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Health Related Quality of Life (HRQOL) Implications for People with Pressure Ulcers

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Introduction

There is no doubt whatsoever that pressure ulcers impact heavily on patient morbidity, mortality, and quality of life [1]. Pressure ulcers are a public health problem that causes suffering and decreased quality life for individuals and their caregivers [2, 3]. The results of a systematic review confirm that pressure ulcers significantly affect HRQOL. Pain was identified as a major concern but other pressure ulcer symptoms and interventions, together with healthcare environment all contributed to reducing HRQOL [1]. In relation to healthcare provision the absence of pressure ulcers is considered an indicator of quality care delivery [4, 5].

The concept quality of life is still indefinite, it is associated with an individual's perspective on life satisfaction regardless of the time in life, the location or situation and may change over time. The World Health Organization, Working Group on Quality of Life (WHOQoL), refers to the perception of the individual in relation to their position in life, within the context of culture and systems values that are related to their goals, expectations, standards and concerns. Price and Harding [6], consider that for the majority of individuals with chronic wounds the main focus of treatment is often complete healing, with the aim of achieving the healed state as quickly as

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possible. However for some individuals healing may not be a realistic expectation, in which case quality of life and symptom management become increasingly important.

Health Belief Model

There are many theories and subsequent models that attempt to provide an explanation and framework to enlighten health related actions. The Health Belief Model is an example of a theory based on the principle that individual's health related behaviour is influenced by their belief regarding the severity of the illness, which is often stimulated by the onset of disease. The model takes into account the wider issues such as cost and benefit of following a specific course of action involving preventative and treatment pathways and subsequent concordance. The main criticism with the model is that is based upon the premise of rational behaviour rather than on the more subjective elements of human behaviour such as emotional responses to health related situations [7].

Measurement of HRQOL

The measurement of HRQOL provides an insight into the impact of disease on an individual [8]. There exists a plethora of scales/tools that attempt to measure HRQOL. The tools differ mainly in the content specific to the four domains whilst acknowledging the pillars of emotional, physical, psychological and social well-being. Each domain has indicators that can be assessed e.g. self-esteem, anxiety and depression, physical ability and the ability to function in social roles [7]. According to Price [9], different researchers have developed models of HRQOL based on different domains. For Fallowfied, HRQOL is a multidimensional construct that encompasses four primary domains (variables): psychological; physical; social and role functioning; and issues relating to well-being [10]. Others have proposed up to six domains, while Todd [11] recommended only three domains, physical, social and psychological, sufficient to describe the impact of disease on patients.

HRQOL scales can be generic or disease specific. A common generic scale that has been used to measure HRQOL in tissue viability is the Short Form 36. The Barthel Index although not a HRQOL tool rather it's a measure of functional independence is also used and focusses on the activities of daily living. The generic aspect of these tools can result in a failure to establish if differences exist between individuals with pressure ulcers and those without, therefore using them in combination has been suggested as a way of overcoming this limitation [12, 13].

There has been growing interest and importance placed upon patient reported outcome measures (PROMs) [14]. Gorecki et al. [15] following a systematic review of the literature combined with patient interviews, developed a conceptual framework that populated four HRQOL domains (symptoms, physical functioning, psychological well-being and social functioning) with 13 pressure ulcer specific sub-domains (pain and discomfort, exudate, odour, mobility daily activities general malaise, sleep, mood, anxiety and worry, self-efficacy and dependence, appearance and self-consciousness, social isolation and participation).

The Impact of Pressure Ulceration on the Individual's Quality of Life

It is often difficult for both healthcare professionals and individuals to establish if it is the pressure ulcer itself or co-morbidities that are having a detrimental effect on an individual's HRQOL [16]. Pressure ulceration is a complication of ill health whether it is acute or chronic disease process. Franks, Winterberg and Moffatt identified 14 co-morbidities in a cohort of 75 patients with pressure ulcers including acute, chronic, and life limiting conditions e.g. fractured neck of femur, chronic heart failure and cancer [13]. A time component can further complicate the ability to tease out the specific effects on HRQOL attributed to pressure damage with acute illness taking precedence over pressure damage whereas the impact of the development pressure ulceration in individuals with chronic conditions caused major impairment and difficulty [8]. The situation is further complicated by elderly individuals who may be confused and cognitively impaired and as such are unable to provide objective information. Whittington [17] found that the majority of people with pressure ulcers were more than 65 years old.

The impact of pressure ulcers on HRQOL is substantial, causing pain and discomfort and affecting sleep, rehabilitation, mobility, and psychological, physical and social aspects of people lives [18–20]. However, pressure ulcers usually develop as a consequence of some other factors which cause restrictions in sleep, mobility and other dimensions, which put the individual at risk of pressure ulcer development. Thus, it is important to gain better understanding of the complex relationship among the various factors that affect HRQOL. In addition, the intensive treatment required for managing pressure ulcers is associated with significant treatment burden, which further impacts HRQOL outcomes [18, 19]. The literature shows that pressure ulcers have a negative impact in all domains of quality of life [21]. The major concerns identified relate to severe and constant pain, and negative impact on physical, psychological and social needs.

Patients often describe constant pain associated with pressure ulcers, which includes pain in general, during dressing change, and when under medical devices for reduction/relief of pressure [18, 21, 22]. Pain was an ever-present feature in the phenomenological study done by Hopkins [16] in patients with pressure ulceration, in which the pain was said to be endless, constant and caused by the treatment and equipment used in the management of pressure ulceration. Health professionals tend to underestimate pain and most of the times the analgesia is insufficient to relieve pain [16, 18, 23]. Some patients don't even complain about their pain and attribute their pain to their age and other co-morbidities. It's a debilitating situation, responsible for physical and social restrictions, namely in performing daily life activities, participating in social activities and sleeping. Patients tend not to move as they know that movement will cause more pain [16].

Exudate and odour are causes of innumerous problems, such as family and social isolation, pain and physical restrictions Wound odour is a very distressing symptom and impacts greatly on quality of life, causing feelings of embarrassment and depression [21, 24, 25].

The effects of immobility are significant in people with chronic ulcers [26–28]. Pressure ulcers reduce drastically physical activity, often confining the person to a wheel chair or bed and delay their rehabilitation [15, 18, 29]. Unlike leg ulcers, pressure ulcers result in physical lifestyle changes, adapted living environments, and eventually could lead to hospitalization [15, 18].

A change in body image is clearly a problem for patients with pressure ulceration [18, 21]. The incapacity of maintaining hygiene affects their well-being. It's frequently the sensation of being dirty or smelling, due to the pressure ulcers, which can lead to family and social isolation behaviours. Fox [21] identified that pressure ulceration produced altered and negative body image and fear. This is understandable due to the tissue death and scarring resulting from pressure ulceration. Pressure ulcer interventions cause substantial burden to patients, with consequences including loss of appetite, feeling powerless and other emotional problems such as low mood, hopelessness and anger [18, 30]. Individuals have verbalized a sense of powerlessness and worthlessness [16].

Nurse visits restrict patients' lives and reduce their ability to remain involved in their social activities [16]. Patients report that the physical restrictions imposed by the pressure ulcers and by treatment, including hospitalization, restricted their social life [18, 21].

Influence of Pressure Ulcers on Patients, Family and Healthcare Professionals

Pressure ulcers affect the quality of life not only of the individuals but also of family, carers and associated healthcare professionals. Living with an ulcer brings several changes to people and their families e.g. by restricting the lives of the individuals and that of their carers [16]. This was also highlighted by Baharestani [31], in wives caring for elderly housebound husbands with deep pressure ulcers. The fragility of the wives was evident along with limited social support systems for the carers.

For clinicians, caring for individuals with pressure ulcers, there is no doubt that having such wounds may impact on the individuals' HRQOL. Clinicians generally accept that a pressure ulcer will have some impact on patients' quality of life and may even make assumptions about what it must be like to experience a pressure ulcer. Healthcare providers should be acutely aware of and sensitive to the impact of pressure ulceration on quality of life. Gorecki [8] used semi-structured interviews with individuals with pressure ulcers (n = 25) to identify many contributory factors that interplay with HRQOL outcomes that included experience of care received e.g. variations in care, relationships with healthcare professionals.

Individuals have claimed that the language used by nurses to describe their pressure ulcers (they were not able to see the ulcer in certain anatomical locations) as horrific [20]. In addition there is an underestimation by medical and nursing staff of the impact of pressure damage on individuals HRQOL, specifically the amount and impact of the pain associated with the pressure ulceration [16, 19, 20]. For individuals with pressure ulcers the vulnerability, fear and dependency experience is not easily shared with others and is often invisible and overlooked by healthcare professionals. On the other hand there is the paradox that even people with disabilities report that they have a good quality of life [32, 33], contrary to the general perspective of the healthcare professionals who tend to assume that people with disabilities have a low quality of life, regardless of reporting otherwise [34].

Attributing blame can be perceived as part of the social processes used by individuals to understand, cope and live with a condition that is felt to be beyond their control [35]. Spilsbury et al. [20], used qualitative semi-structured interviews with 23 hospital in-patients, the results showed that all participants attributed blame for pressure ulcer development. Three reasons for apportioning blame were identified; some participants directed blame at their chronic condition, poor health, or loss of weight and appetite. Others specifically blamed healthcare professionals for failing to attach priority to their reports of an ulcer or delays in skin inspection; and a small number reported it was the actions of healthcare professionals that caused the ulcer.

Gorecki et al. [18] found that many patients had difficulty in accepting their pressure ulcer, but others developed coping strategies and learned to accept the situation. The comparison with other situation worse than theirs, often led participants to an acceptance of their situation as fatalism [16].

Patients with pressure ulcers are usually very passive about asking justifications related to pressure ulcer intervention [36]. However, patients express desire to be involved in decisions about their wound care and want help from health professionals to become independent [18]. Difficulties often arise when the patient, the family and the healthcare team are not prepared to deal with or understand all of the aspects involved in the problem [37].

In theory aggressive prevention strategies can potentially cause more suffering than benefits. Preventing pressure ulceration in patients who are dying can be impossible due to skin failure [38]. It's important to establish, what is the priority, comfort versus prevention. Nevertheless, there is a need to minimize the negative impact of prevention interventions in the decrease of the quality of life of the patient (24).

Financial Implications

Pressure ulcers can play an important role in patients' trajectories from illness to full recovery, they are perceived to increase hospital stays, costs and result in dependency associated with on-going treatments [20]. Beside financial costs to individuals and their families, other indirect costs can be enumerated as time lost from work, forced early retirement and other expenses associated with morbidity and mortality.

Education

Alves et al. [39] highlight the contribution of healthcare professionals in the prevention of complications and maintenance of pressure ulcer with person's quality of life through prevention strategies and the development of educational strategies for caregivers. The level of education is certainly an important factor in relation to self-care and is sometimes a hindrance for treatment. Edwards [40] questioned if education could influence healing rates and found that patients who had knowledge of pathophysiology of ulcer formation had more commitment in maintaining treatment. These results suggest that health education sessions can promote concordance to treatment and therefore improve HRQOL of patients with chronic wounds. However, success is not always achieved, as not all prevention depends directly on the actions of healthcare professionals; there is the influence of contributing factors such as malnutrition, global deterioration of health and palliation as well as shortages of professionals and prevention material. This leads to demotivation and frustration of informal caregivers as well as healthcare professionals. As even with the implementation of all strategies and the provision of material resources for prevention, pressure ulceration will continue to develop.

Organisations

Organisations have an important role in education, research and in providing materials for patients that can be adapted for ethnically diverse populations. Pressure ulcer prevention as a quality indicator has driven institutions to promote pressure ulcer prevention. The international consensus [41] on well-being highlighted the importance of organisations in ensuring the well-being of their employees, to enable them to care for the wellbeing of others [37].

Conclusion

HRQOL is a dynamic multifactorial and patient-centered concept which aims to establish the emotional, psychological, physical and social impact of diseases, symptoms, complications and treatments on an individual. A main objective of health care is to improve the quality of life. Assessment of HRQOL is considered subjective in nature due to the personal nature of the experience that can vary over time. HRQOL can be measured by directly asking the person themselves or through the use of patient-reported outcome measures (PROMs), rating scales and pressure ulcer specific HRQOL assessment tools [42, 43].

When comparing individuals with pressure ulcers to those without ulceration, there is evidence of a significant impact of the disease on the physical, social and psychological aspects of their life. In addition they have to live with the symptoms of the disease, general health problems, care interventions, high rates of depression and a low quality of life [18, 30, 44]. The challenge in these patients is attempting to tease out the factors that are likely to be influenced by the ulceration while acknowledging the broader holistic problems they encounter [45]. Nevertheless, it is possible to improve quality of life of these patients, by adopting best practice and appreciating the individual's perspective and opinion. Education also assumes an important place in improving the quality of life of people with pressure ulcers.

HRQOL data assists clinicians and organisations in determining and subsequently planning to meet individual health needs. Healthcare professionals have a responsibility to assess and manage the impact of pressure damage on the HRQOL of an individual alongside traditional diagnostic and treatment options.

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