

Special Article

Renal Patients' Quality of Life as it is Affected by Pain**Theodora Kafkia, RN, MSc, PhD**

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Correspondence: Theodora Kafkia, A.Nastou 12, 54248, Thessaloniki, Greece**Abstract**

Quality of Life (QoL) is a complex multidimensional concept which is affected by various factors and is affecting various parts of a person's life. Chronic Kidney Disease patients have a high disease burden that has impact on psychological, physical and social aspects of their life and the QoL overall. Pain, a common symptom of renal disease, is evident in a patient's life and it could be clinically inflicted or caused by the primary disease and its complications or comorbidities. Pain is affecting everyday life and daily routine and if left untreated it could result in lower QoL. Renal healthcare professionals are providing emotional, social and spiritual support to their patients, alongside with managing the medical issues of the disease, ensuring higher QoL

Key words: Chronic Kidney Disease, Quality of Life, Psychological Support**Introduction**

Scholars have described Quality of life (QoL) as wellbeing, happiness or good living conditions (Cleary et al. 2005). QoL focuses on the individual's good physical, mental and social condition. Assessment of QoL depends on the theoretical framework within which it is estimated. Anthropology, financial and health sciences, psychology and sociology are all studying human beings, their environment and their QoL, but from different perspective (Polykandrioti et al. 2008).

Quality of life has been investigated since the ancient Greek philosophers Aristoteles and Plato, who wrote that quality of life ("ευδαιμονία"=evdemonia, bliss) is not depending on the quantity of material goods an individual possesses, but on the happiness which derives from virtuous and good acts of the soul (Oikonomou et al. 2001). In the begging of the twentieth century and after the Great War (World War I), QoL was perceived as acquisition of material goods, high standards of living and the ability to have leisure

and free time for relaxation.

It was after World War II (WWII), in 1948, that World Health Organisation (WHO) stated the first formal definition of QoL: *"Quality of life is defined as individuals' perception of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations and standards and concerns. 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 relationship to salient features of their environment"* (WHO 1979, WHO 1995).

From the sixties and onwards, QoL expands further and it includes education, health, economic and industrial prosperity, as well as unemployment rates. It is the time that QoL is measured with materialistic goods, personal freedom, leisure time and well-being (Minasidou & Bellali 2013). Population having achieved a good level of basic needs, "ζήν" (zin= living, surviving), had started to aim at "εϋ ζήν" (ef zin=good living, quality of

living).

Health-Related Quality of Life

The concept of Health-Related Quality of Life (HRQoL), a term firstly used in the 1970s, describes the impact of disease on psychological, physical and social aspects of a person's life, and the coping mechanisms that he/she is using during the disease process according to his/her previous health experiences. HRQoL includes functional capacity, emotional, cognitive, social and sexual functionality, as well as personal perception about illness and health, and is the most reliable indicator of disease and treatment effects on a patient and his life (Minasidou & Bellali 2013).

Quality of Life and Health-Related Quality of Life are not identical, but similar and complementary concepts. HRQoL, as it has been already mentioned, is representing the disease burden and the way the therapeutic management is affecting a person and his/her ability to lead a normal life (Schipper 1990). In conclusion, HRQoL is regarded the individual's personal definition of satisfaction with life, the personal sense of well-being, the ability to be self-dependent, independent and with control over his/her illness.

Research suggest that renal patient's personal perception regarding the disease's physical symptoms is more important in determining HRQoL of themselves and their families (Lindqvist et al. 2000, Shayamsunder et al. 2005, Weisbord et al. 2005, Gamondi et al. 2013, Mercadante et al. 2005, Yamamoto et al. 2009, Harris et al. 2012, Zyga et al. 2015b).

Chronic Kidney Disease and quality of life

Chronic Kidney Disease is a gradual deterioration of renal function and the inability to excrete metabolic waste products (Thomas 2014). It is a process that could last for few months to many years, but inevitable it could lead to need for Renal Replacement Therapy (haemodialysis or peritoneal dialysis) and/or transplantation.

Renal patients are experiencing feelings of despair and anxiety about their disease and its management resulting in lower self-esteem. Fear of the unknown is a common reaction at the onset of renal disease, as unfamiliar terminology and data are presented to patients, various complicated lab tests and procedures need to take place, such as renal ultrasounds and biopsy, insertion of peritoneal dialysis (PD) catheter or Central Venous Catheter for haemodialysis (HD), creation of vascular access (arteriovenous fistula or graft) (Davison &

Jhangri 2010, Baykan et al. 2012, Weisbord et al. 2013). Depression, anxiety and mood disorders, changes in sleep pattern, and thoughts of dialysis withdrawal or to end their lives are not uncommon manifestations of the psychological stress that renal patients experience (Davison & Jhangri 2005, Weisbord et al. 2014).

Diet and therapy restrictions or dialysis schedule could be the reason for isolation from friends and social events, or cause problems in work or inability to maintain a job. As a result, roles within the family could change putting additional burden to the patient, affecting his/her self-esteem and his and the family's QoL.

The impact of Chronic Kidney Disease on various aspects of a patient's life and QoL has been researched since the mid-1980s (Binik et al. 1982, Johnson et al. 1982, Simmons et al. 1984, Evans et al. 1985, Kutner et al. 1986). A decade later, comparison of QoL between renal replacement modalities (haemodialysis, peritoneal dialysis and transplantation) was common within the renal community (Kutner & Brogan 1992, Kimmel et al. 1996, DeOreo 1997, Jofre et al. 1998). Research interest continued to be high at the beginning of the new millennium, with HRQoL (symptoms, function in daily life and well-being) and its impact on outcomes to be on the spotlight (Perlman et al. 2005, Finkelstein et al. 2009, Mujais et al. 2009, Pagels et al. 2012).

Minor psychological problems can be faced with the help of the patient's social network (family and friends), but more severe incidents need to be addressed professionally either with medication or behavioural interventions. The later, help patients to cope with more stressful situations and gradually develop positive self-esteem. Some patients, the more self-dependent, face the chronicity of the disease and/or its handicap alone.

Pain

Pain is a common symptom in patients with Chronic Kidney Disease (Kimmel et al. 2003, Shayamsunder et al. 2005, Cohen et al. 2007, Weisbord et al. 2007, Weisbord 2016). Renal patients' pain levels are similar to those of other chronic non-hospitalised patients, such as diabetics, patients with Chronic Obstructive Pulmonary Disease (COPD) or chronic Heart problems, cancer or Acquired Immunodeficiency Syndrome (AIDS) (Saini et al. 2006, Solano et al. 2006, Cohen et al. 2007, Davison & Jhangri 2010, Lowney et al. 2015).

Pain causes various levels of stress which promote release of glucocorticoids and catecholamines from the endocrine system resulting in catabolism of fat, carbohydrate, and proteins and poor glucose use (Pasero et al. 1999). Further immune system suppression is caused by the same process resulting in higher inflammation rates. Activation of Sympathetic Nervous System (SNS), caused by pain, is affecting other major systems of the human body, such as cardiovascular, gastrointestinal and renal, resulting in higher blood pressure and heart rate, oxygen demands and cardiac workload.

Renal patients experience not only pathological pain deriving from the disease itself or its complications, but also clinical inflicted pain caused by diagnostic and/or treatment procedures/interventions carried out by renal professionals (Aitken et al. 2013). Joint and bone pain due to arthritis or renal osteodystrophy (Davison 2003, Gamondi et al. 2013), abdominal pain as a result of Polycystic Kidney Disease (Bajwa et al. 2004, Torres et al. 2007, Hogan & Norby 2010, Tellman et al. 2015) or neuropathic pain (Atalay et al. 2013, Santoro et al. 2013) could be some major sources of pain for chronic renal patients. Furthermore, the actual Renal Replacement Therapy could cause side effects such as abdominal distension (PD), steal syndrome or muscle cramps (HD) (Davison 2007a, Salisbury et al. 2009, Bagheri-Nesami et al. 2014, Moss & Davison 2014).

Pain, and especially untreated pain, can affect the patient's psychological and mental state, family and social relations and in general his/her QoL as it changes everyday life and daily routine (Chow et al. 2010, Jhamb et al. 2010, Theofilou 2011, Wyld et al. 2012, Bah et al. 2014, Gurkan et al. 2015, Taylor et al. 2016).

Effective pain management results in better performance in everyday activities and improvement in emotional wellbeing and social functioning (Kaba et al. 2007, Barakzoy & Moss 2006, Atalay et al. 2010, Klassen et al. 2013). Renal healthcare professionals are providing emotional, social and spiritual support to their patients ensuring higher QoL (Davison 2007a).

Conclusion

It has been presented that patients with Chronic Kidney Disease have multiple health and social problems that need to be addressed in order to achieve positive outcome and maintain a good QoL. However, personal perception of QoL is

sometimes different than that of the clinicians. For patients it could be that they are able to perform daily activities without any symptoms and/or pain or being able to participate in social life. For healthcare professionals, on the other hand, it could mean good clinical indicators and adequate dialysis levels. It could be the combination of both perceptions that is effective in guiding chronic renal patients through the disease process.

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