

Quality of life and pressure ulcers: a literature review

The interest in quality of life in healthcare has grown enormously over the past three decades. This interest stems from a shift in focus from treatments alone to a desire to really understand the disease process and impact of treatments from the perspective of the individual. This article explores the literature about pressure ulcers and quality of life. The aim is to increase the readers understanding of the impact of pressure ulcers on the individual and in doing so highlight the importance of the development of effective pressure ulcer preventive strategies.

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KEY WORDS

Quality of life
Health-related quality of life
Pressure ulcers
Wound care

The traditional focus of research in healthcare has been on the nature of disease and the development of successful interventions to combat the disease process. Researchers have used outcome measures specifically designed to capture data regarding the efficacy of new treatments and there has been little emphasis placed on the individual's experiences of such treatments. Over the past three decades, however, changes in the traditional role of the healthcare professional combined with increased patient empowerment have stimulated a growing interest in patients' quality of life (O'Boyle, 2008). Developments in healthcare delivery today, must clearly demonstrate health and social gains of which quality of life is now a central tenet.

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The problem of pressure ulcers

Pressure ulcers are localised areas of tissue damage caused by excess pressure, shearing or friction forces that occur in those who cannot reposition themselves in order to relieve pressure on their bony prominences. This ability is often diminished in the very old, the malnourished and those with acute illness (Robertson et al, 1990).

A cross-sectional European study found that approximately 18% of adult hospital patients had a pressure ulcer (European Pressure Ulcer Advisory Panel, 2002). An Irish study confirmed the extent of the problem when, following a cross-sectional survey of 297 hospitalised adult patients, a prevalence of 12.5% was observed (Moore and Pitman, 2000). Reported incidence rates of pressure ulcers range from 2.2–66% in the UK, and 0–65.6% in the USA and Canada (Kaltenthaler et al, 2001). Pressure ulcers are more common in older patients (Whittington et al, 2000), those in orthopaedic settings (Versluisen, 1986), and those who cannot reposition themselves (such as younger patients with injuries to the spinal cord). Other medical conditions can also predispose the development of pressure ulcers (Schoonhoven et al, 2002). Changing population demographics and the rise in the number of older patients in the future means that the number of people with pressure ulcers is likely to increase in the years ahead (Haalboom, 2000).

Pressure ulcers are a significant financial burden to healthcare systems (Clark, 2002). Touche Ross report (1993) estimated the annual cost of treatment for pressure ulcers in the UK in 1993 at between £180m and £321m, with the cost of prevention estimated at £180m to £755m. More recently, Bennett et al (2004) explored the cost of pressure ulcer management and suggested that the total annual cost in the UK is £1.4–2.1bn, or 4% of total healthcare expenditure. It is worth noting that costs of litigation or effects on quality of life, in terms of pain, depression and social isolation, were not included in these estimates. Therefore, at present, the precise economic impact of pressure ulcers has yet to be established.

Evidence-based practice and quality of life

The underlying feature of evidence-based practice is 'the conscientious explicit and judicious use of current best evidence in making decisions about the care of individual patients' (Sackett et al, 1997). This suggests that clinical decision-making should, on the one hand, be cognisant of the specific evidence to support practice, but conversely should also bear in mind the uniqueness of each patient and their individual responses to particular treatments. The emphasis on EBP today has emerged due to changes in health service delivery, including greater emphasis on value for money, risk management, patient empowerment and the ever-expanding role of information technology (Trinder, 2000).

Changes in the traditional, autocratic role of the doctor, combined with a better informed consumer have led to a more questioning approach to care delivery (Muir Gray, 2000). These changes demand increasing accountability, efficiency and effectiveness, however, with limited resources in order to achieve these goals (Muir Gray, 2000). Those wishing to justify continued investment in current practice, or conversely, development of new innovative methods of care delivery, are expected to be explicit in their requests (Muir Gray, 2000). This explicitness has to include evidence-based material to support arguments appropriately, incorporating the impact of the intervention on the patient (Muir Gray, 2000). The impact of disease and subsequent healthcare interventions on the quality of life of the individual are now considered as central tenets of evidence-based practice. Therefore it is important to have an understanding of the impact of pressure ulcers on a patient's quality of life when considering new evidence-based treatment regimens for pressure ulcers.

Defining quality of life

The understanding of the importance of quality of life in healthcare, and the subsequent development of measures to assess quality of life, stem from the work of the World Health Organization (WHO) (O' Boyle, 2008). WHO defines quality of life as 'individuals' perception 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' (The World Health Organization Quality of Life Group, 1995). WHO further argues that the concept of quality of life is multifaceted because it is affected by all aspects of the person's life including their physical, social, spiritual, psychological and environmental domains (The World Health Organization Quality of Life Group, 1995). It is apparent, therefore, that to identify the effects of a particular disease process, one must capture this from the perspective of the individual as it is likely to be influenced by many personal variables.

Measuring quality of life

Based on the complexity of defining and measuring quality of life researchers have had to choose a variety of

different approaches. Some have used a phenomenological approach in an attempt to really gain insight into the patients' own experiences of living with a pressure ulcer (Langemo et al, 2000; Fox, 2002; Hopkins et al, 2006). Phenomenology is concerned with the person's individual life events as experienced by themselves (McCance and McIlpatrick, 2008). The purpose of exploring the lived experience is to engender understanding of what it is like to have a pressure ulcer; for example, and then to use this information to help the person to deal with this experience (McCance and McIlpatrick, 2008).

Challenges to the phenomenological approach are that the information gained cannot be generalised beyond the individual from whom the data came from (Comer, 1991). As such, the data lives and dies with that person because it is fundamentally that person's own individual experience (McCance and McIlpatrick, 2008). It is important, however, to clarify that the intention of phenomenology is not to provide data for prediction or treatment, rather to develop the theoretical understanding of the human experience (McCance and McIlpatrick, 2008).

Other researchers have chosen to explore quality of life using pre-designed measurement tools (Anderson and Andberg, 1979; Krause, 1998, Sapountzi-Krepia et al, 1998). Quality of life measurement tools generally cover broad aspects of life, including physical, psychological and social dimensions and may also include assessment of symptoms of specific disease states (O' Boyle, 2008). The principles upon which they are based emerge from the desire to objectively capture the individuals perceived functioning in all their domains of life, the objective being to determine the effect of disease on the individual's life (Muldoon et al, 1998). In doing this, the focus of the research is often on a sub-component of quality of life, namely health (O' Boyle, 2008). Therefore, it is argued that researchers who choose these methods are exploring health-related quality of life (HRQoL) rather than the totality of the concept of quality of life (O' Boyle, 2008).

Health-related quality of life is defined as 'the value assigned to the duration of life

as modified by ... impairments' (Patrick and Erickson, 1993). Instruments used to measure HRQoL may be generic, such as the Short Form Health Survey (SF-36) (Ware, 2000) or the Nottingham Health Profile (Hunt et al, 1980) or disease-specific instruments, for example, the Cardiff Wound Impact Schedule (Price and Harding, 2004). The tools differ from each other depending on their design. Dimension-specific measures capture information pertaining to a specific aspect of life, for example, psychological well-being. Whereas, generic tools, are broadly based and do not focus on any single dimension, or disease state. Disease specific tools collect information pertaining to a particular healthcare problem, for example, chronic wounds and utility tools yield data related to health economics (Garratt et al, 2002). These tools were not designed specifically for use in individuals with pressure ulcers, therefore, the validity and reliability in this patient group has not been established.

Pressure ulcers and quality of life

For the purpose of seeking literature regarding pressure ulcers and quality of life, PubMed, Cinahl and Medline were searched using the following search terms, singularly and combined:

- ▶▶ Quality of Life
- ▶▶ Health-related quality of life
- ▶▶ Pressure ulcer
- ▶▶ Bed sore
- ▶▶ Pressure sore
- ▶▶ Decubitus ulcer:

The search was limited to papers published in English. This yielded seven hits and one further article was identified following a search of the relevant bibliographies. The research dates from 1979 to 2007 and the sample size in the studies ranges from five to 1017 people. Four researchers chose quantitative data collection methods using pre-designed data collection tools (Anderson and Andberg, 1979, Krause, 1998, Sapountzi-Krepia et al, 1998, Franks et al, 2002), three researchers adopted a phenomenological approach (Langemo et al, 2000, Fox, 2002, Hopkins et al, 2006) and one group of researchers used a semi-structured interview technique (Spilsbury et al, 2007).

Anderson and Andberg (1979), in the USA tested three psychosocial measures

— the individual's willingness to participate in their own skin care. (RESPON), satisfaction with activities of life (SATIS) and the Tennessee Self-Concept Scale — on 141 participants with spinal cord injury. The authors found that RESPON and SATIS scores were significantly associated with the incidence of PU. However, these findings were related to the likelihood of development of a pressure ulcer, rather than the impact that having a pressure ulcer had on the individual's overall scores and therefore does not measure QoL.

Krause's (1998) study included 1017 participants with spinal cord injury in the USA. The participants completed the Life Situation Questionnaire — revised (LSQ-R) (Diener et al, 1985). The questionnaire consists of several sets of variables, biographical status, participation in employment and education, social activities, life satisfaction, problems, fitness, self-rated adjustment, general health and recent medical history. The purpose of the study was to explore the relationship between pressure ulcers and psychosocial adjustment to life after the injury. Specifically the LSQ-R focuses on issues surrounding health problems, career opportunities, finances, living circumstances, interpersonal relationships, negative emotions and positive engagement. Less than half of the respondents (46%) had experienced a pressure ulcer. In those with experience of pressure ulcers, the findings suggest that the pressure ulcer reduced the individual's quality of life and had a negative impact on their adjustment to life after their spinal cord injury. Furthermore, this impact was noted to be related to the number and duration of pressure ulcers. Although the study identified a correlation between pressure ulcers and a diminished quality of life, we are not specifically informed about how this quality of life was affected. This in itself is the challenge in the use of generic tools for very specific healthcare problems. Furthermore, it may be difficult for an individual to separate the effect of a spinal injury from the effect of a pressure ulcer, an issue which has been noted in more recent research (Hopkins et al, 2006).

Sapountzi-Krepia et al (1998) tested the Sarno Functional Life Scale (SFLS) on 98 participants with spinal cord injury in

Greece. This is an instrument intended to describe an individual's overall functioning at any time point since the onset of a disability or injury (Sarno et al, 1973). The researchers (Sapountzi-Krepia et al, 1998) used the part of the instrument that relates to activities of daily living, activities in the home, outside activities and social interaction. The purpose of the study was to determine the impact that pressure ulcers and urinary tract infections had on the participants' everyday life activities. Fifty-nine percent of the participants had experienced a pressure ulcer and 82% had experienced a urinary tract infection. The authors found that the pressure ulcers were negatively related to everyday activities and this finding was noted to be statistically significant ($p=0.021$). Individuals with urinary tract infections were less likely to be involved in outdoor activities; however, this finding was not statistically significant. Once again, in this study, we are not informed how exactly quality of life is affected. In addition, the combination of pressure ulcers, urinary tract infections and spinal cord injury all in the same study, may have made it difficult for the respondents to differentiate the effect that each of the conditions had on their lives.

In the UK, Franks et al (2002) administered the Short Form 36 questionnaire (SF-36) to 175 participants, with and without pressure ulcers, living in a community setting. The purpose of the study was to assess the impact that pressure ulcers had on the individual's quality of life. The authors found that in the 75 patients with pressure ulcers, their experiences were similar to those 100 patients receiving care for other problems, suggesting that the presence of a pressure ulcer did not alter the individual's quality of life. There are a number of points that warrant discussion in this study. The grades of pressure ulcers were mainly 1 and 2 (69%) (Non-blanchable erythema or superficial skin loss (Reid and Morison, 1994). One could argue that, in view of other research in this area (Langemo et al, 2000; Fox, 2002; Hopkins et al, 2006), more severe pressure ulcers would have a greater impact on quality of life. It may also be difficult for participants to separate the effect of other co-morbidities from that of the pressure ulcer (Hopkins et al, 2006). Furthermore, many of the patients were

unable to consent and therefore were excluded from the study. This is a challenge in research into pressure ulcers as many of those affected are elderly, debilitated individuals (Robertson et al, 1990). It means that those mostly affected by the problem often do not have a voice and, therefore, their views are not considered (Donnelly, 2004). In addition, it means that they also cannot benefit from the outcomes of research if they have been deliberately excluded from participating (Donnelly, 2004).

Three studies were identified that adopted a phenomenological approach (Langemo et al, 2000; Fox, 2002; Hopkins et al, 2006). The studies were conducted in the USA (Langemo et al, 2000), the UK (Fox, 2002) and the UK and Belgium (Hopkins et al, 2006). A total of 23 patients with pressure ulcers of grades 2, 3 and 4 (National Pressure Ulcer Advisory Panel, 1989; European Pressure Ulcer Advisory Panel, 2002) participated in the studies. Overall, all of the researchers agreed that the presence of a pressure ulcer has a negative effect on the person's quality of life (Langemo et al, 2000; Fox, 2002; Hopkins et al, 2006). Indeed, a preoccupation with the ulcer was identified (Langemo et al, 2000) with pain regarded as one of the most overwhelming aspects of the patients' experience (Langemo et al, 2000; Fox, 2002; Hopkins et al, 2006). Worryingly, treatments, repositioning and equipment often served to worsen the patient's experience rather than improve it. This is important to consider in view of the fact that many patients with pressure ulcers may not be able to articulate these experiences (Donnelly, 2004).

It was found that movement increased pain; therefore, the patients were inclined to keep as still as possible. However, this was not always possible and repositioning regimens initiated by staff, or spontaneous movements during sleep, brought on the pain cycle (Hopkins, 2006). The use of pressure redistribution devices, particularly alternating surfaces were also problematic, as when the cells inflated, they appeared to 'stick into' the pressure ulcer, exacerbating the pain experience (Hopkins et al, 2006). During dressing change, wound cleansing caused pain for

some patients, conversely, some found that a decrease in pain served as a reminder of wound healing (Hopkins et al, 2006). It is important to consider the impact of prevention and treatments strategies on the individual and to choose those that will reduce discomfort and enhance rehabilitation wherever possible.

The final study is that of Spilsbury et al (2007). These researchers used qualitative, semi-structured interviews, to capture the experiences of 23 hospital inpatients with pressure ulcers of grades 2, 3, 4 and 5 (Nixon et al, 2005). The researchers found that the presence of a pressure ulcer and the subsequent treatments endured had an adverse effect on the patients' lives. The pressure ulcer impacted negatively on the individual from an emotional, physical, mental and social perspective. In keeping with previous research (Langemo et al, 2000; Fox, 2002; Hopkins et al, 2006), pain was also alluded to as an important consideration with 91% of those interviewed experiencing pain. Furthermore, positioning and treatment regimens often exacerbated the individuals' pain levels. As with other studies, it is challenging for the participants to separate the effect of co-morbidities from the effect of the pressure ulcer (Hopkins et al, 2006). This, therefore, limits the quality of the data.

Discussion

Over the past 30 years there has been a rising interest in the subject of quality of life (O'Boyle, 2008). This is also true in the area of pressure ulceration, with the first study published in the 1970s (Anderson and Andberg, 1979). Understanding the impact that pressure ulcers have on the individual provides healthcare professional with a unique insight into patients' lives. Increasingly, healthcare delivery demands efficacy and efficiency of those providing care and as such the patients' point of view cannot be ignored. The literature, clearly articulates the impact of pressure ulcers on the individual's quality of life, noting that the emotional, physical, mental and social domains of life are all profoundly affected (Spilsbury et al, 2007). Worryingly, also, is that many of the treatment regimens adopted exacerbate these adverse effects. Pain appears to be a constant problem for individuals with pressure

ulcers (Langemo and Melland, 2000, Fox, 2002, Hopkins et al, 2006, Spilsbury et al, 2007). Furthermore, both prevention and treatment plans often serve to exacerbate the pain and discomfort and as such this calls on us to revisit our care planning. It is also a concern that many of those affected by the problem of pressure ulcers may not be able to express their feelings and thus may be forgotten about (Donnelly, 2004). Therefore, knowing that pressure ulcers are painful and unpleasant is valuable information for healthcare workers and even though it is not well articulated by some patients this does not mean that their experiences are not similar.

Conclusion

Pressure ulcers are not a plague of modern man, indeed, pressure ulcers have been known to exist since ancient Egyptian times and have probably existed for as long as man has been in existence. Despite this longevity, pressure ulcers remain a significant healthcare problem today. There is a large body of knowledge that demonstrates the adverse affect that pressure ulcers have on the quality of life of the individual. Having a pressure ulcer impacts negatively on all domains of the person's life with pain being one of the most significant problems alluded to. Increasing our understanding of the patient's experience can help towards the development of care plans that are patient-focused rather than treatment-focused. The impact of care provision on health and social gain is now more important than ever, especially when faced with increasingly reduced expenditure. Central to the success of the health service is the experiences of its consumers; therefore, knowing the impact of pressure ulcers on quality of life can stimulate renewed interest in prevention. Indeed, any reductions in the number of new pressure ulcers that develop will have a positive impact on both the individual and the health service as a whole. **WUK**

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