Psychological Aspects and Adjsustment of Pediatric Patients with Chronic Renal Disease

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Abstract
There is an ever increasing number of studies on the experience of pediatric patients suffering with Chronic Kidney Disease (CKD) resulting in the conclusion that chronic kidney disease affects the development of these patients, their behavior, emotions and social relations, causing a series of psychological reactions. The aim of this study was to make a review of the existing literature on psychological experience of patients with chronic kidney disease and their adjustment. The study findings are in the context of previous research and existing theories. Research was made in professional literature related to Chronic Kidney Disease in children and adolescents, selecting works published between years 1981 and 2014, using key terms such as children, adolescent, chronic kidney disease, in different combinations. Children starting from school age and later in their adolescence are in constant change, not only as regards their physical growth but also their emotional and sexual growth and coexistence for a long time with such a problem as kidney disease is very difficult and affects their lives in many ways. Simultaneously, CKD causes grave psychological damages. Survival to the disease is not satisfactory so deepening on disease perception, social and psychological factors affecting patients, are very important elements to improve the quality of life of these patients. Comprehension of their experiences is very important in order to decrease the effect of CKD on their lives and for them to receive the most effective treatment. Nephrologists and psychologists can work together by helping make the connections between psychosocial and biological factors.

Keywords: pediatry, psychological reaction, chronic kidney disease, adjustment

1. Introduction
The aim of this study was to make a review of the existing literature on psychological experience of patients with chronic kidney disease and their adjustment. The study findings are in the context of previous research and existing theories. Research was made in professional literature related to Chronic Kidney Disease in children and adolescents, selecting works published between years 1981 and 2014, using key terms such as children, adolescent, chronic kidney disease, in different combinations. Medical progress such as dialysis and kidney transplant have obviously increased the chances of survival for children and adolescents with CKD. However, non-function of an organ is corrected only partially, leaving great consequences on general health and quality of life of patients (Roventa et al., 2011).

Remarkable advances in the understanding and treatment of ESRD have been achieved over the last 20 yr, there has been increasing attention given to the individual characteristics of patients with an emphasis placed on understanding the effects, the patients' social situation, perceptions and responses to the illness. Although this area of "psychonephrology" has been a subject of research for many years, recent work in patients (Kimel, 2002; Cukor et al., 2006). A wide range of interventions have been designed and delivered to children with chronic illness and their families and reported in the peer-reviewed literature (Kibby, Tyc, & Mulhern, 1998; Bauman et al., 1997).

In earlier work by Bury, chronic illness was conceptualised as a “biographical disruption” that disrupted the patients' relationships and the practical tasks of living. (Bury, 1982).

By Stein et al. Chronic disease is defined as a state of health (a) lasts for years or longer; (b) requires specialised treatment or technology; (c) causes limitations in functioning, activities or social role of patients compared to physically healthy agemates (Stein, Bauman, Westbrook & Irey, 1993). In 1981 Drotar stresses that prevalence of disease impact is affected by the type of chronic disease and disease needs (Drotar, 1981).
Charmaz brought focus to patients’ perspectives in the day–today contexts within which they live, the ‘loss of self,’ and highlighted the complex interactions between different aspects of the illness experience (Charmaz, 1983). Over the past decades, a tremendous amount has been learned about the physiological and psychological reactions of dialysis patients. Despite this growing body of research, there are many essential elements that are still unknown (Cukor et al., 2007). The role that quotidian dialysis might have upon psychosocial variables has also not been studied in a rigorous manner (Cohen et al., 2007). However, many studies are inclined towards clinical studies focusing on psychosocial issues that patients with chronic kidney disease go through.

2. Emotional state and psychiatric changes

Patients with chronic renal disease must adapt themselves to complications caused by the disease on their health, identity, emotions, family, lifestyle, and their relations with others. Excess fatigue, complex treatments, side effects, limitations in consumption of liquids and/or food cause problems in patients. They need a long time to understand the diagnoses and adapt to it, to integrate medical treatment with their daily routine and to reset a sense of normality in their daily life (Tong et al., 2008). Presence of chronic diseases (CD) during childhood and adolescence considerably increases the risk of emotional disorders and those of behavior (Holden et al., 1997).

According to a study of Madden et al. (2003) which explored the cognitive and psycho-social results of children receiving dialysis since little age, it resulted that more than half of participants demonstrated behavior and emotional problems. Different studies showed that correlation analyses identified a number of important factors associated with poor adjustment to dialysis and/or anxiety and depression in children and parents (Fielding & Brownbridge, 1999).

Depression is generally accepted as the most common psychological problem in chronic renal patients. Although depressive symptomatology is commonly encountered in dialysis patients, the syndrome of clinical depression includes sadness, guilt, hopelessness, helplessness and changes in sleep, appetite, and libido (Finkenstein, 2000). Lopes et al. (2002) found a trend towards greater prevalence of depression in patients treated for ESRD for 1 yr. The study of Hedayati et al. (2005) showed that over the course of 2 yr, a diagnosis of depression was associated with more hospitalizations and increased duration of hospitalization but not with overall mortality when variation in demographic and medical factors was controlled.

According to data from literature, prevalence of psychiatric changes among children adolescents with CKD is different. However, it was higher than those observed in healthy population in different studies (Marciano et al., 2010). A series of hypothesis have been suggested to explain this increase in the spread of mental disorders. In addition to stress related to CKD and its treatment, studies have revealed other factors that contribute on the predisposition towards psychiatric disorders in this group. From them we could mention the lowering in levels of neurotropic factors deriving from the brain (BDNF) and low levels of serotonin in patients with CKD. They also reveal uremia, which may be accompanied with irritation, trouble, sleeplessness and delayed development of secondary sexual features (Bakr et al., 2007; Fadrowski et al., 2006). Also Gerralda et al. (1988) compared psychiatric elements of children waiting to receive dialyses and were receiving hemodialyses with a control group. The diseased children reported symptoms related to internalizing symptoms. They reported higher internalizing symptoms for children in the illness groups (McEvoy, 1990).

3. Quality of life

According to the World Health Organization (WHO), QoL is the "individual's perception about their position in life, in cultural context and value system of the place where he lives and in relation to your goals, expectations, standards and concerns". When health-related QoL refers to the measure of the patient's functioning, its physical-psycho-social well-being (The World Health Organization Quality of Life assessment, 1995). QoL of patients with end-stage renal disease is influenced by the disease itself and by the type of replacement therapy (Cernușcă-Mițariu et al., 2013).

Once patients with ESRD start to receive HD, they must face the chronic stress related to restrictions on their time, the economical and vocational costs related to treatment, functional limitations, dietary constraints, and possible adverse
effects of medications. Numerous studies have demonstrated that these patients have a lower QoL than that of healthy populations (Kao et al., 2009; Wolcott et al., 1988).

The study of Tjaden et al. (2002) described that children undergoing dialysis experience impaired growth, invasive procedures, school and social constraints. They often have poor self-esteem and a pervasive sense of losing their identity, body integrity, control, independence and opportunity. Several studies have suggested that QoL is enhanced dramatically in patients with ESRD treated with quotidian dialysis (Kurella et al., 2005; Heidenheim et al., 2003). The cognitive function of patients with CKD must be worse than that of their healthy agemates. This impairment must be related to their exposure to the disease. Cognitive changes are mainly related to learning and intelligence. (Bale et al., 1980).

Wasserfallen et al. surveyed 455 HD patients and 50 PD patients. Recruitment rates were more than 75%. The 2 groups were similar in age, sex, and duration of treatment for ESRD. QOL was similar in both groups, except for a perception of greater restriction of activities by the PD patients. Pain and discomfort and anxiety and depression had the most impact on QOL scores in HD and PD patients, respectively. (Wasserfallen et al., 2004). Anxiety as part of their emotional state is perceived as one of the most important aspects of quality of life related to health. Because of this anxiety must be identified at an early stage and be treated (Goldstein et al., 2007; Grootenhuis et al., 2006; Fadrowski et al., 2006). Although anxiety which coexists with CKD may have negative effects in functioning and physical health, so far there is no sufficient data on QOL which indicate that psychological treatment of stress and difficulties in patients with CKD improves clinical symptoms and quality of life (Reuben et al., 2012).

4. Adolescents and Chronic Kidney Disease

In patients with CKD, adolescence usually brings about a worsening in clinical control and therapeutic adherence. Moreover, there is an additional stressor, which is the change in the healthcare team that cares for the patient. A worsening in the clinical control has been demonstrated when these patients were referred to healthcare teams that treated adult patients (Reynolds et al., 1993). It was observed that the adolescents with CKD presented a high level of dependence, associated to the overprotection by family members and teachers. When these patients became adults, they reported that their inclusion in the treatment and clinical decisions and adequate explanations were considered very important contributions in their own management of the disease. (Reynolds et al., 1993).

In the study by McDonagh, the CKD itself, plus the side effects of the medications, the school absenteeism and the psychosocial alterations, notably the low self-esteem observed in these patients, resulted in growth and development retardation, pubertal delay and worse cognitive performance. (McDonagh, 2000, Choquet, Du Pasquier, Fedaeysky & Manfredi, 1997). These pubertal patients showed more concern regarding the normal adolescence questions, such as alcoholism, illicit-drug use, sex, weight, contraception and wanted these subjects to be debated during the treatment. (Choquet Met et al., 1997; Reynolds et al., 1993).

5. Intervention

A chronic illness can affect the individual child's psychological adjustment as well as his or her activities and level of functioning in a wide range of important settings, such as health care, school, and with peers. In addition, the impact of a pediatric chronic illness transcends the individual child and includes his or her family members (Drotoar, 2006). The multifaceted impact of pediatric chronic illness has a number of relevant implications for the design and implementation of psychological intervention research. First to be more effective, interventions generally need to be focused on specific target problems that are interfering with child's functioning (health or psychological adaptation) in specific settings (Kazdin, 2000). Target problems should have a clinically significant impact on the current functioning of children or family members in at least one clinically relevant context (Drotoar, 2006). Research on childhood chronic illness has considered a number of potential targets for intervention methods and outcomes (Kibby et al., 1998; Bauman et al., 1997; Thompson & Gustafson, 1996; Eiser, 1990; Garrison & McQuiston, 1989; Hobbs & Perrin, 1985; Pless & Pinkerton, 1975). Theoretical models and frameworks can facilitate practitioners and researchers decision making concerning designing and delivering psychological interventions with children with chronic illness.
Concern to promote quality of health care in children with (CKD) has developed together with the model of humanization of medicine which cares for patient satisfaction, suggesting special management choices which may have been adapted according to the needs of patients and personal choices (Varni, 2004). Addressing of patient’s preferences and needs in order to improve health care is ever more acknowledged as an important component to offer better health care especially to patients with chronic disease (Tong et al., 2008). However, treatment remains very invasive and requires deep changes in behaviour and lifestyle. Based on this fact treatment of chronic kidney disease requires multidisciplinary care: medical, psychological and social treatment. Medical issues are doubled by psychological effects and other personal factors such as difficulties of age, kind of family and educational level. Patient’s survival is not sufficient, in that aspect offering of care is important to increase quality of life (Iorga et al., 2014). Interventions on patients are important to increase their abilities to manage the disease, to engage themselves in the community, to participate in creative activities, and to stay attentive towards dialyses adn respective treatments (Tjaden et al., 2012).

Several studies have suggested interventions to increase exercise are associated with improved QOL in patients with ESRD. Although this is not unexpected if the criterion is functional scores, some investigations have suggested effects on mood predominate. (Koudi, 2004). Few studies have focused on the treatment of depression and anxiety disorders in ESRD patients. Treatment options including psychotherapy, cognitive behavioral therapy, and pharmacologic agents are similar to those used in the general patient population (Cohen et al., 2007; Mann, 1819 –1834, 2005). Ameliorating the symptoms of depression is important because it may improve other adverse outcomes associated with ESRD, including poor nutritional status and treatment compliance. (Kimmel & Peterson, 2006).

CKD patients and their families need to understand the importance of resilience, and medical personnel need to be educated in this area as well, in order to provide timely correct messaging that will help reduce the stress and frustration associated with chronic disease. An important factor affecting resilience in patients with CKD is the failure to give sufficient attention to health-promoting behaviors such as good nutrition, selfrealization, stress reduction, proper sports, and fitting leisure time. Ignorance of such health promoting behaviors can lead to increased morbidity and mortality and even suicidal behavior (Hedayati & Finkelstein, 2009). The treatment options for anxiety disorders are similar. Like antidepressants, adjustment of anxiolytic dose for level of GFR is needed when these agents are prescribed. (Rickels & Moller, 2002). The study of Balen et al., showed that stimulation of these children to carry out activities that are normal for their peers may be useful (Balen et al., 1996).

5.1 Coping with te stressor

Some literature has called engagement coping with the engagement coping with the stressor “primary control engagement coping” stressors and engagement with one’s emotions about the problem “secondary control engagement coping” (Connor-Smith et al., 2000). The third dimension represents “disengagement” or efforts to withdraw from the stressor and one’s emotions. According to this model, primary control engagement coping includes: problem solving (e.g., “I try to think of different ways to change the problem or fix the situation”), emotional regulation (e.g., “I get help from other people when I’m trying to figure out how to deal with my feelings”), and emotional expression (e.g., “I let someone or something know how I feel”). Secondary control engagement coping includes: positive thinking (e.g., “I tell myself I can get through this or that I’ll do better next time”), cognitive restructuring (e.g., “I tell myself that things could be worse”), acceptance (“I just take things as they are, I go with the flow”), and distraction (“I think about happy things to take my mind off the problem or how I’m feeling”). Disengagement coping includes: denial (e.g., “I try to believe it never happened”), avoidance (e.g., “I try not to think about it, to forget all about it”), and wishful thinking (e.g., “I deal with the problem by wishing it would just go away, that everything would work itself out”) (Connor-Smith et al., 2000). Initially, cognitive distraction was placed under disengagement coping, but factor analyses revealed that it correlated more strongly with secondary control coping than with disengagement.

The authors noted that because distraction requires engagement with a thought or activity unrelated to the stressor, with the goal of decreasing emotional arousal, it is a form of secondary control engagement coping (Connor-Smith et al., 2000). Using this model, both primary and secondary control engagement coping were related to lower levels of internalizing and externalizing symptoms, and disengagement coping was related to higher levels of internalizing and externalizing symptoms (Connor-Smith et al., 2000). Snethen et al., (2004) investigated the coping strategies used by adolescents with end-stage renal disease. Within this group of adolescents, the most frequently used coping strategy by healthy and ill

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children was listening to music, with over half of the participants indicating they used this strategy “most of the time.” Strategies that were “never” used by most of the participants included: taking drugs not prescribed by the doctor and talking to a rabbi/priest/minister.

Adolescents with end-stage renal disease used different coping strategies than healthy adolescents, but they used a similar number of total copies strategies. Compared to healthy adolescents, adolescents with end-stage renal disease more frequently coped by venting their feelings (e.g., letting off steam by complaining to family members) and avoiding problems (e.g., telling yourself the problem isn’t important), and less frequently coped by engaging in demanding activities or seeking professional support. It is concerning that adolescents with end-stage renal disease were less likely to seek professional support; perhaps because they were so involved with the medical profession, they perceived seeking professional support as a further sign of weakness or another invasive procedure (Snethen et al., 2004).

Support received by others is also important in addition to self-adaption of patients with chronic renal disease. Social support and integration are now acknowledged as important factors in adjustment to chronic and acute illness. Social support has been broadly and consistently linked to improved health outcomes in a variety of chronic illnesses in numerous studies independent of geographic settings, SES, and ethnic backgrounds (Christensen et al., 2000; Brissette et al., 2000). A wide range of interventions have been designed and delivered to children with chronic illnesses and their families and reported in the peer-reviewed literature (Kibby, Tyc & Mulhern, 1998; Bauman et al., 1997).

Pediatricians and pediatric nephrologists as well as other health care providers such as nurses and social workers remain the cornerstone for early detection and intervention. They may assume the supervisory role of direct patient care, provide emotional support and perform or supervise follow-up activities (Assadi, 2013).

6. Conclusions

Reconsidered studies revealed that chronic renal disease is a very serious chronic state which has an important impact on the lives and adolescents, causing a series of improper psychological reactions. Understanding of their experiences is very important to reduce the effect of CKD on their life and in order to receive effective treatment. Nephrologists, psychosocial can work together to understand the connections between psychosocial and biological factors. Survival from the disease is not sufficient so deepening on the perception of the disease, social and psychological factors which affect patients are important elements to improve the quality of life of these patients.

References


