Chapter 1.4.4: The impact of illness on quality of life

Intended Learning outcomes

1. To discuss the quality of life as a multidimensional, dynamic and subjective construct
2. To explain the demographic, clinical and psychosocial influences on perceptions of quality of life
3. To list the benefits and disadvantages of common methods of assessing quality of life
4. To Discuss the need to consider specific populations when developing measurement tools

Learning Questions:

1. What is quality of life as a multidimensional, dynamic and subjective construct?
2. How demographic, clinical and psychosocial influences on perceptions of quality of life?
3. What is the benefits and disadvantages of common methods of assessing quality of life?
4. What is the need to consider specific populations when developing measurement tools?

Illness is a dynamic process, beginning with perception of symptoms or a diagnosis and continuing or changing over time as a function of the disease pathology, treatment possibilities and the responses to illness by the person affected and those around them. The impact of illness on an individual’s emotional wellbeing and adjustment, on their global and health-related functioning – in other words, their quality of life (QoL).

While the primary goal of medicine and health care is to improve health and/or treat and cure illness and its symptoms, there is a need to address more global outcomes of health-care treatments and services, such as patient wellbeing. It is important to evaluate clinical outcomes such as symptom reduction and also the individual’s own perceptions of how the treatment or intervention has influenced their illness experience and their general psychosocial functioning. Having this fuller knowledge has implications for future care, treatment and service provision.
Furthermore, patients may derive great benefit from certain treatments or interventions in terms of enhanced quality of life, even though these same treatments or interventions may not extend survival or quantity of life.

In general terms, quality of life (QoL) can be referred to as an individual’s evaluation of their overall life experience at a given time (global quality of life), with the term ‘health-related QoL’ emerging to refer to evaluations of life experience and how they are affected by symptoms, disease, accidents or treatments. According to the World Health Organization Quality of Life (WHOQOL) working group (1993, 1994), QoL is a person’s perceptions of their position in life in relation to their cultural context and the value systems of that context in relation to their own goals, standards and expectations. Quality of life is considered to be a broad concept affected by an individual’s physical and mental health, level of independence, quality of social relationships, social integration and, added subsequently (WHOQOL 1998), their personal, religious and spiritual beliefs. This working group has produced a generic and cross-culturally valid assessment tool (WHOQOL-100), which addresses twenty-five different facets of QoL grouped into one of six domains:

1. **Physical health**: pain and discomfort; energy and fatigue; sleep and rest;

2. **Psychological**: positive feelings; self-esteem; thinking, memory, learning and concentration; bodily image and appearance; negative feelings;

3. **Level of independence**: activities of daily living (e.g. self-care); mobility; medication and treatment dependence; work capacity;

4. **Social relationships**: personal relationships; practical social support; sexual activity;

5. **Relation to environment**: physical safety and security; financial resources; home environment; availability and quality of health/social care; learning opportunities; leisure participation and opportunities; transport; physical environment;

6. **Spirituality, religion and personal beliefs**.

Rather than considering disease, disability and handicap as indicative of quality of life, they could therefore be considered as potential influences upon it, that may or may not affect a person’s perceived QoL, depending on the extent to which that individual rates them as important to that judgement. For some individuals, the inability to perform valued activities as a result of impairment or disability may be considered a ‘fate worse than death’; however, for others they will continue to find meaning and purpose in life in spite of disablement. In the spotlight (below) raises the question of whether the outcomes important to the person concerned are the same as the outcomes valued by the health profession or, in particular, health economists.
Many factors influence QoL:

1. Demographics: e.g. age, culture;
2. The condition itself: e.g. symptoms, presence or absence of pain, functional disability, neurological damage with associated motor, emotional or cognitive impairment, sensory or communicative impairment;
3. Treatment: e.g. its availability, nature, extent, toxicity, side-effects, etc.;
4. Psychosocial factors: e.g. emotions (anxiety, depression), coping, social context, goals and support.

Age and quality of life
While age has been shown to influence the aspects of life considered to be important to people the effect of age on QoL ratings is not inevitable. For example, age was not predictive of quality of life in a one-year longitudinal study of stroke survivors ranging from 32 to 90 years old, where other factors, such as physical disability, depressed mood and gender (females had poorer QoL) were (Carod-Artal et al. 2000).

Over half of the older people surveyed by Evandrou (2006) who had long-standing limiting illness self-rated their health as good or fairly good, highlighting the fact that quality of life is about more than just physical health and physical function. While a key global aim of interventions to enhance QoL, regardless of disease type, is the improvement and maintenance of physical and role functioning, in old age as at all ages QoL continues to be multidimensional. Even among the ‘oldest old’ (i.e. 85 or older), QoL encompasses psychological, social and environmental wellbeing (Grundy and Bowling 1999). issues (below) addresses the question of whether or not QoL is attainable at the end of life, as a result of either ageing or terminal illness.

Psychosocial influences on quality of life
Among physically healthy populations, the presence of anxiety symptoms or disorder has been associated with poor QoL (e.g. Mendlowicz and Stein 2001). Among those with physical illness, emotional responses have also been shown to impact upon quality of life. For example, both depression and anxiety symptoms measured within fifteen days of a heart attack were found to predict low QoL at four months, although depression was the strongest predictor.
Measurement of Quality of Life

Several main reasons have been suggested as to why QoL assessment is useful in clinical practice. These include:

**Measure to inform:** to increase understanding about the multidimensional impact of illness and factors that moderate impact, in order to (a) inform interventions and best practice, and (b) inform patients about treatment outcomes or possible side-effects in order that they are mentally ‘prepared’ for them, or, so that supportive resources can be put in place. Descriptive data from QoL studies can also be used to inform patients and their families about likely treatment experiences so that treatment choices can be made.

- **Measure to evaluate alternatives:** QoL measures may be used as a form of clinical ‘audit’ to identify which interventions have the ‘best’ outcomes – for the patient, but also often in relation to costs.
- **Measure to promote communication:** while this is unlikely to be the primary motive for conducting a QoL assessment in a clinical setting, engaging patients in QoL assessment may require health professionals to address areas that they may not otherwise have done, for example about treatment satisfaction, family interactions, hobbies or sexual functioning. This will provide health professionals with a more holistic view of the impact that illness or treatment has had upon their patient and may help future treatment decision making or health care.

**Culture**

Measures of health-related QoL have been developed predominantly in the English language, meaning that for use in non-English-speaking countries, measures have to be translated. Bowden and Fox-Rushby (2003) reviewed the process of translating measures, generally developed in English, in twentythree countries across Africa, Asia, Eastern Europe, the Middle East and South America. These authors concluded that in the process of translation the meaning of items may be lost, and that using measures that have been generated predominantly from samples of Western populations assumes that words and concepts have equivalent meaning in different cultures, and that domains have equal salience. Furthermore, the nature of disease varies considerably between countries, with, for example, the authors citing evidence that in Europe only 6 per cent of mortality is attributable to communicable diseases (such as HIV, TB), whereas in Africa and South-east Asia communicable diseases account for 71 and...
39 per cent of deaths, respectively. Differences in disease experience such as these are likely to have an effect on illness and QoL expectations. Such findings have been reported within other Asian cultures and need to be borne in mind when pooling the data obtained from multidimensional measures used within mixed cultural samples. Cultural differences are likely to affect statistical findings and thus the conclusions drawn from the data.

Age

McEwan et al. point out that adapting an adult questionnaire into a child version ‘fails to acknowledge important aspects of child and adolescent development and functioning’. The young child may, for example, have cognitive limitations that make it difficult for them to understand abstract questions such as those concerning life satisfaction or global wellbeing.

Parent–child agreement was greater for observable aspects of QoL such as physical functioning but less for emotional or perceived social functioning. In Bijttebier et al.’s (2001) study of QoL among young cancer patients (using parental proxy reports), predominantly observable aspects of QoL were assessed in relation to:

- physical restriction: e.g. my child has been able to perform as usual;
- emotional distress: e.g. my child has anger outbursts;
- discomfort from medical treatment: e.g. my child complained of pain after a medical procedure.

As further illustration of possible discrepancies between proxy and ‘real’ reports, a study of 100 children with congenital heart disease and their parents found that while both parents and children reported reduced child motor functioning and autonomy when compared with healthy children, the children reported lower levels of emotional QoL than did their parents.

Older patients who were in the experimental group had a better disease-specific QoL than controls; and both older patients, and males of any age, in the experimental group had better mental QoL than control group patients.

Summary

This chapter has provided evidence that QoL is an important concept that encompasses a person’s subjective belief about the quality of various life domains of importance to them. The domains generally considered in quality of life research include:

1. physical functioning
2. role functioning
3. emotional functioning
4. social functioning
5. environmental aspects, and, increasingly,
6. spiritual functioning.

We have described a range of influences on the experience of quality of life, including aspects of the disease and its treatment, as well as aspects of the individual such as their age, ethnicity, mood or levels of social support. We have also shown that, in spite of difficulties in clearly defining and measuring QoL, there is a growing recognition of the need to do so, and for research and practice to look beyond traditionally clinical outcomes of illness, such as disability, symptomatology and mortality, to more holistic psychosocial outcomes. While there is increasing evidence of the inclusion of QoL assessment in clinical trials of treatments or in psychosocial interventions, the debate as to whether it is best assessed objectively or subjectively, generically or specifically remains. There is also the need to be sensitive to the needs of specific populations, for example children, and to address cultural variation in the understanding of QoL. We have described various methods of assessing this subjective construct including:

- self-report interview
- self-report questionnaire completion
- proxy report (either interview or questionnaire).

As with beauty, quality of life is in ‘the eye of the beholder’ and therefore this presents challenges to interventions based on identified predictors of quality of life, as it is unlikely that ‘one size will fit all’. However, this chapter has, it is hoped, presented some of the general influences and is a starting point from which to develop interventions.

Reference and Further Reading