “all clinicians must act to enable incompetent patients to flourish as persons to the degree to which they are capable ” (11) is also without argument.

On the other hand there are situations where stopping or withholding treatment in incompetent elderly patients is acceptable and justified. Such situations include (11):

1. Imminent and irreversible closeness to death.
2. Extensive neurological damage leading to the permanent destruction of both self-awareness and intentional action.
3. Little self-awareness and severe motor disability.
4. Destruction of both long-term and short-term memory such that the person who used to exist, no longer exists.

5. Distressing and marginally effective life-saving treatment that leads to a demonstrably awful life.

These are guidelines and clinicians have to make decisions according to a range of personal beliefs. Decisions have to be made in consultation with relatives and with other members of the multidisciplinary health care team looking after the patient.

Health-related quality of life - the wish to die.

In general elderly people do not express a wish to die. For example in a study carried out in Australia (12), it was noted that only 2% of the elderly interviewed wished to die. In this study, depression, poor self-rated health, disability and living in residential care were considered to be important risk factors towards expressing a wish to die. It is important to remember that depression, which can lead to death wishes and suicidal thoughts, can respond to treatment even in elderly people.

Also, in a study published on “Active Euthanasia and Physician Assisted Suicide in Dutch Nursing Homes” (13), it was noted that the characteristics of the patients (86 cases) who were helped to die were different from the average elderly resident. The majority (65%) were male (whereas normal deaths showed a ratio of 37% males and 63% females). Their average age was 70 years (whereas the average age for residents was 80 years), 53% suffered from malignant disorders, and 21% suffered from either motor neurone disease or multiple sclerosis.

Therefore elderly people do not usually express a wish to die just because they are old.

Health-related quality of life - the situation in Malta.

As far as I am aware, there are no published studies on health-related quality of life research carried out on the elderly in Malta. However, a number of thesis, some at Masters level, are available to read and digest and contain information relevant to this talk.

For example, a study carried out on self-perceived health and health practising behaviour on a sample of Maltese older people found that community dwellers had positive attitudes about their health and were health conscious and associated health-related quality of life with self-care abilities in activities of daily living (14).

A recent study on long-stay residents at St. Vincent de Paule Complex has indicated that their quality of life, especially their dignity and autonomy, is being undermined and the reasons given for this situation included negative and abusive practices as well as staffing oriented issues (15).

The issue of inadequate staffing levels and their ramifications at St. Vincent de Paule Complex were also tackled by another author. In this thesis the author also asked staff members, which consisted primarily of nurses, about end of life decisions. A higher percentage were against the acceleration of the dying process by limiting or stopping medical intervention indicating that health care professionals in Malta remain reticent to withdraw or withhold treatment (16).

Conclusion

Tools to measure health-related quality of life, as well as guidelines on the withdrawal and withholding of treatment in end of life situations are available to guide decisions on the elderly. They should be used in Malta either as everyday

instruments or as research tools or both. The majority of elderly people have positive attitudes and want to improve, and expect us as health care professionals, to improve their health-related quality of life, not end it.

References:

1. Lothian K and Philp I, '*Maintaining the dignity and autonomy of older people in the health care setting*', BMJ 2001; 322: 668-70.
2. Roberts H, Sek Khee Teo and Philp I, '*Setting priorities for measures of performance for geriatric medical services*', Age and Ageing 1994; 23: 154-157.
3. Roberts H and Philp I, '*Prioritizing performance measures for geriatric medical services: what do the purchasers and providers think?*', Age and Ageing 1996; 25: 326-328.
4. *Standardised assessment scales for elderly people*, The Royal College of Physicians of London and The British Geriatrics Society, 1992.
5. *High quality long-term care for elderly people*, The Royal College of Physicians of London and The British Geriatrics Society, 1992.
6. *Enhancing the health of older people in long-term care*, The Royal College of Physicians of London and The British Geriatrics Society, 1998.
7. *Audit measures: quality of life instruments*, Fletcher AE, Dickinson EJ and Philp I, Age and Ageing 1992; 21: 142-150.
8. Gladman JRF: '*Assessing health status with the SF-36*', Age and Ageing 1998; 27:3.
9. Hobson P, Holden A and Meara J.: '*Measuring the impact of Parkinson's disease with the PDQL questionnaire*', Age and Ageing 1999; 28: 341-346.
10. Dudley NJ and Burns E: '*The influence of age on policies for admission and thrombolysis in coronary care units in the United Kingdom*', Age and Ageing 1992; 21: 95-98.
11. Doyal L and Wilsher D: '*Withholding and withdrawing life sustaining treatment from elderly people: towards formal guidelines*', BMJ 1994; 308: 1689-92.

12. Form AF, Henderson AS, Scott R, Korten AE, Christensen H and Mackinnon AJ: *'Factors associated with the wish to die in elderly people'*, Age and Ageing 1995; 24: 389-392.
13. Muller MT, Van der Wal G, Van Eijk TM and Ribbe MW, *'Active euthanasia and physician-assisted suicide in Dutch nursing homes: patients' characteristics'* Age and Ageing 1995; 24: 429-433.
14. Aquilina V: *'Perceptions of health and health promoting behaviours: the views of older community-dwelling adults'*, 1999, Thesis, University of Greenwich, UK.
15. Fenech MA: *'Abuse within a chronic care institutional setting for older persons in Malta'*, 2001, MA Thesis Gerontology and Geriatrics, University of Malta.
16. Tanti D,: *'Rights of the elderly: the situation at St. Vincent de Paule Residence'*, 1996, Thesis, Dip Ger, Institute of Gerontology, University of Malta.