Psychonephrology: Psychological aspects in autosomal dominant polycistic kidney disease

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ABSTRACT

The biological, physical and psychological burden of a chronic disease has an impact on the quality of life of people who suffer it. The perception of quality of life is affected by psychological disorders such as anxiety and depression that have a high prevalence in people with chronic kidney disease (CKD). These factors are also related to a lower life expectancy. It is surprising that the psychological aspects surrounding people with autosomal dominant polycystic kidney disease (ADPKD), have received so little attention in the scientific literature, despite of its importance in the overall health of these patients. The relatively new discipline called psychonephrology provides a broader view of the impact that these aspects have on individuals with chronic renal disease with a consequent practical application. In this article we delve into the consequences and prevalence of psychological problems that can be related with CKD and ADPKD. First of all we will focus the subject matter of this article in the field of CKD and ADPKD within the scope of psychonephrology. In second place the article introduces the

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Servicio de Nefrología. Hospital Universitario de Gran Canaria Dr. Negrín. Universidad de Las Palmas de Gran Canaria. Las Palmas. Sapin. jrodperd@gobiernodecanarias.org concept of quality of life as a basic foundation that is affected when a person is diagnosed of CKD. In third place, we will present a recapitulation of the main research related to anxiety and depression disorders in CKD and ADPKD. Finally, the article makes a synthesis of the different lines of research presented.

Keywords: Chronic kidney disease. Autosomal polycystic kidney disease. Quality of life. Anxiety. Depression. Psychonephrology.

Psiconefrología: aspectos psicológicos en la poliquistosis renal autosómica dominante

RESUMEN

La carga biológica, física y psíquica que caracteriza a las enfermedades renales crónicas repercute en la calidad de vida de las personas que las padecen. Y a esto se suman los trastornos psicológicos, como la ansiedad y la depresión, que tienen una alta prevalencia en esta población de pacientes. Por ello, sorprende la ausencia de datos e investigaciones

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Palabras clave: Enfermedad renal crónica. Poliquistosis renal autosómica dominante. Calidad de vida. Ansiedad. Depresión. Psiconefrología.

INTRODUCTION

Autosomal dominant polycystic kidney disease (ADPKD) is a chronic renal disease that affects one in 400 people, and it is responsible for 6% of all cases of terminal kidney failure (TKF) in Spain.¹ Furthermore, ADPKD sufferers have one of the highest anxiety and depression rates among kidney patients. According to a meta-analysis by Nejatisafa (2007),² the combined prevalence estimates for depression and anxiety in patients with chronic renal failure (CRF) are 55.91 % and 46.72 %, respectively. This means that we are faced with an entity that affects patients' psychological and emotional state in addition to their physical condition.³

Studies of the psychological aspects of patients with chronic kidney disease (CKD) have multiplied in recent years, especially those intended to evaluate cognitive and emotional response as quality indicators for renal replacement therapies (haemodialysis, peritoneal dialysis and transplants).⁴ CKD takes a heavy biological, physical and psychological toll on the patients it affects. Patients' perceptions of their quality of life will therefore be affected by psychological disorders such as anxiety and depression, conditions which are not only highly prevalent among the CKD population, but which are also associated with lower life expectancy. Studying the psychological variables of patients with a chronic disease is a relatively new undertaking. It requires more in-depth research into non-

traditional risk factors such as anxiety, stress and depression. This line of research, known as psychonephrology, may provide new insight into the development and evolution of kidney disease.^{5,6}

Psychonephrology studies the psychological problems that affect people with kidney disease, those on dialysis and those having undergone a transplant. We hope that the new discipline will provide a more precise picture of the consequences of CKD. Fortunately, this is not a recent initiative. The 1980s saw a surge in research into how social, economic and psychosocial factors affected CKD development and evolution.7 These studies focused on discovering which problems were associated with the disease, and in particular, on the reasons why these patients did not comply with treatment. Researchers observed that the most frequent psychological problems associated with kidney disease were depression and anxiety. In addition, these disorders lead to attitudes that decrease treatment effectiveness. Patients with CKD not only refused to accept their disease as a reality, but also tended to oppose changing their lifestyles.

If we undertake a literature review focusing on the psychological aspects of ADPKD, the first conclusion is that this area is largely unexplored and filled with immediate challenges. With this in mind, the Nephrology Service at Dr. Negrín University Hospital is firmly committed to the study of the psychological impact of CKD and ADPKD. The second conclusion taken from the publications we reviewed is that most are concerned with two aspects which we believe to be important: quality of life and the concurrence of anxiety and depression. In this article, we will provide a summary of the main studies on quality of life and anxiety/depression in CKD. Lastly, we will outline the different lines of research presented here.

QUALITY OF LIFE

Studying a patient's quality of life involves striving to add more "life" per year, and not just adding more years to life expectancy (WHO, 2000). In this respect, Kaplan (1985)⁸ states that health policies should have a double focus: increasing lifespan and improving quality of life. This requires paying more attention to perceptive processes and to the subjective explanation of the new reality of CKD and the impact it has on a patient's psychological and physical condition.

To a great extent, quality of life is a subjective assessment made by a patient based on the different physical, psychological, social and environmental factors that affect his or her health. The physical factors comprise the symptoms of the disease and the treatment side-effects. The psychological factors include mental disorders. However,

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patients' surroundings, that is, their relationships with others and the social support they receive, plus the environmental factors of the residential and hospital space, also determine how well patients react and adjust to their disease.

The importance of these factors obliges to monitor and measure quality of life in order to plan a more overarching approach to caring for the patient. This evaluation should be a very useful instrument for predicting potential adverse consequences as the disease progresses, and to evaluate the effectiveness of the treatment.⁹ The variables most commonly associated with subjective well-being in scientific literature are physical symptoms, anxiety, depression, social support and the impact of the disease.¹⁰⁻¹²

ADPKD is an untreatable disease, and it is therefore possible that a diagnosis of ADPKD would affect a patient's psychological well-being, as is the case with other incurable hereditary diseases such as Huntington's disease. In addition, ADPKD presents with a series of associated complications which may also affect subjective well-being. These complications include chronic pain, hypertension, the development of cysts in other organs and gastrointestinal complications. All of the above, added to the hereditary and chronic nature of this disorder, have an obvious effect on the patient's quality of life.

However, one of our main problems when evaluating quality of life in CKD patients is the lack of studies on these patients during disease progression but before kidney failure. Although it is possible for drastic changes in life expectancy and lifestyle to occur, to date we have only been able to show (as in Perlman et al 2005) that the subjective wellbeing of patients without renal replacement therapy is greater than that of dialysis patients, but lower than that of the normal population.¹³

Something quite different occurs in patients who undergo transplants. According to various studies, these patients are the ones presenting the best indicators for quality of life and impact of the disease compared to those who receive haemodialysis (HD) treatment.14,15 In addition, the levels of subjective well-being in kidney transplant patients are similar to those among the general population. What is truly surprising is that the level of psychosocial dysfunction in kidney transplant patients is twice the level of their physical dysfunction. This indicates that they have more psychological problems. However, these studies also suggest that kidney transplants have more advantages and that comparing the two types of dialysis does not always provide significant results.16 According to some authors, the quality of life of patients undergoing outpatient peritoneal dialysis (OPD) is higher than that of patients undergoing inpatient HD.^{17,18} However, this conclusion is not solidly founded. There are also studies that point to similar levels of subjective well-being in both dialysis groups.¹⁹ This

similarity disappears when we focus on the degree to which health problems limit daily life activities. In effect, the score on the SF-36, a questionnaire measuring eight generic concepts having to do with health (Physical Functioning, Role-Physical, Bodily Pain, General Health, Social Functioning, Role-Emotional and Mental Health), is significantly lower for individuals undergoing outpatient PD.²⁰

In any case, the important conclusion when we compare both types of treatment is that both have a negative impact on quality of life. Nonetheless, the percentage of the score related to adverse affects associated with the progression of kidney failure and the percentage of the score stemming from the stress of beginning dialysis have not yet been calculated.

An even more uncertain picture is offered by studying ADPKD in patients who have not yet suffered kidney failure. The few public observations that have been obtained show that ADPKD patients have quality-of-life scores that are similar to those in the general population.²¹ In the same study, Ritz et al highlight that the scores for subjective wellbeing are similar to those obtained by patients affected by other chronic diseases. They also state that complications associated with ADPKD, such as haematuria, calcifications and infections related to the increase in kidney size, are unrelated to the overall mental health assessment.

ANXIETY AND DEPRESSION

The subjective quality life of the CKD patient depends greatly on the incidence of psychological disorders such as anxiety and depression, which are also highly prevalent in this disease.^{22,23}

People with chronic diseases are subjected to more stressful situations than the normal population is. This is especially true for patients with more symptomatic disorders, those suffering from diseases that require unpleasant treatments and all patients who must learn to accept lifestyle changes in general. This prospect of uncertainty, which is typical of CKD, gives rise to an uncomfortable feeling of alarm²⁴⁻²⁶ which can be perceived from the early stages of disease, when the patient is diagnosed, and continues to kidney failure and the onset of dialysis. With this in mind, it is normal for patients to feel distressed and uneasy when they are on the waiting list for a transplant.

Experts in this field of study have mainly focused on two objectives. The first is to determine the specific sources of stress for kidney patients. Many studies find that dietary restrictions, sexual dysfunction, changes in social and family relationships, loss of image and the work and economic issues account for most of the dysfunctional responses by patients.

On the other hand, researchers have taken care to determine the anxiety levels associated with different types of renal replacement therapy and related elements. Most of these studies recognise that treatment time, physical complications, age, sex, marital status, social support and employment can all be sources of anxiety.

Gala et al compared different types of treatment and discovered that patients on HD had higher scores for anxiety than those on outpatient PD.²⁷ This result stems from the fact that outpatient PD patients enjoy more control and independence. Furthermore, this sensation of control increases the patient's satisfaction and quality of life. However, we should point out that the training that this technique requires can cause some patients to suffer from anxiety and fear of learning, which would cause them to prefer HD.

The study by Gala et al²⁷ also shows that patients who have undergone transplants have similar scores to those who are on dialysis. This means that they suffer from new types of insecurity having to do with hospital discharge and fear of transplant rejection. Engel contributes another factor that can cause anxiety: detachment on the part of the family that believes that the patient now leads a completely normal life.²⁸ All of the above factors cause anxiety disorders to spike when patients are discharged and a prevalence of between 3 % and 33 % during the first years following the transplant.²⁹

One factor that plays an important role in the anxiety experienced by patients with kidney failure is the family environment. In this respect, studies show a large correlation between family support and the patient's psychological adjustment.³⁰ A supportive family is an important source of well-being and adjustment for the patient, as shown by Christensen et al³⁰ in their study of the effect of perceived family support, state of deterioration, and emotional adjustment in a sample of 57 transplant patients. According to their results, the most severely affected patients perceived less family support, meaning decreased family cohesion and interaction with more conflict, and their levels of depression and anxiety were higher than those in patients with more family support. The effect of family support was not significant for less symptomatic patients, however.

The second important psychological aspect that we must consider, "depression", is associated with the onset of a feeling of loss experienced by many patients with kidney failure as they discover that they are losing independence, their physical abilities are decreasing and there are noticeable differences in their family and job roles. Depression has a marked effect on the evolution and development of chronic diseases. This effect manifests as a decrease in self-care habits, poor treatment compliance, indifferent compliance with diet and decreased immunological state, and even abnormal family and marital relationships.³¹ All of the above indicators maximise the association between depression and mortality in patients on dialysis.^{32,23}

We have no precise data on the prevalence of major depression in patients with kidney failure, but different observations estimate it at approximately 25 %.34 We do know, however, that the prevalence tends to drop to 6 % in patients who begin outpatient PD, while 8 % tend to suffer from dysthymia. Recently, Abdel-Kader et al compared a group of HD patients with another group of CKD patients without kidney failure and found that the prevalence of depression was similar in both groups.³⁵ This is because despite having a better quality of life, patients in outpatient PD have worse psychological adjustment. Griffin et al also showed that 39.7 % of patients treated with outpatient PD versus 25.7% of patients undergoing HD had significant levels of depression, and that patients in outpatient PD had higher levels of anxiety.36 As shown by Watnick et al, the symptoms of depression and anxiety are even more common at the onset of dialysis treatment.³⁷ In this respect, Lopes et al found that responses to simple depression indicators, such as "do you feel so dispirited and sad that nothing motivates you?" or "do you feel dispirited and sad?" were associated with a higher risk of mortality and hospitalisation among patients on dialysis.³⁸ This correlation has been found for other groups in addition to patients receiving renal replacement therapy. In a more recent study, Kellerman et al examined the correlation between depression in early stages of the disease and mortality. They found that patients who scored one standard deviation above the mean had an estimated mortality rate 21.4 % above average.39

According to Lew and Piraino, the decrease in depression prevalence among patients undergoing outpatient PD is due to patients' having adapted well to the treatment, and also to the fact that symptoms of depression are associated with a high risk of mortality.⁴⁰ Low scores in perceived-well being plus depression are related to poor nutritional state, anaemia, decreased kidney function, and higher hospitalisation rates. In addition, higher depression indices themselves are related to a higher risk of peritonitis, which is likely due to poorer self-care habits and reduced immune defence.

In addition to the factors indicated above, there are others that help explain symptoms of depression in patients with kidney failure. These include the medication used, the stress associated with the disease, hospitalisation, concomitant infections and the simple fact of not feeling well. Consequently, depression, hopelessness, and feeling unwell decrease quality of life among patients undergoing renal replacement therapy.⁴¹

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In short, our data is sufficient to consider that anxiety and depression disorders are entities that present with kidney disease^{42,43} and have a significant impact on the treatment provided by nephrologists. Little is known to date regarding a more comprehensive way to approach the problem, but some studies provide clues to obtaining better results. One such study by Care et al⁴⁴ found that patients who are treated for depression are more able to cope with the stress of a transplant and at less risk for suffering problems that could interfere with self-care than those who do not receive treatment. Another study also found that untreated depression increases the risk of using maladaptive coping strategies.⁴⁵

It is therefore necessary to carry out more empirical studies that take the early stages of the disease into account and include detailed records of the psychological conditions that present with kidney failure. Even at a time when research on the effect of depression on survival provides inconsistent data, enough evidence exists for us to consider this psychological problem associated with other biomedical factors.

To the best of our knowledge, only one study explores the psychological aspects of ADPKD, and it finds a significant, positive correlation between depression and that disease.⁴⁶

CONCLUSIONS

In recent decades, different studies have suggested that CKD patients have a lower quality of life and higher prevalence of anxiety and depression disorders than the general population. In addition, suffering from one of these psychological disorders in the early stages of CKD is a predictor of higher risk of mortality once patients enter the more advanced stages of kidney disease. Although the correlation between mortality and symptoms of depression is unclear, it is possible this is the result of misleading factors in the samples, particularly, the death of the most depressed patients. In any case, psychosocial factors, subjective wellbeing and the development and progress of the disease are clearly inter-related in a way that requires more study.

Considering that results are scarce, particularly for ADPKD, and given the prevalence of this disease in the population (1/400), we must undertake research exploring the psychological aspects that contribute to the poorer quality of life experienced by these patients and their increased risk of starting dialysis earlier and having a shorter life expectancy.

On the other hand, some scientists suggest that the high prevalence of depression among CKD patients is mediated by a factor that must be considered in future investigations. They are referring to the similarities between the physical symptoms shared by patients with depression and those on dialysis as a result of their nephrological condition: pain, gastrointestinal disorders, weight gain, sleep disturbances, and fatigue.⁴⁶ Given that these coinciding symptoms can lead to overestimation of the prevalence of this psychological problem in patients with kidney disease, more rigour and precision will be needed in order to make a valid diagnosis. To that end, we are using the hospital anxiety and depression questionnaire⁴⁷ in our study. It does not contemplate physical symptoms in the overall score to diagnose depression; rather, it includes the cognitive symptoms characteristic of this mood disorder.

As for subjective well-being, Rizk et al warn, as other authors who study kidney disease, that the SF-36 survey is not sensitive enough to detect an unsatisfactory quality of life in patients with ADPKD.²¹ With this evaluation in mind, our study makes use of the KDQOL questionnaire, including a section specifically designed to measure quality of life in kidney disease.

We are convinced that biopsychosocial research can offer better care for the psychological problems and complexities associated with a kidney patient's condition. The results of this line of work will have implications on the field of nephrology. Early identification of psychological problems and their context can reduce disparities in the development and progression of kidney disease in both the short and the long term. Even more importantly, it could improve the quality of life of patients.

Conflicts of interest

The authors report potential conflicts of interests.

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