International Journal of Innovation and Research in Educational Sciences
Volume 3, Issue 2, ISSN (Online): 2349–5219

Focus Group with Pediatric Patients Diagnosed with Chronic Renal Disease

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Abstract – **Coexistence for a long time of children and teenagers with chronic kidney disease is very difficult and affects their life in many ways. Patients need to change their lifestyle and adopt to medical treatment in order to prevent progress of their disease. The aim of this study was to explore experiences and perspectives of patients who have been diagnosed with Chronic Kidney Disease. Participants in the study were 12 children and teenagers of age 11-15 years diagnosed at University Hospital Centre "Mother Theresa" at Pediatric Nephrology-Dialyses department. Through a careful analysing process were identified 4 important themes. It is concluded that Chronic Kidney Disease has a huge impact on the patients' life during the whole course of the disease. The way the chronic disease progresses in patients depends on the level of knowledge they have on the disease, psycho-social impact and healthy conversation.**

Keywords – **Experience, Perspective, Chronic Kidney Disease, Need.**

I. INTRODUCTION

Chronic Kidney Disease (CKD), is a term which includes the disease in which the patient has a grave and irreversible reduction of the kidney function for over 3 months. CKD is a progressive disease of a foreseeable trajectory which requires lifelong treatment. Within 5 years of determining of diagnoses with CKD, 80 % of the patient's progress to the last stage of the disease (ESRD). In the advanced stages 4, 5 (End-Stage Renal Disease, ESRD), during which the kidneys can no longer support the body homeostasis, the patient is dependent on renal replacement therapy (RRT): the patient undergoes the process of dialyses or kidney transplant. Patient faces a series of other medical problems related to the kidney operation and therefore he must placed under very long treatment and management of the disease in order to survive (Snethen et al., 2001). While dealing with the chronic disease, a series of factors affect evaluation of the situation, such as uncertainty related to the situation, responsibility for treatment, limitation of activities, and disease duration (Van Veldhuizen & Last, 1991).

Any changes of the state or factors related to the disease demand new efforts by the patients to face them. Everyday life of these patients changes because of some limitations, mainly the physical ones, because of the characteristics of the disease which require constant adoption as well as development of strategies to face the disease. They undergo dietic and hydric limitations, difficult invasive treatments and hospitalization. Quality of life (QoL) of patients with CKD suffers considerable damage because of requests deriving from their clinic conditions and treatment (Soliday, Kool & Lande, 2001). Patients experience a wide range of somatic symptoms, anxiety and lower quality of life (Murtagh et al., 2007).

Studies which focus on the perspective and experiences of patients are few, they are mainly focused on patients who do dialyses (Gregory, Way, Hutchinson, Barrett & Parfrey, 1998; Bass et al., 1999; Curtin, Mapes, Petillo & Oberly, 2002; Al-Arabi, 2006;) and patients who have undergone kidney transplantation (Crowley-Matoka, 2005; Waterman et al., 2006; Orr, Willis, Holmes, Britton, & Orr, 2007), while studies focused on the other stages of CKD are very few.

Concern to promote quality of health service has developed together with the model of medicine humane which is concerned about the pleasures of patients suggesting special management solutions which could be more tailored to the needs of patients and personal choices (Varni, 2004). Although CKD could have negative effects on physical functioning and health, so far there is considerable data of Quality of Life which show that psychological treatment of anxiety and difficulty of patients with CKD improves clinical symptoms and quality of life (Reuben & Tinetti, 2012).

Addressing of preferences and needs of the patient to improve health care is considered every day more as an important component to provide ever better health care, especially to patients with chronic disease (Tong et al., 2008). Effective strategies which aim to prevent progress of CKD, must understand better which are the viewpoints, ideas and needs of patients. This way learning programs will satisfy the needs of patients to get informed and to increase their abilities to deal with the changes in their lifestyle.

Theme	Sub-theme
1. Understanding of the Disease	➢ Difficulty in understanding the disease. ➢ Emotional Experiencing.
2. Management of the disease	➢ Lack of knowledge. ➢ Management of dialyses.
3. Changes in lifestyle	➢ Interruption of school. ➢ Physical limitations. ➢ Social isolation. ➢ Entertainment activities.
4. Patients' needs.	➢ Need for emotional support. ➢ Financial needs.

Focus groups are a series of discussions planned so that they can collect perceptions related to a special issue. This method allows participants to make questions to each other, exchange experiences and perspectives with each-other. The group process helps the group participants to explore their viewpoints in such manner that cannot be achieved by means of an individual interview and also discuss on issues they find difficult to discuss in an individual interview. The participants can present their ideas and can avoid some aspects of the topic which they do not consider important to discuss. Focus groups do not serve only to discover what the people think, but also to understand the way they think and what they do.

II. MAIN TEXT

In this study were developed two focus groups where each group consisted of 6 participants. The focus groups lasted 2 hours and were directed by the study author (J.A.). Participants in the study were patients who had been diagnosed with CKD and belonged to stages 3-4 of the disease (n=6), patients who were undergoing Haemodialysis (n=5) and Peritoneal Dialyses (n=1). Number of participants involved in the study is a considerable one as regards the number of patients diagnosed with chronic kidney disease at “Mother Theresa” University Hospital Centre. Many of the mentioned topics were present with the majority of participants in the study, a fact that increases the significance of the study.

The list of main topics that were discussed in the focus group was compiled based on consideration of literature and talks with the medical staff. The list was reviewed through the pilot test with 4 patients with CKD. Transcription was achieved through the use of program QSR Nvivo 7, transcriptions were analysed by identifying codes and categories. Later, codes and categories were grouped in a database and were integrated into bigger topics. Through the topics were examined the changes in patients before dialyses and those who were under dialyses process as regards the way they perceived their disease.

The focus groups developed in the study included 12 participants of age 11-15 years. Participants in the focus group discussed about their experiences, perspectives, ideas and ways of adoption with chronic kidney disease. From analyses of the transcripts there were identified 4 main themes.

2.1 *Understanding of the Disease*

Difficulty in Understanding of Chronic Kidney Disease: Patients state that they find it difficult to understand their medical diagnoses. They feel confused and do not have knowledge about what will happen with them in the future.

"I do not know what is happening to me and my body”
(Patient, pre-dialyses)

"There is a bad thing in my body which I will have forever"
(Patient, pre-dialyses)

"I do not know what I have but I know that I can not recover"
(Patient, dialyses)

"I know I am in a very bad state, this pipe (catheter) at the neck helps me live, if this pipe weren’t ....."
(Patient, dialyses)

Living with chronic kidney disease is explained by the patients as loss of their daily normality. The illness impacts the way patients see their life.

"I have been in hospital for many days, I do not know when I will return home”
(Patient, pre-dialyses)

"I come to hospital every second day, I am not like the other children ...I am different"
(Patient, dialyses)

Emotional Experiencing: Patients feel anxiously, they have uncertainty about their health state, experience fear from medical procedures, feel unprotected and hopeless. The dialyses patients, experience a very aggravated emotional state.

"I am very sad, I fear that something bad could happen to me unexpectedly”
(Patient, dialyses)

"I do not want to get injections, they really hurt"
(Patient, pre-dialyses)

"I am very frightened when I see the nurse at the door"
(Patient, pre-dialyses)

"I do not want to come here anymore, I want to stay home and play with my brother?"
(Patient, dialyses)

"I get up very early in the morning when I come for dialyses, I have no strength and I am very unhappy with everybody"
(Patient, dialyses)

2.2 *Management of the Disease*

Lack of Knowledge: Patients with chronic kidney disease stated that they did not know what medicaments they should take, only their parents had the knowledge, they did not know the time of taking them also and they were not informed about the nutritional limitations they should follow and the minerals which were harmful to their body.

"I do not know what medicaments I should take, my mom gives them to me all the time"
(Patient, pre-dialyses)

"Yes, mom always reminds me to take my medicine"
(Patient, pre-dialyses)

"I like chips very much, I cry until mom buys them for me"
(Patient, dialyses)

"I know that's salt is harmful to me but sometimes I eat it hiding from mom"
(Patient, pre-dialyses)

"Sometimes I want to drink a lot of water but mom always keeps it away from me"
(Patient, dialyses)

Management of Dialyses: Patients who undergo dialyses find it very difficult, adding to this the time spent, trip, fatigue.

"We travel every second day to come to Tirana ... I get really tired"
(Patient, dialyses)

"I always cry when I wake up in the morning, I do not want to come"
(Patient, dialyses)
"When I go home I do not have strength for anything....."
(Patient, dialyses)
"I sometimes throw up in the minibus"
(Patient, dialyses)

Patients who have never had dialyses fear the process seeing the other children who are carrying a foreign object in their body

"I am afraid to pass near there where those machines are"
(Patient, pre-dialyses)
"Why does he carry that pipe at the neck...., I am very scared"
(Patient, pre-dialyses)
"The nurse took me in there to see, I do not want to get in there any more...."
(Patient, pre-dialyses)

2.3. *Changes Interruption of School*

Most of the patients , mainly the dialyses patients do not attend school any more or miss it a lot because of the dialyses process. Other patients who do not do dialyses are absent because of their difficult health state, hospitalization or constant check-ups with doctors. Also the patients state that they can not participate in different physical activities or play with their friends.

"I am absent a lot at school... I also have fallen behind with lessons"
(Patient, pre-dialyses)
"I no more go to school...."
(Patient, dialyses)
"I sometimes go to school but I do not stay more than 1 or 2 hours"
(Patient, dialyses)
"They do not let me go out with my neighbourhood friends"
(Patient, pre-dialyses)

Physical Limitations: Patients are obliged to limit themselves from certain physical activities

"The doctor has prohibited for me to run, play ....I can not play with my friends"
(Patient, pre-dialyses)
"After dialyses I feel very tired, all I want is sleep"
(Patient, dialyses)
"When it is time to end dialyses I always feel sick in the stomach"
(Patient, dialyses)

Social Isolation: Patients state that they feel tired, exhausted and differently from their age mates this situation makes them more withdrawn and affects their level of self-esteem. Many of them also had to face their age mates who constantly asked them about the pipe in the neck, why they were absent so often, what was wrong with them that they were so small. All these elements affected the social withdrawal of the participants.

"I want to get out and play with my friends but I have no strength and then they laugh at me"
(Patient, pre-dialyses)
"Every time I get out they ask me about the pipe"
(Patient, dialyses)
"They laugh at me because I am the smallest of all friends"
(Patient, dialyses)
"During the school break I stay in the classroom because I cannot eat things like them"
(Patient, pre-dialyses)

Entertaining Activities: Patients felt bad because the disease hinders them for many activities, they cannot pay visits to their relatives, cannot go on excursions with their age mates etc.

"I do not go anywhere where my class goes ... I always cry"
(Patient, pre-dialyses)
"I want to go to my grandmother's...I have many cousins there but mom and dad do not take me there...we go there very rarely, and this makes me sad"
(Patient, dialyses)
"Now that I have dialyses I do not get out to play at all"
(Patient, dialyses)
"I used to be in a football team but now I do dialyses"
(Patient, dialyse)
"I want to go with my sister to dance but mom no longer takes us there"
(Patient, pre-dialyses)

2.4. *Patients' needs*

Need for Emotional Support: Patients stated that they really needed support from their siblings, relatives and age mates.

"When my sister stays with me and plays with me ... I get well and forget my disease"
(Patient, pre-dialyses)
"I really love it when my cousin comes to my house"
(Patient, pre-dialyses)
"I get happy when my close friend calls me on the phone when I am absent at school"
(Patient, dialyses)

Financial Needs: Families and children who deal with chronic kidney disease in addition to their difficult emotional state also have to deal with economic problems. Family must cover the disease expenses and special needs of the child. Dialyses patients state that one of the parents has had to give up working in order to assist the child.

"Mom does not go to work ... she stays with me all the time"
(Patient, dialyses)
"I know that mom and dad can not satisfy all my desires"
(Patient, pre-dialyses)
"I have heard them quarrel and say they money is not sufficient"
(Patient, pre- dialyses)

The majority of patients with chronic kidney disease do not have much information on their diagnoses, cooperate very little, and are not aware of the medical treatment they have to follow to improve their health state. Patients need specific counselling as regards their nutritional diet, liquids they must consume and the effect of medicaments (National Collaborating Centre for Chronic Conditions. Chronic Kidney Disease, 2008).

Most of the patients do not know why they must not eat certain foods. Lack of knowledge causes problems with managing of the disease, lack of cooperation and having of unalloyed food hiddently. Also patients express themselves frightened from the dialyses process as they do not have information's on its usefulness for their health. Patients need to be assisted while they are taking important decisions through effective patient-doctor communication (Hack, Degner & Parker, 2005; Wikblad, 1991).

Being constantly absent at school, detachment from entertainment activities, having a series of physical limitations, caused to the patients the feeling of being different from others revealing problems with self-esteem. The participants were withdrawn socially and preferred to stay alone rather in the company of others because they felt different in their relationship with age mates. CKD has a huge psycho-social impact on the diagnosed patients (Marland, 1995; Kimmel, 2002; Perez Dominguez et al., 2011).

As regards their needs the patients state that they were in desperate need of emotional support but their financial issues also need to be taken into consideration. Economic support would also be a very important element for them. Lack of cooperation's comes as a result of lack of information about their disease and the instructions they need to follow. The parents' role is very important in this aspect. Patients who have little knowledge and do not follow medical instructions have a very slow progress and disease complications. Parents must inform their child and explain reason for the use of medicaments and nutritional limitations they must follow not by strictly banning them but with explanations. This way the child understands and becomes cooperative with the medicals staff and medicament treatment.

Also patients despite their age, although they are children, need to be explained not only the current situation but also what is the future step they are going to take, what procedure they are going to follow (dialyses, transplant), where will the future take them, what it means to live with chronic kidney disease. So patients will not see dialyses as a terrifying process but as an important means for their physical health. Supporting patients and their education on self-management helps them take an active role and make decisions related to their health, thus assisting the improvement of their own health (Anderson & Zimmerman, 1993; Bodenheimer, Lorig, Holman & Grumbach, 2002).

III. CONCLUSION

Chronic Kidney Disease has a huge impact on life of patients during the whole course of the disease. The way the chronic disease progresses for patients depends on the level of knowledge they have as regards the disease, psycho-social impact and healthy conversation with the medical staff. Some limitations of the study: It must be admitted the fact that the experience of patients involved in the treatment of chronic renal disease is very complex. Some simplifications done to the way of their experiencing are unavoidable.

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