

How to Improve The Quality of Life in Patients Living with End Stage Renal Failure

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Abstract

Quality of life (QoL) is important for all people, especially those with chronic illnesses such as end stage renal failure (ESRF). QoL can be a difficult concept to define, as it is highly subjective and intricately linked to psychological, physical and social aspects. People with ESRF often experience many physical changes which can negatively impact on their psychological status and interfere with their social functioning. Nurses are in an ideal position to enhance their patient's QoL as they spend large portions of time with the patient. There are various QoL measurement tools available to monitor patient QoL and nurses should be aware that their perception of the patient's QoL may differ from the patient's perception. It is vital that nurses value the importance of patient QoL and recognise the need for a multifaceted approach involving physical, psychological and social aspects. Nurses can contribute to improving patient QoL by providing optimal dialysis which includes minimising technical errors, adhering to strict infection control practices and maintaining current professional knowledge. Appropriate education is important for patients with ESRF so they are able to develop realistic expectations about their illness, treatment and achievable health status. Nurses can play a major role in providing their patients with current and relevant educational material and resources. Nurses are also able to refer patients to other members of the multidisciplinary team for specialised treatment when necessary. QoL is an essential component for any health practitioner who strives to provide their patients with holistic health care and should be recognised as having particular importance for patients with ESRF.

Introduction

Healthcare has traditionally focused on diagnosing and treating physical signs and symptoms. However, it is now recognised that quality of life (QoL) is an important issue to consider when caring for people with chronic illnesses

such as end-stage renal failure (ESRF). QoL is difficult to define because it is a broad description of how the person perceives their functional ability and life in general. It is highly subjective and influenced by physical, psychological and social aspects of a patient's life. For these reasons assessments are necessary

Key words:

Quality of life, end stage renal failure, dialysis.

so that a comprehensive picture can be achieved. Various methods are available to monitor QoL in people with ESRF and they include physical measurements such as dialysis adequacy along with QoL measurements such as patient surveys. By improving health-related aspects of care, it is expected that patients should also experience an improvement in QoL. Nurses play an important role by providing optimal dialysis, a supportive environment and comprehensive and continuous education. In addition nurses play a significant role in coordinating other members of the multidisciplinary team to ensure holistic care.

Defining Quality of Life

People with ESRF are now able to live longer due to medical advancements, so the focus of healthcare has shifted from survival to achieving an acceptable QoL. The World Health Organization (1993) defines QoL as: "an individual's 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." In simpler terms, QoL can be said to encompass physical, psychological

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and social function and is determined by how well the patient's perceptions correlate to their expectations of their functional status and subsequent QoL.

Kimmel and Levy (2001, p. 413) state that 'dialysis patients lead a highly abnormal life'. Patients with ESRF undergo many changes to their physical, psychological and social functioning that can be attributed to both the disease process and the patient's ability to adapt to such changes. While this may be the case, dialysis is intricately linked with the patient's way of life and therefore evolves into a somewhat normal situation for them. Dialysis patients often focus less on the clinical procedure itself and more on activities during the procedure such as eating, reading and dozing which bring a sense of normality to the situation (Auer 2002). It is important that nurses recognise that their own definition and perception of QoL may be vastly different to that of their patients'. It is not surprising that various studies have shown discrepancies between patients' with ESRF perceptions of QoL and health care professionals' perceptions of the patient's QoL (Meers et al. 1995; Polaschek 2003). In many incidences, healthcare professionals underestimate the patient's QoL, which can potentially affect patient outcomes through changes to treatment and management regimens based on differing opinions of patient needs (Meers et al. 1995). These issues will now be discussed.

Physical Changes in Patients with ESRF

Physical changes stemming from ESRF are not restricted to the renal system. Other body systems can also be affected and lead to a decreased health status and QoL (Daugirdas et al. 2001). Both ESRF and dialysis are associated with numerous physical symptoms and complications (Goodman and Ballou 2004).

Cardiovascular disease is the leading cause of death in patients with ESRF and

this has been mainly attributed to the development of ischaemic heart disease and left ventricular hypertrophy (LVH) (Sehgal 2003). According to Caring for Australians with Renal Impairment (CARI) guidelines (2003), 74% of patients commencing dialysis demonstrate LVH compared with a prevalence of 20% in the general population.

Anaemia can greatly impact on a person's QoL through the debilitating effects of oxygen depletion on cognition, energy levels and the ability to perform activities of daily living (Gregory 2003; Kirilin 1992). Numerous studies have shown that patient QoL has been improved since the introduction of erythropoietin therapy and subsequent reduction in anaemia side effects (Adamson & Eschbach 1998; Breiterman-White 2005; Gregory 2003; Kirilin 1992; Rebollo & Ortega 2002).

Patients with ESRF commonly experience sleep disturbances that can be due to uraemia, duration of dialysis therapy and chronic pain (Wallace-Williams et al. 2002). Other common manifestations of uraemia include sexual dysfunction and infertility, bleeding disorders, malnutrition, and altered immune response (Hricik 2003; Terrill 2002; Vanholder et al. 1996). In addition, neurological effects of uraemia can include restless legs syndrome, burning foot syndrome, memory dysfunction, and emotional lability (Hricik 2003; Terrill 2002).

Other uraemic effects such as uraemic pruritus are associated with hyperparathyroidism or a high calcium phosphate product and can cause significant discomfort for the patient (Hricik 2003). Renal osteodystrophy can also occur as a result of calcium, phosphate and parathyroid hormone imbalance and may be fatal if left untreated (Negrea 2003).

There are many gastrointestinal symptoms that patients with ESRF experience and each one has the ability to negatively impact on a patient's

QoL. Common symptoms include anorexia, nausea and vomiting, dyspepsia, diarrhoea, constipation, hiccups and dysgeusia (metallic taste in the mouth) (Lew et al. 2001).

Chronic pain is an issue for many patients with ESRF. Such pain may be related to primary illnesses such as polycystic kidney disease or due to secondary complications such as peripheral neuropathy or even age-related arthritis (Iacono 2004).

Separately, each physical change has the potential to decrease QoL. Unfortunately many people with ESRF commonly experience many symptoms simultaneously, which can make QoL more difficult to achieve. For example, it is not uncommon for people with ESRF to demonstrate LVH, anaemia, hypertension and hyperparathyroidism along with gastrointestinal and dermatological disorders (CARI 2003; Hurst 2002). Factors such as psychological and social functioning can be influential in allowing a person to accept and cope with such physical difficulties.

Psychological Changes in Patients with ESRF

Patients' psychological responses to illness can vary and is often related to loss, either actual or potential, and have been likened to the grief process (Auer 2002). Depression is the most common psychological response to dialysis and has been reportedly associated with a lower health-related QoL (Janssen van Doorn et al. 2004; Kimmel & Levy 2001; Mollaoglu 2004). The consequences of depression can be far-reaching and affect not only psychological functioning. It is now known that depression can lower the immune response, and for patients with ESRF who have already altered immune systems, the addition of depression to the mix can be devastating (Dayton & Lancaster 1995; Rosen 2002).

Helplessness, anxiety, fears of death and even feelings of guilt are all emotions that

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patients with ESRF often experience (Rosen 2002). Anger and denial are frequently employed by the patient to protect themselves from such intense and potentially uncontrollable emotions however, this can have the added negative effect of decreasing patient adherence to treatment regimens and reducing effective communication between the patient and healthcare team (Rosen 2002).

Social Changes in Patients with ESRF

Nutrition is an essential and major component of every person's life. For people with ESRF the importance of nutrition is increased due to potential adverse effects from poor dietary management. Such adverse effects include hyperkalaemia, hyperphosphataemia, protein-related malnutrition and fluid overload (Vennegoor 2002). A considerable part of social interaction between people involves eating and drinking so it is not uncommon for patients with ESRF to reduce their social involvement due to strict dietary and fluid restrictions (Mollaoglu 2004).

Other social issues can be affected by chronic illness and include the patient's employment status, relationships between family and friends, and even the desire to undertake leisure activities. Changes in social aspects can be due to physical and/or psychological alterations and there can be a negative cycle maintained in which the cause may also become the effect (Rebollo & Ortega 2002). For instance, the patient may withdraw from a leisure activity due to depression, which may cause the depression to be exacerbated.

Monitoring Quality of Life

Monitoring QoL can provide additional information on which to base clinical decisions regarding treatment, which in turn can improve patient care (Unruh

et al. 2005). Meers et al. (1995) highlight the importance of including the patient's perception of their own health status and QoL into patient care assessments so that healthcare professionals will possess similar perceptions of QoL to that of their patients. Measurements of health-related QoL are multidimensional and include physical, psychological and social functioning assessments made by various members of the multidisciplinary team (Unruh et al. 2005). Due to the complexity of determining QoL, there is no single standard method of measuring QoL in any group of patients, including those with ESRF. Rather, there are numerous instruments available that can be used to collect data on the various aspects of a patient's health status and provide an overall assessment of the QoL for that person.

In addition to objective physical measurements, there are many different QoL surveys available to assess the patient's perception of their physical, psychological and social functioning. These include the Kidney Disease Quality of Life Scale, Short Form (SF)-36 Health Survey, Mini-Mental State Evaluation, Short Depression Score and Instrumental Activities of Daily Life assessment (CARI 2004; Janssen van Doorn et al. 2004; National Kidney Foundation 2002).

Dialysis adequacy is a measurement of the physical response to treatment and there is little doubt that an increase in dialysis adequacy can improve the health status of the patient, which in turn can result in an improvement in QoL. Mollaoglu (2004) suggests that physical and mental health are mutually reinforcing so that an improvement in one area should lead to improvement in the other area. Measurements of dialysis adequacy are performed in Australia according to the clinical practice guidelines set out by CARI, a national organization which uses evidence-based medical practice (CARI 2004). These include the use of urea kinetic modelling, target biochemical and

haematological markers and assessments in nutritional status (CARI 2004).

Questionnaires have been developed which ask patients to rate their health-related QoL according to their physical, psychological and social functioning (Meers et al. 1995). Mittal et al. (2001) state that instruments using self-assessment by the patient are far more accurate in assessing the patient's QoL than those that are based on assessments made by healthcare professionals.

Nursing Involvement in Improving Patients' Quality of Life

Nurses can end up spending substantial amounts of time with their patients so they can be well placed to improve their patient's QoL. It is simply not enough to extend the lifespan of the patient with ESRF; it is also imperative to rehabilitate them as best as possible (Sesso & Yoshihiro 1997). Auer (2002, p81) put it succinctly when she wrote: 'the object of dialysis is to enable life to be lived and to provide a life that is worth living, not simply to keep the patient alive to be dialysed'.

It is essential that nurses identify areas of patient treatment regimens which may be adversely affecting the patient's QoL and develop strategies to reduce them. As Gregory (2003) suggests, health-related QoL components are often the areas of greatest concern for patients. While achieving adequate dialysis has long been the goal of many treatment regimens, Twardowski (2003) suggests that the goal should now be focused on achieving optimal dialysis. The role of nurses in providing patients with the best optimal dialysis involves minimising technical errors, adhering to strict infection control practices, working closely with the multidisciplinary team and maintaining current professional knowledge (Lee et al. 2003).

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Maximising patient function and well-being should be a priority in nursing care alongside actions that reduce morbidity and mortality (Trbojevic et al. 1998). Psychosocial aspects of a patient's QoL have been shown to be equally important as physical aspects and nurses can assist in improvements in this area. Iacono (2004) suggests that the haemodialysis setting may prevent depression in some patients because it allows frequent contact between staff and patients and can be a source of psychosocial support. Nurses should not underestimate the value that a supportive environment can have to improving patient QoL through understanding and reassurance. Workload constraints can make it difficult for nurses to find time to provide an opportunity to listen to their patients.

Nurses are an important educational resource for patients, not only regarding their illness and treatment, but also concerning coping strategies and available support groups. Patient's expectations of their illness, treatment and subsequent health status affect how they perceive their QoL, therefore education is vital as it can provide patients with the opportunity to develop realistic expectations. There are many different ways in which nurses can teach patients about their illness, treatment and methods of improving QoL. These can range from formal education such as individual or group information sessions, to informal teaching such as that given during the treatment process. With regards to the latter method, staff rotation means that many nurses perform the dialysis treatment for each patient and education often is repeated in various ways. While this may seem unnecessarily repetitious, it can be beneficial for the patient because it increases the likelihood that the patient will understand difficult concepts such as fluid overload and cardiac consequences. It also is important that nurses provide patients with the information on where to source further educational material themselves.

Nurses play a central role in the multidisciplinary team and can link the patient with other members of the team who can provide the patient with services that may improve their QoL. Nurses who develop a therapeutic relationship with their patients and spend time communicating are able to identify patient referral needs (Morgan 2000). If required, referrals can be made to social workers, occupational therapists, dieticians, physiotherapists and pastoral care. Nurses should always follow-up with the relevant health professional and discuss the patient outcomes from the referral.

Conclusion

QoL is a difficult concept to define as it is highly subjective and can be influenced by physical, psychological and social aspects which vary between individuals. As patients with life-threatening illnesses are now able to survive due to advancements in medical technology, it is important that the increase in the quantity of life is also matched with an acceptable level of QoL. An acceptable level of QoL will be one that has been decided by the patient as it is their perception that determines their QoL. Various QoL measurement tools exist that can be incorporated into patient assessments so that the broad picture of QoL can be monitored. Nurses have an important role to play in both monitoring and assisting their patients to improve their QoL. They can achieve this through the provision of optimal dialysis, a supportive environment, continuous education and involving other members of the multidisciplinary team. QoL should be a major consideration for all healthcare professionals who strive to provide their patients with holistic care, particularly in those with a chronic illness such as ESRF.

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