Quality of life of adolescent patients undergoing hemodialysis at Dr. Soetomo General Hospital, Surabaya (instrumental case study)

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ABSTRACT

Background: Chronic Kidney Disease (CKD) is defined as a decrease in kidney function or kidney damage that lasts more than three months, which can affect all stages of age. The end stage of kidney disease is End Stage Renal Disease (ESRD), which requires dialysis or a kidney transplant. The long course of the disease and the long treatment procedures can affect the quality of life of patients. All dimensions of the quality of life of adolescents undergoing hemodialysis, namely physical, functional, psychological and social dimensions are affected during the course of the disease. Hemodialysis, which is a central element for adolescent CKD patients, can affect quality of life, either increasing or even decreasing quality of life. The aim of this research is to qualitatively analyze the quality of life of adolescent patients undergoing hemodialysis at Dr. Sutomo Hospital Surabaya.

Methods: Qualitative with a case study approach. Data collection used interviews (in-depth interviews), observation and documentation and research subjects were determined purposively. Data analysis used Miles and Huberman’s interactive model analysis technique.

Results: There were 7 subjects consisting of 4 teenage girls and 3 teenage boys, with an age range of 12-18 years. The four dimensions of quality of life studied, namely physical (short stature), functional (educational barriers), psychological (embarrassment, sadness) and social (peer relationships) are affected by CKD. There are dynamics between dimensions so that not all dimensions worsen in the subject, so that subjects can accept and undergo hemodialysis as a part of their life.

Conclusion: Findings on quality of life dimensions can be used to provide recommendations for adolescent patients to maintain their quality of life while undergoing hemodialysis and to optimize Consultation Liaison Psychiatry to develop more optimal treatment strategies for adolescent patients undergoing hemodialysis.

Keywords: Quality of Life, Adolescents, Chronic Kidney Disease, End Stage Renal Disease, Hemodialysis.

INTRODUCTION

Chronic kidney disease (CKD) is a major health problem in the world whose incidence and prevalence are increasing. Chronic Kidney Disease is a clinical syndrome with a gradual decline in kidney function over time.1 The Indonesian Renal Registry (IRR) reports that the number of kidney failure sufferers continues to increase. In 2015, there were 2105 patients undergoing hemodialysis with 30,554 active patients.2 The frequency and prevalence of CKD are increasing globally and it is estimated to be the sixth leading cause of death in the world.3 Over the last two decades there has been an increase in the incidence of CKD in the child and adolescent population. The etiology of CKD in children and adolescents is mainly caused by Congenital Anomaly of Kidney and Urinary Tract (CAKUT), Steroid Resistant Nephrotic Syndrome (SNRS), chronic glomerulonephritis such as Lupus Nephritis or Alport Syndrome, with a small number of cases caused by nephrolithiasis, Wilms Tumor, and infectious and interstitial diseases.4

Indonesia does not yet have national data on the incidence of CKD in adolescents. Data from Kariadi Hospital in 2015-2017 was 566 patients, while Dr. Soetomo in 2019 collected data from 2009 to 2019 and there were 139 new pediatric CKD patients during that time period (Data from the Pediatric Nephrology Division of Dr. Soetomo Hospital). Previous research shows that the quality of life aspects most affected in adolescents with CKD are the cognitive, pain and emotional domains. Pain is present in 60% of hemodialysis patients. Two-thirds of patients complain of emotional decline, while half of the population experiences cognitive impairment. Low socioeconomic status related to unpleasant emotional status and physical/short stature make patients different from their normal friends.5 Adolescents undergoing hemodialysis must experience adjustments to changes in their lives related to their disease conditions. These adjustments include limited physical and motor abilities, lifestyle, dependence on parents or caregivers, and dependence on dialysis machines for the rest of their lives. This can reduce the quality

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of life of these teenagers. Decreased quality of life, which can be caused by abnormalities in kidney function itself and facing other challenges in the form of repeated hospital stays, painful medical procedures, school absences and activity restrictions. The aim of this research is to analyze and explain the spectrum of quality of life consisting of a picture of the physical, functional, psychological, and social dimensions of adolescent patients undergoing hemodialysis at Dr Soetomo Hospital Surabaya.

**METHOD**

This research is an instrumental case study, which is often called a single instrumental case study. Data analysis used Miles and Huberman’s interactive model analysis technique, which consists of data collection, data reduction (verbatim), data presentation, and drawing out conclusions or verification. The location selection for this research was carried out purposively (with certain considerations and objectives). This research was located at the Dr. Soetomo General Hospital, Surabaya. Research subjects were taken using a purposive sampling technique until saturation from adolescent individuals undergoing HD with various characteristics. Subjects who met the inclusion criteria underwent intensive interviews, individually, and separately from their caregivers. Intensive interviews were conducted with a duration of 30-45 minutes per session per research subject. Interviews can be conducted more than once for each research subject. This study used inclusion criteria in the form of subjects still undergoing hemodialysis for at least three months, subjects who underwent hemodialysis twice a week, and subjects aged 12-18 years. The subject can communicate in the Indonesian language and understand the meaning or content of the conversation. Subjects and families are willing to take part in the research and sign the research consent form (informed consent). The patient is in stable condition (not weak). Meanwhile, the exclusion criteria were patients with communication problems (intellectual disorders, autism, Down syndrome) who were assessed during the initial interview through observation by the researcher.

The questions used in this research use guidelines from the PedsQL instrument which can measure the four domains of quality of life and are supplemented with a number of qualitative questions which are open-ended questions that were developed from certain theories with the aim of exploring the four domains of quality of life.

**RESULTS**

This research involved 7 subjects. Of the seven subjects, there were four teenage girls and three teenage boys. All subjects are Muslim, live with their parents and are not married. Three subjects are still registered as active students at school and four subjects are no longer in school. Four subjects live in Surabaya, three subjects live outside Surabaya. All subjects underwent hemodialysis twice a week.

Discussion of research results is carried out directly in reporting research data in the form of narratives of groupings of themes and sub-themes obtained from observations and interviews with research subjects. Themes and sub-themes in the results of this research are classified based on the interview guide which serves as a guide during the interview process and refers to the research objectives.

**Physical dimensions**

What is included in the physical dimension are the physical changes experienced by the subject before and after undergoing hemodialysis. Hemodialysis itself, although it is a therapy, can actually have an impact on the subject’s appearance because it involves routinely inserting needles into the subject’s body, which means that apart from experiencing physical changes due to CKD, the subject also experiences physical changes due to the hemodialysis procedure. The two subjects who wore the hijab did not mind the problem of physical changes due to the HD procedure because they were not visible from the outside, thereby reducing embarrassment. Two subjects actually felt proud of the injection marks at the location of their AV Shunt. Four subjects felt embarrassed about their short body posture due to illness since childhood.

“It's okay, I'll just think of it as decoration... this is a limited edition, not everyone has it.... Besides, I always wear Muslim clothes so it's not visible.”

“In fact, I'm proud, I think this is a sign that I've fought to recover.” “From the start, I was proud because I knew there would be scars... so it's just like a tattoo. My friends even said it was cool”

"Since I was little, my right leg has been deformed, it was amputated, so now I wear a prosthetic leg... so that I look like a normal person, even though in reality I'm not like that." “How come I'm not tall? I am now 134cm tall only.”

**Functional Dimensions**

The functional dimension consists of the subject’s ability to perform physical activities, mobility, and self-care. Physical activity includes hobbies, formal and informal learning activities, playing and other activities as a teenager. Two subjects are no longer in school. Four subjects are still registered as students, but only one is actively participating in the educational process at school, while the other three subjects are on leave from school. Having to undergo HD regularly causes disruption to the educational process which in the future can hinder the subject’s potential to develop.

“But I'm still at school now... yes, even though I haven't been to school for four months now... yes, because I'm still adjusting to my condition, so it's okay not to go to school, rather than later I'll be tired, right?” “I haven't used CAPD since then I have to have regular HD, I'm not going to school... yes, I haven't been to school since three months ago” “I haven't been to school for three years... since the start of my illness, I was in the third grade of junior high school and after graduating from junior high school, I haven't been to school anymore.”

**Psychological Dimensions**

All subjects now appear to have entered the acceptance phase of their illness and the HD procedure they are undergoing. Six subjects experienced psychological changes when they first discovered they were sick, and are now psychologically quite stable and able to control their emotions. One female teenage subject had been treated by a psychiatrist. Six subjects
still have anxiety and fear about the future, such as whether the subject will be able to go to school again, whether the subject will be able to get married, and whether the subject will be able to make his parents happy.

“If I’m sad, I’m really sad at the start... well, a week early... at the start of CAPD, then when I was told that my CAPD was a problem, I was really sad, I was already thinking about having to have HD, it’ll make me weak, I can’t do this, I can’t do that, but turns out it’s okay, my imagination is like that” “It’s just that sometimes I feel down, why should I... Just yesterday when I was hospitalized I was also being treated by a psychiatrist because I was sad. But now I’m not sad anymore... I realize I have to start getting up” “There’s sadness... why do I keep doing this... I used to feel tired in the first two years, I’m tired, why do I keep doing this, when will I get better... now I don’t feel that way anymore”.

Social Dimension
Social interactions both qualitatively and quantitatively are aspects seen in the social dimension. CKD patients, especially those undergoing HD, tend to withdraw from social interactions/friendships. Several influencing factors are the HD schedule which is quite long and the routine frequency which makes HD teenagers reduce the time and quality of their social interactions, physical fatigue before and after HD makes patients have no passion for socializing with the environment, feeling embarrassed about their self-image makes the patient's self-confidence decrease. One Subject is still socialized and can still enjoy going to recreation areas with friends and family. Two subjects considered HD time as the time to go for a walk and get out of the house for a while. The other four subjects stayed at home more.

“I still like going to the mall with my friends” “Since I got sick, I haven't played much...I've just been sick too, so a lot of my friends and teachers have also come to me several times. At home or call to ask about news” “At home I rarely leave the house, I rarely play with the neighbors either...not because I’m embarrassed...but because I’m too lazy to talk...I haven't socialized for a long time, I haven't been to school for a long time, but my friends are okay, it's only on HD here, just chat while HD”.

Meaning of Illness
Researchers explore the meaning of pain experienced by research subjects to find out to what extent the subjects accept their condition. Two subjects considered their illness as a means to erase sins. Three subjects felt that their pain could make them stronger individuals and better children for their parents.

“As an expiation for sins... Allah is testing me... so that I become stronger” "so that I become a more disciplined person... obeys my parents... surrenders, to get close to God.” “So that I can be more grateful and remember God more because I used to be so engrossed in my own world that I forgot about God, rarely prayed, played all the time, I was a naughty child.”

DISCUSSION
In accordance with the results of previous studies which stated that the quality of life of adolescents suffering from CKD and undergoing hemodialysis decreased, this was also found in this study. Adolescents with CKD have significantly lower health-related quality of life in physical, school, emotional, and social domains than healthy adolescents. CKD patients with physical limitations due to the disease or its complications will affect their independence, leading to disappointment and ultimately low quality of life. This is because CKD affects the work function of all body organs which reduces the body's ability to work optimally, affects body growth and causes body deformity which makes patients feel inferior, feel a lack of control over their own body, experience social isolation, feel inadequate. Unable to become independent, uncertainty about their health and future, and lifestyle restrictions. Subjects felt that no one would accept them as life partners when they were adults. The researcher carried out supportive psychotherapy to the subject that everything that happened had been arranged by God Almighty, including a soul mate for the subject and the researcher taught the subject to focus on the current treatment process, taught the patient to improve their abilities in accordance with current limitations so that they could improve values and self-confidence in the future.

Chronic Kidney Disease and its treatment often decrease participation in school-based academic activities. Prolonged absence from school and delays in submitting school assignments due to medication-related problems can have detrimental effects on maintaining relationships with peers, self-esteem, and academic achievement, negatively affecting quality of life so strategies are needed to optimize education. Subjects can take formal or informal education programs which can be done when the patient is at home so that it does not interfere with the subject's rest time and hemodialysis time or can also take part in virtual learning at school.

The psychological dimensions of CKD adolescents undergoing dialysis treatment were lower than those of healthy controls. This is closely related to the domains identified by Tjaden et al. which state that CKD adolescents feel themselves losing control, high dependence on caregivers, endless dependence on dialysis machines, impaired body integrity, limited lifestyle, limited opportunities for social interaction, and hampered academics. In addition, they face limitations in developing healthy activities with their peers, such as having fun, playing, and feeling comfortable with themselves, especially their body image as they grow up. Situations like this can cause feelings of depression and can even lead to mental disorders such as depression, where patients will easily feel hopeless, less able to adapt in facing changes caused by their illness, blaming other people, themselves and even God Almighty for the illness they suffer and might affect the quality of his life. Interdisciplinary health teams consisting of play therapists, social workers, psychologists and family psychotherapists along with doctors and nurses need to continually address the real potential problems and emotional distress suffered by children and adolescents, along with a coordinated plan of care. That includes self-care strategies, psychosocial programs, and planned sessions for self-
management, information, and contact with other patients to improve their emotional condition. The positive side that they get is that the presence of chronic kidney disease at an early age strengthens family ties because the social support that appears in the family allows the child to adapt to the changes produced by the disease, increasing his independence, self-esteem and self-confidence.

The limitations of this study include the research topic being quite sensitive because it makes the subject remember their illness, so the subject easily becomes sad during the interview, so an intensive and good report and communication approach is needed. All subjects come from the same ethnicity and religion made lacking exploration from a cultural and cultural perspective. Our suggestions for further research include additional criteria for research subject characteristics, a larger research sample and/or from various locations (other hospitals in Surabaya or outside Surabaya) as a comparison and to provide a picture of the general population, research could involve families/parents/caregivers in research, and hemodialysis units can provide recreational and educational facilities: reading books, collaboration with schools and good report and communication also plays a role in his social skills.

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ETHICS APPROVAL AND CONSENT TO PARTICIPATE
This study protocol was reviewed and approved by Dr. Soetomo Academic Hospital Ethical Board (0544/KEPK/XII/2022). Because all data were provided by the database retrospectively, informed consent of the participants was not required.

CONSENT TO PUBLICATION
Not applicable.

COMPETING INTERESTS
The authors declare having no competing interests.

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