

Palliative care and quality of life assignment



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Quality of life (QoL) is a frequently used term within society, yet there remains a lack of consensus as to its definition, with one review identifying three categories of QoL within the literature (Farquhar, 1995): global definitions (i. e. QoL is referred to in general terms, e. g. life satisfaction); component definitions (i. e. QoL is divided into dimensions, e. g. health, psychological well-being, social well-being); and focused definitions (i. e. where the emphasis is on one or two of the possible component definitions).

Despite the inconsistency in how QoL is defined, it has been agreed that it is a multidimensional concept comprising the following dimensions: physical function; symptoms; global judgments of health (i. e. perceived health status); psychological well-being; social well-being; cognitive functioning; role activities (e. g. employment, household management); personal constructs (e. g. life satisfaction, spirituality); and, satisfaction with care (Fitzpatrick, Davey, Buxton, & Jones, 1998). This multidimensionality is most clearly reflected in the definition proposed by the World Health Organisation (WHO, 1995): “ the perception by individuals of their position in life, in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.” WHO also clarify that “ It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships and their relationships to salient features of the environment.”(p. 1405)

In distinguishing between active life-expectancy versus actual life-expectancy, Katz et al. (1993) introduced the concept of QoL in palliative care. The difference between active and actual life-expectancy is reflected in

the following quote, “ And in the end, it’s not the years in your life that count. It’s the life in your years” (Abraham Lincoln). In other words, length of life does not equate with quality of life. This is the approach taken within palliative care, also referred to as end of life care, where the focus shifts from treating pathology to tending to the individual (George & Jennings, 1993). Traditionally, the key aim of medicine and healthcare has been to increase actual life expectancy (number of years alive). However, now that people are living for longer as a result of improved treatment, the focus has moved to what Katz refers to as ‘ active’ life expectancy – i. e. not just enhancing years of life, but the quality of that life. The notion is that quality of life is subjective. For example, some patients choose treatments that reduce their life expectancy in order to avoid treatment side-effects that would compromise the quality of the years that they do have left – they actively choose quality over and above length. Some people who believe in ‘ the right to die’ advocate that keeping someone alive might be lengthening the number of years they are alive, but that life isn’t a ‘ life’ in the sense of having any quality to it. In palliative care, the focus is on maintaining quality of life during the dying process by reducing pain, keeping the patient comfortable, ensuring their needs are met, etc. Keeping a person alive is not the priority – making their final years as comfortable as possible is.

Palliative care emphasises that even when someone cannot be cured, their life is still the main focus of healthcare professionals, as is their quality of life. Thus, palliative care is directed towards the priorities of an individual and what might make the time an individual has left as comfortable and fulfilling as possible. One key aspect of this is providing a dignified and pain-

free death. Paradoxically, this has been found to increase life-expectancy as well as quality of life in people reaching the end of life (Temel et al., 2010).

Controversially, palliative care has been associated not with enhancing QoL by providing individualised care early on within the disease trajectory, but more so as ‘giving up’ and admitting defeat. During debates over US health reforms, palliative care was described by some as ‘euthanasia,’ the practice of intentionally ending a life to ease pain and suffering (Mongan, Ferris & Lee, 2008).

For those providing palliative care, however, the service is about life rather than death, about maintaining a patients’ QoL (as perceived by them) by bringing together experts and specialists who can assist with symptom control (Agar et al, 2008). Rather than palliative care being an alternative to life-prolonging or curative care, providers view it as an adjunct to disease-focused treatment, which should be integrated into standard treatment pathways. Traditionally, palliative care has been provided at the last minute, as a last resort and a sign that the patient needs to prepare for death. This is despite evidence suggesting that to have a meaningful impact on QoL, palliative care needs to be provided earlier on in the disease trajectory (Temel et al., 2010). Fortunately, practice is changing and palliative care is provided sooner rather than later, so that patients can prepare not for death but to fulfil the time they have left.

This new, individualised, quality of life approach to palliative care introduces new ways of working for health professionals and those close to the patient. Rather than working with the concepts of pain, suffering and death, these

concepts are being replaced with achievements, rewards, improvement, and quality (Claffey, 2005). There is a whole new narrative being utilised within palliative care. Palliative care used to have negative connotations attached to it (i. e. death, suffering, pain, deterioration, loss, ending). In the present day, palliative care has a less fatalistic association attached to it, with the recognition that it isn't merely about preparing for death but also about enhancing the remaining weeks, months, or years of life. Of course, it remains a daunting term to people, but at the same time it offers comfort and support. Indeed, rehabilitation, a term traditionally associated with cure and recovery, is a key component to palliative care, helping patients to gain opportunity, control, independence and dignity (National Council for Hospices and Socialist Palliative Care, 2000). There is now a dual approach to working with people whose illness cannot be cured. On the one hand, the focus is on maintaining QoL and on the other it is preparing for death. Therefore, maintaining QoL through palliative care requires a holistic approach based on the QoL components offered by Fitzpatrick et al. (1998).

It could be argued that if palliative care is about maintaining QoL, then allowing a prolonged death is not consistent with the palliative care ethos. However, the duty of health professionals is to provide the patient with care and ease their suffering without prolonging or hastening their death. Again, the focus is on life, not death, with any medical intervention being designed to ease suffering and enhance independence and dignity (Jeffrey, 1995). This is related to active versus actual years. Some people advocate euthanasia, arguing that keeping someone alive is inhumane if they no longer have any quality to their lives. Palliative care could be viewed as keeping someone

alive despite loss in quality of life (it has been found that people do live longer if they receive palliative care). However, a challenge to the notion of palliative care being inhuman would be that it does not prolong death – it enhances life by reducing pain, keeping the patient as comfortable as possible, and ensuring their needs are met.

Palliative care is, in the main, available for cancer patients who can benefit from medical support to control physical symptoms of pain and dyspnoea, as well from emotional and spiritual support to assist with fears or feelings of grief or anger (Morrison & Meier, 2004). Such care is reported to be low for other conditions, such as chronic pulmonary disease, raising the question of where QoL is incorporated into their care (Yohannes, 2007).

The effectiveness of healthcare has traditionally been measured via increased life-expectancy, yet palliative care demonstrates that the recent move towards considering QoL outcomes as a measure of healthcare efficacy is apt. With a greater focus on quality rather than quantity of life, patient-reported outcomes are becoming important indicators of healthcare effectiveness (Clavarino, 1999). This also takes into account the subjective nature of QoL and healthcare needs, with different people placing different levels of importance on various aspects of health and well-being. It could be argued that the lack of consensus on a definition for QoL is due to the very subjective nature of the concept. Measuring QoL or healthcare effectiveness purely by disease outcomes takes a 'one size fits all approach,' which is no longer sufficient in efforts to provide individualised patient care at a time when personal needs are at their greatest – during the end of life.