

Experience of Pediatric Patients with Chronic Renal Disease at "Mother Theresa" University Hospital Center

Jeta Ajasllari

Phd. Candidate, University of Tirana, Faculty of Social Science,
Department of Psychology and Education, Albania.

j.ajasllari@live.com

Abstract

The aim of this study was to present a better understanding of the illness, needs of patients with this type of pathology. Participants on the interview were 15 children and adolescents of age 11-15 years old diagnosed at "Mother Teresa" University Hospital Center, Nephrology Department. To draw the study results it was used "Nvivo" software, where through a careful analyzing process were identified four key topics: Physical impact (medical treatment); psychological impact (anxiety, difficulties they face); impact on social relations (family, activities and relations with age mates); way of adaption (self belief, religious belief, multidisciplinary staff). The findings reveal the impact of the illness on the life of the patients all over the illness course. The main recommending of this study are based on deepened exploration of the patients' perception of the illness setting up an appropriate program to support patients with chronic renal disease as well as their families.

Keywords: experience, child, adolescent, chronic kidney disease, need

1. Introduction

Like most chronic illnesses of childhood, CKD seriously affects children's lives as they negotiate the stress associated with disease management and the prospect of a shortened life span (Frauman & Lansing, 1983; Hobbs, & Sexson, 1993).

Additionally, patients undergoing chronic HD show evidence of accelerated protein catabolism, which might be due to the significant loss of amino acids induced by dialysis (Pertosa, Grandaliano, Gesualdo, & Schena, 2000). Thus, it is reasonable to presume that lower levels of albumin can be significantly correlated with greater levels of fatigue (Bonner, Wellard, & Calabiano, 2010). Dialysis treatment can significantly impact upon body image, as patients might perceive themselves as unattractive. For example, procedures to create a point of access for dialysis via a fistula, neck line, or catheter can all change the appearance of the body. Immunosuppressant drugs taken to prevent organ rejection also contribute to obvious bodily changes impairing self-acceptance (Thomas, 2002).

In one of our previous studies, 21% of dialysis patients had symptoms of anxiety. In addition, 15.5% of these subjects had co morbid depression and anxiety, and 44.3% of depressed patients had co morbid anxiety (Chen et al., 2010). Furthermore, suicide risk was not only attributed to depression, but also to anxiety. Uncertainty about the future and fear of losing control of one's life are important factors associated with anxiety that adversely impact emotional stability (Haenel, Brunner, & Battagay, R, 1980). Anxiety is a common psychological problem that may emerge during the initial course of dialysis, and is a reminder to clinicians to pay close attention to this issue.

As already discussed in the previous sections, several studies have investigated the relationship between illness perceptions and treatment perceptions of patients with ESRD on the one hand, and quality of life on the other hand (Covic, Seica, Gusbeth-Tatomir, Gavrilovici, & Goldsmith, 2004; Fowler, & Baas, 2006; Griva, Jayasena, Davenport, Harrison, & Newman, 2009). From all these studies, it can be concluded that more perceived personal control, less perceived (negative) consequences (from both the illness and treatment), and a lower emotional response are generally associated with better outcomes in patients on dialysis (Covic, Seica, Mardare, & Gusbeth-Tatomir, 2006). Investigated whether illness perceptions of patients on haemodialysis', reported at a certain point in time, could actually explain subsequent changes in quality of life outcomes over time.

Among psychological issues, uncertainty about the future and lack of energy emerged as the major contributors to poor QoL (Tsay & Healstead, 2002). A patient's dependency on treatment may negatively impact his or her QoL and exacerbate feelings of a loss of control (Chilcot, Wellsted, Da Silva-Gane, & Farrington, 2008). Improved QoL is correlated with higher self-esteem and lower levels of mood disturbances (Wolcott, Nissenson, & Landsverk, 1988).

Survival of patients is not enough, in that aspect provision of care is important to improve quality of life (Iorga et al., 2014). Based on this fact treatment of chronic renal disease requires a multidisciplinary approach: medical, psychological and social treatment. Interventions on patients are important to increase their ability to manage the illness, to involve themselves in the community, in order to participate in creative activities and to stay alert towards dialyses and respective treatments (Tjaden, Tong, Henning, Groothoff, & Craig, 2012).

2. Research Methodology

2.1 Methodology

Participants of this study were 15 patients of age 11- 15 years old, diagnosed and being treated at "Mother Teresa" University Hospital Center. The participants participated at the qualitative stage of this study to explore their experience with CKD. The participants were patients diagnosed with chronic renal disease, from whom 11 were at the pre-dialyses stage and 4 patients were having dialyses. From the study were excluded patients with mental deficiencies, limited abilities and patients who had undergone kidney transplant.

Table 1. Number of participants in the study

Sex	Number of patients participating in the study (15)
Male	9
Female	6

Table 2. Treatment of patients participating in the study

Treatment of patients	No.
Pre-dialyses	11
Peritoneal Dialyses	1
Haemodialysis	3

Half structured interview

It was used the qualitative method of half structured interview consisting of 15 open and close questions, which are administered face to face the participants in the study. Practically were held 15 half structured interviews. The interview was divided into three key parts which explored:

1. Experience of patients during their coexistence with CKD,
2. Quality of life as regards their living with renal disease.
3. Exploration of their physical, psychological, emotional needs related to the disease and their treatment.

All participating patients in the interview together with their parents gave their consent to participate in the study. After the interviews it was done the analyses of topics and it was used Nvivo version.7 software to analyze the interview data.

The interviews were analyzed identifying the codes and categories later, the respective codes and categories were grouped based on data and integrated into larger topics. By analyzing the half-structured interviews with patients diagnosed with CKD were identified the following topics:

2.2 Findings

The aim of the study is to understand the impact of chronic renal disease on the quality of life of patients.

Impact of CKD

1. Physical impact (medical treatment)
2. Psychological impact (anxiety, difficulties they encounter)
3. Impact on social relations (family, activities and relations with age mates).
4. Way of adaption (self-belief, religious belief, multidisciplinary staff).

3. Results and discussion

Physical Impact

Based on the explored topics. As regards the first category physical impact, the patients express that they experience great physical fatigue and loss of energy. The below stated statements of the patients reflect the way they experience the disease. The dialysis process is very difficult for them, following the sessions and the several-hour procedure itself causes them great fatigue.

"I prepare well after I sit there ... I know I will have to stay for several hours until I finish all ... and when I get out of there sometimes I am so exhausted that I cannot walk"

The constant consultations they have to follow affect their normal life.

"I have to come to hospital now and then for check-up, analyses, controls.. I can no longer continue like this, I feel very tired without energy"

A great number of patients reveal how their physiological changes affect their cognitive functioning, the relation between the psychological functioning and the psychological one such as memory and concentration. Below illustration:

"Everything changes when you are in dialyses, memory also included, sometimes I forget what I have to do for the moment and get back from the street"

"I cannot concentrate when I read a book, I start to read a few sentences then I lose my concentration"

Impact of treatment

Receiving of medicaments is part of treatment of patients with CKD. In addition to the positive effects on the health of patients, medicaments have their side effects on the physical aspect; the patients receive medicament cortisone which affects their image for themselves.

"I have small body"

"I started to swell ever and ever, so that when cousins and friends meet me are surprised by my change, my hair started to fall to the extent that could not distinguish myself"

"We do not grow..."

The dialysis process is another part of the treatment of patients with CKD, participants reveal dependence to treatment with dialyses, which affects their time, quality of life and sense of control.

"Dialyses takes so much time and hinders me in many things. When I want to visit cousins or other I cannot because I have to follow dialyses 3 times a week and cannot go out to play with friends or attend a sport activity"

"It is very tiring for me to follow dialyses, it feels like I no longer have my life in my hands but it depends on that little apparatus which seems to control everything about my life"

Holding of catheter in the neck or inner side of the thigh (femoral) is something indispensable for their life but very fastidious and that affects their image for their own self.

"I keep the catheter on the neck at such a visible place, and get more bothered from my friends who are curious to know what that is, the peoples' eyes are fixed on me as if I were having something strange"

Psychological Impact

Based on the stages of kidney disease, some stages are the most difficult and the disease is experienced in a very traumatic way, depending on the knowledge the patients and their family members have on the disease. The way they experience it affects the way they adapt to the disease and follow medical treatment.

"I really felt it when they inserted the catheter on my shoulder, there was blood all over and the catheter was getting inside... I was not aware that the tube would be place in there and they did not tell me it was frightening, I could not sleep for days and even now I tremble when I recall that"

Negative feelings

Participants experienced negative feelings like fear, insecurity, despair, loss of hope for the future. State of anxiety was experienced by all the interviewed participants.

"I feel terrible.... this illness does not let me do anything, I cannot even go to school"

"What if I cannot have kidney transplant, what do I do !?"

"Every time I want to do something I fear that it will be bad for my disease, even when I am with friends I have a feeling of fear that something will happen from one moment to another"

In the interviews with these patients they frequently mention death and fear of the procedure.

"Sometimes when the dialyses starts I get scared that i feel that blood will burst from the tubes and I will die"

Impact on daily life activities

Patients with CKD very much limited in their life style, they are subjected to a series of limitations, in food and liquids. These limitations cause a series difficulties in the daily routine of the patients and their social relations,

"Food and liquids have been prohibited to me, I am allowed to drink very little water during the day, but this is difficult for me because it is not easy for me to go to school not only because of physical fatigue but also because others can eat what they want unlike me"

"It is more difficult when they sometimes offer things to me but I cannot eat and move away"

Social activities and free time

Chronic disease limit patients in their daily and social activities, they have to follow therapy sessions three times a week for several continuous hours. Travel from the districts to Tirana and the dialyses process itself limits them.

"Dialyses takes a lot of time, all day is used up I get up very early to be at hospital at 8 o'clock and after dialyses travel home but when I return I am tired and only sleep and this happens three times a week every time i have dialyses"

"I cannot play any kind of sport"

Relations to others

Patients state in their interviews that they feel upset, hopeless, very tired and without energy and also the impact of medicaments on their physical appearance makes them retire from company and condoned to their own selves. Their looks are different from that of their age mates. They are smaller than them because their body ceases to develop, dialyses patients have a visible foreign object (catheter- drainage tube) and those who sue cortisone are swollen, all these affect negatively their self-esteem and self control.

"I try to approach other children to play with them, but I do not feel strong enough to play, and if I join I will spoil their game"

"I have abandoned my friends, I feel different from them, they are very well, they look very well, there is something wrong with me"

"I sometimes had better stay alone, and the parents give so much care to me, but I am taking so much time from their life"

"My mother is with me everywhere, but my brother and my sister need her and I am taking mother from them"

Adaption to the disease

Taking of control - It is paramount that the patients do not get demoralize and fall prey to the suffering, sadness and insecurity that they have in themselves. Some participants see their treatment and dialyses as a very important process for their health.

"...at the beginning it was very difficult for me to do dialyses, I felt reluctant and the idea of the apparatus upset me but slowly I began to perceive it as something for my good that would help me"

"With the help of the apparatus I will get better, it will keep me alive till i do the transplant"

Belief in God – some participants although still at small age had belief in religion, which helped them to move forward.

"I believe that God will help me, mom often says that Him (God) knows well what he does"

"I always say God, Please help me, every time I enter the dialyses"

"Even though now I am suffering a lot at with my illness i know that God will cure me and that I will also become like others"

Care for Patients- From the interview with them, the participants state that psychological assistance in addition to their medical treatment is very important. Multidisciplinary treatment of the patients is necessary.

"I do not want to keep inside me what I feel, I need to express them otherwise they will suffocate me"

"I want to participate in different activities which will attract my attention away from this, which will make me feel good and also useful. "

"I want to accept my disease and coexist with it without the fear of death"

As seen from the interviews, patients with chronic renal disease experience negative feelings like fear, insecurity, hopelessness and anxiety. They experience a wide range of somatic symptoms, anxiety and decrease of quality of life (Murtagh et al., 2007).

In this study the participants refereed that they would not prefer to engage in different social activities, they felt tired, consumed and without energy. According to Snethen et al, it also presents a social cost especially as result of treatment regimens which limit the "activity" of these children and socializing (Snethen, Broome, Bartels, & Warady, 2001).

Participants were withdrawn in the social sphere and preferred to stay alone rather than in the company of others, even family. They felt different in their relations with their age mates and sometimes redundant in the family. Children with CKD are often reported to face difficulty with their psycho-social adaption (Marland, 1995).

The psychological effect of the illness on the quality of life of the participants is quite big impacting all aspects of their life. However they needed assistance and they asked for that. Some of them assisted themselves through self-control and change of thoughts and expectations on the disease, some others asked for that from others and some in religion by believing in God.

Although anxiety, which accompanies CKD, may have negative effects on functioning and physical health, so far there are no satisfactory data on QOL which reveal that psychological treatment of anxiety and difficulties of patients with CKD improves the clinical symptoms and quality of life (Reuben & Tinetti, 2012). 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, Drotar, Leventhal, Perrin, & Pless, 1997).

Such interventions get focused on specific problems demonstrated by patients with chronic disease in their functioning. Research on this matter reveal a considerable number of factors that can be taken as targets for the method of psychological intervention (Garrison & McQuiston, 1989).

Many studies utilizing self-reports in children have consistently reported lower levels of distress, depression, and behavioral problems in children with cancer than in healthy peers (Phipps & Srivastava, 1997; Schoenherr, Brown, Baldwin, & Kaslow, 1992). Moreover, Phipps and Steele documented that repressive adaptation is also characteristic of children with chronic physical illnesses (Phipps & Steele, 2002).

4. Conclusions

In this qualitative study i have explored the experiences and needs of patients with chronic renal disease. The findings lead us to the understanding of quality of life of the patient and their experience treating the illness based on personal feelings and understanding of the illness.

Some limitations of the study: It must be accepted the fact that the experience of patients included in the treatment of chronic renal disease is very complex. Some simplifications done to the way of their experience cannot be avoided during processing of data. The findings reveal a big impact of the illness on the life of patients during the whole illness course. The main recommendations of this study are based on the deepened exploration of the patients' perception on the disease by setting up a suitable program to support patients chronic renal disease and their own families.

References:

- [1] Bauman, L.J., Drotar, D., Leventhal, J.M., Perrin, E.C., & Pless, I.B (1997). A riview of psychosocial interventions for children with chronic health conditions. *Pediatrics*, 100, 244-251.
- [2] Bonner, A., Wellard, S., & Caltabiano, M. (2010). The impact of fatigue on daily activity in people with chronic kidney disease. *J Clin Nurs*, 19, 3006-3015.
- [3] Covic, A., Seica, A., Gusbeth-Tatomir, P., Gavrilovici, O., & Goldsmith, D.J. (2004). Illness representations and quality of life scores in haemodialysis patients. *Nephrology Dialysis Transplantation*, Vol.19, No.8, pp. 2078-2083.

- [4] Covic, A., Seica, A., Mardare, N. & Gusbeth-Tatomir, P. (2006). A longitudinal study on changes in quality of life and illness representations in long-term haemodialysis patients with low co morbidity. *Medica – A Journal of Clinical Medicine*, Vol.1, No.4, pp. 12-19.
- [5] Chen, C.K., Tsai, Y.C., Hsu, H.J., Wu, I.W., Sun, C.Y., Chou, C.C.(2010). Depression and suicide risk in hemodialysis patients with chronic renal failure. *Psychosomatics*, 51, 528-528.
- [6] Chilcot, J., Wellsted, D., Da Silva-Gane, M., & Farrington, K. (2008). Depression on dialysis. *Nephron Clin Pract*, 108, 256-264.
- [7] Fowler, C., & Baas, L.S. (2006). Illness representations in patients with chronic kidney disease on maintenance hemodialysis. *Nephrology Nursing Journal*, Vol.33, No.2, pp. 173-186.
- [8] Frauman, AC., Lansing, L. (1983). The child with chronic renal failure: 1. Change and challenge. *Issues Compr Pediatr Nurs* 6, 127–133.
- [9] Garrison, W. T., & McQuiston, S. (1989). Chronic illness during childhood and adolescence: Psychological aspects. In D. Drotar (Ed.), *Psychological Interventions in Childhood Chronic Illness* (pp. 45-46). American Psychological Association Washington, DC.
- [10] Griva, K., Jayasena, D., Davenport, A., Harrison, M., & Newman, S.P. (2009). Illness and treatment cognitions and health related quality of life in end stage renal disease. *British Journal of Health Psychology*, Vol.14, No.1, pp. 17-34.
- [11] Haenel, T., Brunner, F., & Battegay, R. (1980). Renal dialysis and suicide: occurrence in Switzerland and in Europe. *Compr Psychiatry*, 21, 140-145.
- [12] Hobbs, SA., Sexson, SB. (1993). Cognitive development and learning in the pediatric organ transplant recipient. *J Learn Disabil* 26,104–113.
- [13] Iorga et al. (2014). Psychological and social problems of children with Chronic Kidney Disease. *European Journal of Science and Theology, February*, Vol.10, No.1, 179-188.
- [14] Kibby, M.Y., Tyc, V.L., & Mulhern, R.K. (1998). Effectiveness of psychological intervention for children and adolescents with chronic medical illness. A meta - analysis. *Clinical Psychology Review*, 18, 103-117.
- [15] Murtagh, FE., Addington-Hall , JM., Edmonds, PM. (2007). Symptoms in advanced renal disease: a cross-sectional survey of symptom prevalence in stage 5 chronic kidney disease managed without dialysis. *J Palliat Med*. 10, 1266–1276.
- [16] Marland, S. (1995). 25th annual conference of the European working group on psychosocial aspects of children with chronic renal failure. *Pediatric Nephrology* 9, 123.
- [17] Pertosa, G., Grandaliano, G., Gesualdo, L., & Schena, F.P. (2000). Clinical relevance of cytokine production in hemodialysis. *Kidney Int Suppl*, 76, S104-111.
- [18] Phipps, S., Srivastava, D.K. (1997). Repressive adaptation in children with cancer. *Health Psychol* 16, 521–528.
- [19] Phipps, S., Steele, R. (2002). Repressive adaptive style in children with chronic illness. *Psychosom Med* 64, 34–42.
- [20] Reuben, DB., Tinetti, ME. (2012). Goal-oriented patient care—an alternative health outcomes paradigm. *N Engl J Med* 366, 777–779.
- [21] Snethen, JA., Broome, ME., Bartels, J., & Warady, BA. (2001). Adolescents' perception of living with end stage renal disease. *Pediatric Nursing* 27, 159–161.
- [22] Schoenherr, S.J., Brown, R.T., Baldwin, K., Kaslow, N.J. (1992). Attributional styles and psychopathology in pediatric chronic illness groups. *J Clin Child Psychol* 21, 380 – 387.

- [23] Tsay, S.L., & Healstead, M. (2002). Self-care self-efficacy, depression, and quality of life among patients receiving hemodialysis in Taiwan. *Int J Nurs Stud*, 39, 245-251.
- [24] Tjaden, L., Tong, A., Henning, P., Groothoff, J.C., & Craig, C. (2012). *Arch. Dis. Child.*, 97(5) 395-402.
- [25] Thomas, N. T. (2002). *Renal Nursing*, Baillière Tindall, London, UK, 2nd edition.
- [26] Wolcott, D.L., Nissenon, A.R. & Landsverk, J (1988). Quality of life in chronic dialysis patients. Factors unrelated to dialysis modality. *Gen Hosp Psychiatry*, 10, 267-277.