



Subjective Well-Being in People with Nephrotic Syndrome: Exploring Role of Lifestyle and Self-Confidence

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INTRODUCTION

Nephrotic syndrome can affect both children and adults and is found in both developed and developing countries. In developed countries, the percentage of adult individuals suffering from nephrotic syndrome is generally in the range of 30% to 35% (McCloskey & Maxwell, 2017). In contrast, in Indonesia, 10% to 15% of adults are afflicted by nephrotic syndrome (Wiguna & Sudhana, 2019). Every year, a significant number of adults receive a nephrotic syndrome diagnosis, with several Indonesian hospitals reporting a considerable number of patients diagnosed with chronic kidney disease, particularly nephrotic syndrome. For instance, at Dr. RSUP. Soetomo Surabaya, it was reported that 90% of men and 39% of women were diagnosed with nephrotic syndrome (Ifadha et al., 2021). The substantial prevalence of nephrotic syndrome in Indonesia poses a significant challenge to the subjective well-being of affected individuals.

Research reveals that a majority of nephrotic syndrome sufferers are high school students, accounting for 91.9% of cases, and indicates that male sufferers tend to experience higher levels of anxiety than females (Peng et al., 2015). This underscores the fact that some individuals with nephrotic syndrome struggle to attain subjective well-being. This challenge arises because nephrotic syndrome, without proper treatment, can lead to other conditions such as kidney failure, causing anxiety if not addressed promptly. Prolonged nephrotic syndrome can progress to chronic kidney disease and kidney failure, with a prevalence rate of 4% to 5% (Basir et al., 2018). In fact, the number

of chronic kidney disease cases continues to rise, necessitating caution. According to a survey conducted by the Indonesian Ministry of Health, there were 324 chronic kidney disease patients, with 111 patients recovering and 199 succumbing to the condition. CNN Indonesia (2018) reported that the prevalence of chronic kidney disease reached 33.7%, with a mortality rate of 13.8%. Unfortunately, the high mortality rate associated with chronic kidney disease only exacerbates the anxiety of sufferers and makes it even more challenging for them to achieve subjective well-being.

Nephrotic syndrome is a dangerous chronic condition that cannot be completely cured (Carter et al., 2020). It is characterized by the body's deficiency in protein, resulting in proteinuria, edema, hypercoagulability, hyperlipidemia, and other metabolic disorders (Cancarevic et al., 2022). Common traits of nephrotic syndrome include edema, hypertension, hypoalbuminemia, and frequent relapses (Lionaki et al., 2021). People with nephrotic syndrome may experience difficulties in social interactions and behavior, often leading to isolation and limited activities (Puspasari et al., 2016).

In addition to affecting social interactions and behavior, drugs containing steroids can negatively impact the quality of life for nephrotic syndrome sufferers. The side effects of treatment can affect various aspects of life, leading to physical disorders, nervous system issues, and psychosocial problems that can significantly affect overall quality of life (Kartawijaya et al., 2022). This diminished quality of life can have psychological consequences, including depression and anxiety among people with nephrotic syndrome (Peng et al., 2015). Consequently, nephrotic syndrome has a profound impact on all aspects of a sufferer's life.

This is partly because individuals with nephrotic syndrome have ample free time due to limited activities, which can lead to a sense of reduced productivity and difficulty in achieving subjective well-being (Sharif et al., 2021). Naturally, it is challenging for those with nephrotic syndrome to maintain a positive outlook and attain subjective well-being in the midst of their illness. This is further evidenced by the way nephrotic syndrome patients react to high proteinuria results with negative emotions, leading to increased stress (Bakkum et al., 2019). Individuals with nephrotic syndrome also frequently experience feelings of depression and anxiety, making it challenging for them to find happiness and satisfaction in their lives. This underscores the difficulty in achieving subjective well-being for people living with nephrotic syndrome.

Rationale of Study

Research conducted by Palareti et al. (2016) reveals that subjective well-being among individuals with chronic diseases is generally at a low level. This low subjective well-being is attributed to the stress resulting from the lengthy treatment process, as well as the frustration and hopelessness arising from restricted activities. The prolonged treatment regimen can lead to exhaustion and impair memory function. Additionally, individuals with chronic illnesses often experience strained social relationships with those around them, further contributing to their diminished subjective well-being. In a separate study Newi et al. (2022) demonstrate that individuals can attain higher levels of subjective well-being when they successfully manage stress and cultivate positive relationships with their peers. Furthermore, research conducted by Sutton et al. (2023) indicates that individuals with chronic diseases who are capable of setting their own goals, maintaining their roles within the family, and participating in daily activities tend to experience higher levels of subjective well-being.

Objectives

Based on the previous explanation regarding the challenges faced by individuals suffering from nephrotic syndrome, there is a pressing need for researchers to conduct a more comprehensive study on the subjective well-being of these individuals. Nephrotic syndrome presents a significant and daunting challenge to the well-being of those afflicted by it. Psychologically, individuals dealing with nephrotic syndrome require effective strategies to attain subjective well-being and alleviate the

issues they encounter as sufferers of this condition. Therefore, researchers are committed to delineating a comprehensive picture of the subjective well-being experienced by individuals with nephrotic syndrome.

METHODS

Design

The research employs a qualitative approach with a descriptive phenomenological design. Qualitative research methods are utilized to gather in-depth data by examining the naturalistic conditions of objects, with the emphasis on deriving meaning rather than making generalizations (Sugiyono, 2015). This phenomenological approach delves into the subjective experiences related to individuals' personal perspectives on the events in question (Nuryana, Pawito, & Utari, 2019). The objective of employing descriptive phenomenology is to meticulously examine the portrait of subjective well-being in individuals with nephrotic syndrome.

Participants

The participants for this research will consist of individuals aged between 20 and 40 years, both male and female, who are diagnosed with nephrotic syndrome, have been undergoing treatment for more than one year, and are willing to participate as research subjects by providing informed consent. The sampling technique employed will be purposive sampling, which involves selecting samples based on specific criteria and considerations (Sugiyono, 2013).

Data Collection Procedures

Data collection was conducted using various methods, including the examination of documents such as participants' lab test results and photographs depicting their condition during disease recurrences. Interviews were based on components of subjective well-being, including life satisfaction, negative affect, and positive affect (Diener, 2013). Additionally, researchers conducted interviews that explored questions related to factors influencing subjective well-being, such as personality factors, demographic factors, social relationship factors, and health factors (Diener et al., 2018). Prior to the interviews, participants were asked to complete the Satisfaction with Life and PANAS scales. Subsequently, interviews were conducted to follow up on participants' responses in accordance with the scales they had filled out. The research instruments used during the interview process included writing materials for note-taking and recording devices, with analysis being carried out after the interviews were completed. For the qualitative data analysis, the interactive analysis technique based on the Miles and Huberman model was employed (Sugiyono, 2013).

Data Analysis

In this qualitative research data analysis technique uses interactive analysis, an interactive data analysis technique inspired by the Miles and Huberman model (Sugiyono, 2013) is employed. The data analysis process consists of two distinct stages. First, prior to any fieldwork, preliminary data analysis is conducted. This initial analysis serves the crucial purpose of defining the research focus. It draws from two key data sources: interviews with two informants, providing primary insights, and secondary data obtained from previously conducted research. The second stage of data analysis occurs during fieldwork and adheres to the Miles and Huberman model. It comprises several steps, starting with data reduction. During this phase, the data is summarized, emphasizing essential elements and critical themes. This process helps create a clear research framework and streamlines further data collection. Following data reduction, the findings are presented through narrative text, illustrating the data collection process. Finally, the research concludes by drawing credible and well-

supported conclusions, derived from a careful examination of the data and valid, consistent evidence. This systematic and structured approach ensures the reliability and validity of the research findings.

RESULTS AND DISCUSSION

Results

Overview of Research Participants

SS (Participant 1)

SS is a man aged 21 to 22 years, which falls into the early adulthood category. He was born and raised in the Garut area. SS carries out his activities mostly at home or is currently not working due to being laid off from a factory. The reason for SS's job termination was frequent medical check-ups. SS has been diagnosed as a nephrotic syndrome sufferer and has been dealing with this condition for 2 to 3 years.

WAN (Participant 2)

WAN is a male overseas student residing in the Tangerang area, although he was born and raised in Lampung. As the youngest of six siblings, WAN is currently 22 years old, marking his early adulthood. Lately, WAN's schedule has been occupied with student activities, primarily focusing on assignments. A medical diagnosis has confirmed that WAN is grappling with nephrotic syndrome, which he has been battling for 1.5 years.

J (Participant 3)

J is a married man and a father of two children. He previously lived abroad with his family while working in Taiwan but has since returned to Lampung with his wife and kids. At 38 years old, J is still categorized as an early adult. Presently, he is engaged in farming as his primary occupation, and he has been coping with nephrotic syndrome for a duration of 4 to 5 years.

Background of Being a Nephrotic Syndrome Sufferer

Everyone worldwide desires a healthy body, and happiness often accompanies good health. However, when one's health falters, it can disrupt every aspect of life. This holds true for the research participants, each of whom has been profoundly affected by their nephrotic syndrome diagnosis. Several factors contributed to the participants' diagnosis, with unique experiences for each individual. For SS, an unhealthy lifestyle played a central role in developing nephrotic syndrome. SS frequently consumed beverages loaded with preservatives, such as Kratingdeng. Over time, SS's condition worsened due to a misdiagnosis by a doctor, resulting in inadequate treatment. SS experienced symptoms like swelling and nausea.

Similarly, WAN's nephrotic syndrome can be attributed to an unhealthy lifestyle before the diagnosis. WAN regularly consumed sugary and fizzy drinks, as well as unhealthy foods. Symptoms experienced by WAN included vomiting, dizziness, and generalized swelling. Eventually, WAN sought medical attention in a Lampung hospital and was confirmed as a nephrotic syndrome sufferer.

According to J, genetics played a significant role in his nephrotic syndrome diagnosis. However, lifestyle choices, such as smoking, alcohol consumption, and an unhealthy diet, still had an impact on his condition. J developed nephrotic syndrome while working in Taiwan and received medical treatment for his illness there.

Life Satisfaction of Nephrotic Syndrome Sufferers

SS (Participant 1)

As a sufferer of nephrotic syndrome, SS finds it difficult to achieve satisfaction in his life. This is because the nephrotic syndrome suffered by SS makes him limited in carrying out activities and unable to work.

"...That's right, sis, if I do something hard my waist immediately hurts, sis. This is where the kidneys are in the second position, right? So, if you lift heavy things, your waist immediately hurts, sis..."

Not being able to work makes SS feel sad because he feels he cannot make his parents happy, whereas he will feel satisfied if his parents are happy.

"...It could be, sis, it could be because previously what it was called to make parents happy wasn't just with money, sis, but with energy, hard work could also be called filial piety to parents and if, for example, I was healthy, maybe there would be no obstacles to making my parents happy, bro..."

WAN (Participant 2)

Satisfaction can be felt because WAN is able to accept and try to always be grateful for his condition.

"...Yes, just carry on, accept it, accept the situation as a person suffering from nephrotic syndrome, so just undergo treatment and lectures, balance being grateful, yes, many, many grateful because you can still live like that..."

However, WAN could not fully feel this happy feeling because he felt happier before suffering from nephrotic syndrome. WAN cannot feel satisfaction with life because he experiences limitations in his activities.

"...Yes, the activity that is starting to get hampered is that in the past, I used to get tired often, I did excessive exercise and heavy lifting, but now I can't because I feel like my body is no longer as strong as it used to be..."

This makes him unable to take part in non-academic activities in lectures because he cannot get tired and cannot work hard. Since suffering from nephrotic syndrome, WAN has felt stressed because he has to maintain his lifestyle, so he feels dissatisfied with his life.

"...Why? Because I also have to maintain my lifestyle more than other normal people, I also have to limit my activities. So these things make my quality of life decrease, so I want to be healthy and be able to carry out activities like normal people in general..."

J (Participant 3)

The demand to work and fulfill household needs while suffering from nephrotic syndrome makes it difficult for J to feel happy. This is because as a sufferer of nephrotic syndrome, your activities are limited and you cannot work because you get tired easily.

"...Yes, what that means is that if you work all the time you're often tired, if you work you're often really tired. If you work a little, you often get tired, if you lift a little you won't be strong enough..."

However, as time goes by, J tries to accept and adapt to nephrotic syndrome even though he still finds it difficult to achieve satisfaction in life.

"...For now, thank God, I'm rich and I can adapt, which means adaptation is possible..."

Negative Effects Felt by People with Nephrotic Syndrome

SS (Participant 1)

Symptoms caused by nephrotic syndrome, such as swelling all over the body, made SS feel hopeless.

"...Well, after walking for a long time, it was already flat and not swelling after a few months. It felt like it was coming back again. The swelling of all the lids of my hands, eyes and feet was there. I was desperate, why was the swelling not going away? "After that, I was taken to the clinic. The first time I was there, I was able to take the right medicine, and everything was right, after a week it went flat, and there was no swelling anymore..."

SS felt that his illness was not getting better and that the side effects of the medication were making his physical condition worse, such as the appearance of stretch marks on his body. This disease also disturbs the mind because everything planned fails and everything does not go according to expectations.

"...Yes, for example, this is my example from before New Year's Eve 2020 or 2021, I think in 2021 I was planning to go on holiday, well, this is a holiday with friends, December 2021, on the 3rd, I was admitted to the hospital, bro, so it didn't meet my expectations for a holiday with friends, it turns out "That's not happening, bro..."

SS has also felt negative emotions since suffering from nephrotic syndrome, such as becoming irritable.

"...Well, what do I do with negative feelings? Since I suffer from nephrotic syndrome, I often get angry at other people because I have high blood pressure. In fact, the reason behind this disease is that most of these illnesses have high blood pressure, sis, so I often get angry, sis..."

Sometimes, as a sufferer of nephrotic syndrome, SS feels anxious and makes SS unable to sleep well.

"...What I'm worried about is just worrying about what I want, bro, I'm not clear about what I want, I'm not clear about what I want. Feelings of anxiety, not sleeping well, wanting to sleep, not being able to sleep..."

Feelings of disappointment also interfere with his life, with feelings of disappointment about his life in the past. He was disappointed because he had not maintained his lifestyle in the past.

"...I was once disappointed when I was healthy when I was working, I was disappointed that if I didn't drink kratingdeng, I definitely wouldn't be like this..."

WAN (Participant 2)

Since becoming a sufferer of nephrotic syndrome, WAN has had negative emotions, where he becomes easily sad and annoyed.

"...Sad, disappointed, and what was certain was that I was annoyed and confused, and at that time I didn't know about nephrotic syndrome and when I found out that nephrotic syndrome was dangerous, I was definitely sad, disappointed, sometimes in despair..."

Being a sufferer of nephrotic syndrome makes WAN always feel hopeless in living his life because he has to take medicine that costs a lot but never gets better.

"...Often, I often give up, often when it recurs, for example, like a cold, fever, usually it can, what can it do, be, it can also connect to the kidneys, that's why I have to keep taking kidney medicine. I had to be excused from going to class, I had trouble eating because I was nauseous, so these things made me despair and there was also financial support that was less supportive when I wanted to have a check-up. This also made me despair. I also saw that my friends could be free. I'm shackled in pain, that's what makes me jealous and makes me feel hopeless..."

As time went on, WAN felt stressed because his illness was interfering with his studies and he had to always have check-ups.

"...It's often stressful, stress is often what makes it stressful, sometimes it's sometimes a month, for example, this check-up result goes up, sometimes it's also what makes you stressed, sometimes it's what I should have today at lectures for presentations or final exam assignments, that's how it turns out. That's when I checked up, so I had to email the lecturer to change the time for final exams or presentations and so on, so it took a lot of time to study, and the same thing that took up check time, this took up time that should have been used for studying and this lecture was instead used for check-ups..."

In addition, the feeling of disappointment about himself and his future always haunts WAN's life.

"...Um, maybe it's sad, right? "Maybe the picture after getting nephrotic syndrome is more like being disappointed with yourself because before that you didn't take care of yourself, that's how you got nephrotic syndrome..."

This feeling of disappointment is accompanied by a feeling of anxiety about the future that WAN feels every day.

"...I'm always anxious, every day I worry when I think about it, how will I recover in the future, or what will my job be like, what will happen in the future ?..."

J (Participant 3)

J felt sad when he was declared a sufferer of nephrotic syndrome and felt that he did not deserve to live.

"...Wow, it's very sad, sis, sis dropped e. It's really sad to feel like there's no use in living. It means there is no mentality to live..."

J always feels tired because he has to keep working through pain and often forgets check-ups because he is afraid of his boss.

"...I'm tired of having to be tired, especially since I was working on a contract then, so I had to get permission from the chairman and the boss first. Sometimes, how do you work when your parents don't like it? It's sad, I want to control it, but sometimes I skip that control..."

J experiences stress because he experiences pressure from within him regarding the fate of his family, especially his children, whose needs must be met.

"...Very often, very often at first, it is very stressful..."

Positive Effects Felt by People with Nephrotic Syndrome

SS (Participant 1)

As a sufferer of SS nephrotic syndrome, I am enthusiastic about undergoing treatment even though there are side effects that are felt.

"...If I have a strong determination to recover, I have done a lot. First, I tried herbal medicine, second, I tried alternative medicine, and third, I tried not to think about this disease in me. So, I was determined to undergo treatment..."

The people around SS encouraged him to recover and be strong in living life as a nephrotic syndrome sufferer.

"If the people around me really make me strong, bro and give me enthusiasm, give me motivation to recover and be healthy, that's where I feel strong, bro."

SS also felt inspired to recover, this was because he wanted to return to his activities smoothly.

"...If you want to be inspired, you might want to be active again. Well, finally being active again has motivated me to be healthy..."

WAN (Participant 2)

WAN feels enthusiastic about recovering because he gets support from the people around him and wants to achieve his goals.

"...Yes, what makes you strong is of course also because there is hope for recovery. That encouragement or support is what makes me strong. I also have aspirations, there is a future goal of becoming a teacher, so I have to do it even though I am limited, but I can show that I am enthusiastic, so it can show that I am no less likely to achieve my goals than normal people in general. This is what keeps me enthusiastic about undergoing treatment..."

WAN is also motivated to recover because there are several nephrotic syndrome sufferers nearby who can recover.

"...Actually, how do you feel inspired, but actually it's a responsibility, so in the past, I felt inspired or not, but it's a responsibility, if not, I didn't fulfill my responsibilities as a person with nephrotic syndrome, but I was also inspired to live it well because there are also my neighbours who suffered from nephrotic syndrome and he was able to recover so I was inspired to recover so I underwent good treatment so that I could recover quickly. That's it..."

J (Participant 3)

Since suffering from nephrotic syndrome, J has always tried to think positively and believed that he would get a cure, even though it was difficult.

"...Em, just start thinking positively, sis. That there is no disease that has no cure, there must be a cure, I think that's the way the process is..."

This was done so that he always believed that there was still a chance of recovery. J made him feel happy and not think too much about his condition and was able to focus on his family.

"...That's the happiness, just make it happy, sis, don't think too much about that situation, basically don't think about it, there are wife and children at home, just make it happy, don't think too much about it..."

Demographic Factors

SS (Participant 1)

Finances were one of the factors that SS experienced obstacles in undergoing treatment because he did not work and his family had a poor economy.

"...Well, in the future, if I have the funds, I want to check the lab, sis, like checking urine and blood once a month, bro. I just hope you get good luck, sis..."

This is because SS does not have BPJS and decided to carry out his own treatment at home. SS also feels sad when he has to resist the urge to buy things for treatment.

"...It's very sad, Sis, so we don't want to buy this example, I want to buy attractive clothes and buy medicine, but I'm like if I want snacks, I have to buy this, I have to buy that now, if I want to buy anything, compared to before, Sis..."

WAN (Participant 2)

Financial problems also occur with WAN, so WAN uses BPJS because it helps ease the burden of spending on treatment.

"...BPJS helps in treatment..."

However, the costs incurred for transportation during check-ups for WAN are quite large.

"...Yes, yes, it's more about what you use for transportation and check-up needs, rather than me making cakes, for example, for my friends to have snacks like that..."

A sad feeling always comes to WAN when he realizes that he has to spend a lot of money on the treatment process compared to buying food and clothes.

"...Well, first of all, it's obviously sad, so the money should be for snacks, but instead it's for medical treatment, so it's a bit sad..."

J (Participant 3)

As a worker and sufferer of nephrotic syndrome, J feels that his income is sufficient to meet his daily needs because he receives assistance with medical costs.

"...If it's rich there, it's BPJS. The point is, if you live there, it's still affordable. If you use BPJS, it's cheap there..."

However, when J's illness recurred seriously, he was unable to work and unable to provide money for his family.

"...Yes, that's true, sometimes it's like working there and you can't rent a house for a few months..."

Sometimes the needs of the wife and children become less when they have to spend a lot of money for the treatment process.

"...Others, how do I feel? I'm sad, sis, I should be able to support my child's life at home, but I'm using it there..."

Support Factors

SS (Participant 1)

One of the things that makes SS feel enthusiastic about living life is because of the support given by his friends and siblings.

"...If you have a lot of support, sis, from friends and also from siblings, there are lots of big sisters who will support your enthusiasm..."

The support provided is in the form of words of motivation and attention. As a nephrotic syndrome sufferer, SS joins the community on Facebook and gets support from fellow nephrotic syndrome sufferers.

"...To go to a new community yesterday I joined and I found 1 person suffering from nephrotic syndrome he has been walking for 10 years, maybe 8 years and he also means he is longer than me, I'm only 3 and a half years old and I hope I can recover soon Amen's illness... for my friend, it's been almost 8 years or 9 years..."

WAN (Participant 2)

The support given by the people around WAN made him feel enthusiastic about living life as a sufferer of nephrotic syndrome. This support made WAN feel that he still had a chance to recover.

"...Um, because yes, I have a family that always supports me and always supports me. Then I have a girlfriend who supports my brothers and sisters who always support me and don't mind anything, so I'm just enthusiastic, the point is that there is hope, someone who supports me means I have hope that I will definitely recover. If not, there are several neighbours here who suffer from nephrotic syndrome too, right now or not? I'm taking medicine so I still hope for a real recovery, I see..."

This support was provided by parents, older siblings, friends, neighbours, girlfriends and pastors who always provided encouragement.

"...Yes, for example, my parents clearly provide material, yes, material such as money, if my boyfriend gives me comforting words, and if my neighbour visits me. If the church congregation visits too. If my pastor was like my pastor, he would take me like a check-up, right?..."

Apart from that, support was also received from fellow nephrotic syndrome sufferers who gave each other encouragement to get well soon.

"...Yes, I joined a Facebook group that cares about nephrotic syndrome, and there is one, there are 2 more with 2 more specifically for Nephrotic Syndrome, Lampung. I live in Lampung, but right now in Tangerang, it's Karawaci and the other one I don't know about the nephrotic syndrome group. So from there, lots of people suffering from nephrotic syndrome throughout Indonesia joined so they shared things like that..."

J (Participant 3)

J often felt like giving up on his life, but he always had support from the people around him.

"...Yes, if I were, maybe there would be a lot of support from friends and family, that would speed up our spirits, we would definitely be able to recover, I'm sure that's all..."

J's doctor stated that there was still a chance to recover and gave support to J not to give up on his illness.

"...Heem, the doctor said, yes you can, but what is called gradual, don't give up, he said, basically what the doctor said first, stay away from it..."

Family, especially children and wife, are the main factors for J's enthusiasm in achieving recovery.

"...Oh, that's how it started at first, so at first I almost gave up, sis, my wife encouraged you, you're still young, remember kids like that, right?..."

Social Relationship Factors

SS (Participant 1)

Despite being a sufferer of severe nephrotic syndrome, SS still has a good relationship with God and never blames God.

"...I never blame, but I accept what God has given me..."

The relationship he has with his family and people around him is also good because there are no arguments in it.

"...Hey, it's good, there are no fights, there are no bad feelings, everything is positive, thank God..."

SS also doesn't feel hostile towards other people and doesn't want to have problems with other people because it will only stress him out.

"...If you want to be hostile, there's no need to be hostile because that can affect my mind so I'm mostly stressed thinking about him..."

WAN (Participant 2)

When WAN was first diagnosed as suffering from nephrotic syndrome, he was angry with God and felt that God was unfair because he always did good.

"...Yes, because I feel why should I be the one affected by someone like me who likes to drink fizzy drinks, in fact many people who drink alcohol smoke, how come they don't get nephrotic syndrome like that..."

However, as time goes by the WAN can accept its condition. Your relationship with God is also getting better, proven by always worshiping and praying.

"...Yes, pray, worship because in my Christian religion, I pray a lot and worship..."

WAN feels that the relationship he has with his family and the people around him is well established.

"...It's fine, that's why I said earlier that my family is becoming more solid..."

J (Participant 3)

Since suffering from nephrotic syndrome, J feels he has an increasingly good and close relationship with God.

"...No, if I didn't, sis, I would want to be closer, it's not nice to ever blame God, that's the point, it's actually closer..."

This is because J is increasingly asking God for healing and not blaming God.

"...Yes, if you are with God, you will usually be more enthusiastic about asking. Usually, in the holy month of Ramadan, we don't fast, we just fast more than that..."

J feels he can have a good relationship with his family, namely his parents, siblings and especially his wife.

"...If you have a relationship with your wife, even your wife...she is more supportive..."

Lifestyle

SS (Participant 1)

SS has a bad lifestyle so he has nephrotic syndrome and finds it difficult to feel happy since suffering from nephrotic syndrome.

"...Well, for this lesson, there are a lot of people who need to take care of their health, it's really expensive. Previously, I neglected my health and didn't care about myself at that time. It's really a lesson, sis, for example, at that time, my social relationships weren't very good, bro. Maybe the lesson of this disease was a warning from God. Maybe in the future, we can be better off being closer to God, remembering God, and what is it called, health must be really good. take care of it because if I was already rich, I would be rich, maybe it would be said that we are giving up hope, right? You can't give up, right? You have to look after it and keep doing it, but as best as possible, don't let it become like that. "If you're already sick, what kind of pain do you feel ?..."

However, over time SS tried to improve himself so that he had a good lifestyle. This is done by maintaining your diet so you don't eat unhealthy foods.

"...If attention is like food that is not edible, I don't eat it, and I eat food that is edible, and I eat food that I shouldn't eat, I drink it, I don't do that, bro, maybe that includes attention to my health, yes, for myself..."

WAN (Participant 2)

A bad lifestyle can cause dangerous diseases and make it difficult to feel happy.

"...Yes, the thing I won't do in the future is don't stay up late, continue to eat or drink, reduce drinking coloured fizzy drinks because they can damage the

kidneys, as far as I know, don't stay up late because staying up late can cause a lot of pain according to my doctor..."

WAN's lifestyle is bad because he often stays up late, and consumes bottled drinks and fizzy drinks which are not good for the body. However, after suffering from nephrotic syndrome, WAN improved his lifestyle by avoiding an unhealthy lifestyle and food.

"...Yes, of course, what I want to change is maintaining my body's health. In the past, I often drank Coca-Cola, Fanta, extrajos, since then I don't want to repeat the mistake twice, so that's what I want to change in the future, so I want to change it from now on. By not staying up late, I also avoid consuming fizzy drinks, coloured drinks, and instant noodles. I also avoid them because I used to like instant noodles, but now I don't consume them anymore. These are the things that I'm quite late for now, but I'm still doing it like that..."

J (Participant 3)

J's lifestyle before suffering from nephrotic syndrome was very bad, he consumed alcoholic drinks and smoked.

"...Yes, I used to be a smoker, I used to drink with my friends. Now, absolutely no smoking, no drinking alcohol. Well, that pattern food is not allowed, it's red meat like beef, goat, it's not allowed..."

This makes J suffer from nephrotic syndrome and it is difficult to achieve happiness after becoming a sufferer of nephrotic syndrome. Since suffering from nephrotic syndrome, J finally decided to improve his lifestyle.

"...Yes, it's changed, basically it's changed completely. Previously, the diet was free, now it's normal. I used to smoke, but now I don't, my life is getting better. Being disciplined is the point..."

Self-Confidence

SS (Participant 1)

This treatment for nephrotic syndrome has side effects that are detrimental to SS's physical condition and make SS feel less confident. This is because SS has a moon face, acne, hair loss, stretch marks and a hot face.

"...The first month, the second, acne appeared from the face to the neck, and the hair fell out, the face was hot, so the face often felt hot because of the drug methylprednisolone. If you stop, you won't have a moon face, if you stop you won't have acne..."

This feeling of insecurity makes SS embarrassed to socialize with his friends because of these physical changes.

"For now, I don't have confidence anymore. I've lost my social life; I don't socialize anymore, and I rarely see friends at social gatherings. So, I've truly lost my confidence..."

Apart from that, SS also avoided socializing with neighbours and chose to break up with his girlfriend because he felt insecure.

"At that time I was there but in the midst of my illness at that time I decided to break up with my girlfriend because I felt like I didn't deserve to have nephrotic syndrome because I felt sorry for my girlfriend so I decided to stop the relationship."

WAN (Participant 2)

Physical changes due to the treatment he underwent as a nephrotic syndrome sufferer made WAN feel less confident. This is because WAN feels embarrassed that his friends have stretch marks, damaged nails and moon faces.

"...Um, hanging out is reduced. It's really reduced because you can't do too much activity, right? And if you hang out until late at night, my friends, if I'm insecure, I'm definitely insecure, I rarely wear shorts. Always wear trousers because there are stretch marks. I also have a chubby moon face. But now the moon face seems to have decreased a bit because the dose of the medicine has been reduced..."

His friends always mention WAN's physical appearance and make him feel even more insecure.

"...Yes, yes, what's going on, like, how come the WAN is so chubby, unlike in the photo? Well, maybe like that..."

Finally, WAN chose not to socialize and limit his interactions with his friends.

"...Yes, of course, the first blush is the moon face, the moon face is rich with swelling in the cheeks. I don't have PD to socialize and I also don't have PD after the swelling has left stretch marks so I'm disappointed there..."

Discussion

Based on the results of the data analysis, differences and similarities were identified in the subjective well-being of nephrotic syndrome sufferers. Evaluating the scale responses, it becomes evident that individuals with nephrotic syndrome generally exhibit low subjective well-being, albeit with varying experiences. Subjective well-being involves a person's evaluation of life satisfaction or dissatisfaction, ranging from moments of joy to experiences of misery (Kapteyn et al., 2015). Achieving subjective well-being hinges on whether an individual perceives higher life satisfaction and more positive emotions than negative emotions. Conversely, for participants struggling to attain subjective well-being, these factors are not in balance (Wicaksana et al., 2019). Some participants manage to achieve subjective well-being despite their nephrotic syndrome, while others find it a challenging endeavor. Achieving subjective well-being can be influenced by factors such as social support and a sense of gratitude, which can mitigate negative emotions like stress and anxiety (Haerianti et al., 2022).

The process of attaining subjective well-being among nephrotic syndrome sufferers exhibits various nuances. One of the contributing factors to achieving subjective well-being is life satisfaction. However, all participants encountered challenges in achieving life satisfaction as individuals grappling

with nephrotic syndrome. Their limitations in engaging in activities and their inability to work or undertake strenuous tasks presented formidable obstacles. These findings align with previous research conducted by Moza et al. (2021), which emphasizes the importance of acceptance in attaining life satisfaction. Independence in carrying out activities is a crucial aspect, as individuals often experience dissatisfaction when they must rely on others for assistance in their daily lives. As sufferers of nephrotic syndrome, there are numerous life goals that remain elusive, such as bringing happiness to their parents, maintaining good health, possessing a robust physique, and securing stable employment. These unattainable objectives contribute to the participants' struggle to experience life satisfaction. This corresponds with research by Dewi & Nasywa (2019), which posits that well-being is intrinsically tied to the fulfillment of one's goals in order to attain happiness. When individuals can realize all their aspirations, they are more likely to experience satisfaction, whereas unfulfilled desires can lead to diminished well-being and life satisfaction.

In addition, negative emotions pose a significant hindrance to nephrotic syndrome sufferers in their pursuit of subjective well-being. These emotions encompass anxiety, anger, worry, and depression, as documented by Huang et al. (2018). Nephrotic syndrome disrupts the lives of participants in multiple ways, impacting their educational endeavors, medication regimens, necessitating adjustments to cope with the disease's consequences, and inducing stress when contemplating their own and their family members' futures. These findings are consistent with the research of Freire et al. (2020), which posits that heightened stress levels can engender negative thought patterns, give rise to negative emotions, influence physical well-being, and ultimately affect an individual's overall well-being. Nephrotic syndrome sufferers also grapple with additional negative emotions, such as annoyance and disappointment in themselves, as well as feelings of having let down their loved ones, including their parents. Some participants exhibit heightened sensitivity and frequent bouts of anger. These behavioral observations align with the conclusions of Gerontoukou et al. (2015), who assert that individuals coping with chronic illnesses face ongoing struggles that lead to feelings of exhaustion, discomfort, depression, and anger.

Nephrotic syndrome sufferers also contend with additional negative emotions, including anxiety. This anxiety often stems from their employment situation, as they must undergo medical tests, grapple with physical changes, and cope with limitations in activities. This anxiety can extend to thoughts about marriage, with concerns that their condition may burden their future spouse. Furthermore, nephrotic syndrome sufferers experience heightened anxiety and restlessness when their condition deteriorates, potentially leading to kidney failure and necessitating lifelong dialysis. These findings align with the research of beyoğlu & Avci (2020), which asserts that a significant portion of patients grappling with chronic diseases encounter psychological issues, including anxiety, depression, fear, and other related concerns. The depression experienced by all participants in this study can be described as a sense of despair, with each participant reaching a nadir in their lives as they contend with nephrotic syndrome, ultimately leading to a loss of hope. Herrera et al. (2021) corroborate these findings, indicating that individuals living with chronic diseases often grapple with feelings of hopelessness regarding their future due to the emotional toll of ongoing treatment.

Hence, it can be deduced that the participants experienced a range of negative emotions, including stress, despair, anger, disappointment, annoyance, restlessness, sadness, and anxiety. These emotional states were also reflected in their behaviors, such as expressions of unhappiness and anger, self-isolation, and tendencies towards self-harm. This aligns with the findings of Al-Majali & Ashour (2020), who assert that negative emotions can have severe repercussions, exacerbating physical ailments due to mental health issues. Conversely, participants reported fewer positive emotions, such as motivation and enthusiasm for recovery. These positive emotions play a crucial role in fostering well-being for individuals with nephrotic syndrome. This correlation is corroborated

by the research of Tulip et al. (2020), which suggests that positive emotions can significantly enhance an individual's attainment of subjective well-being in their life.

In addition to positive emotions, several factors influence the attainment of subjective well-being. Among these factors, demographic considerations play a significant role. Financial assistance from the government can alleviate the financial burden for some nephrotic syndrome sufferers, allowing them to avoid using all their income for medical expenses. However, it is noteworthy that one participant encountered difficulties covering medical costs due to a lack of BPJS coverage. This observation aligns with the findings of Yu & Wang (2017), which suggest a positive correlation between income and well-being, as individuals with higher incomes tend to feel more prosperous.

Furthermore, the quality of relationships participants maintained with various individuals, including God, parents, siblings, neighbors, partners, and fellow nephrotic syndrome sufferers, contributed significantly to their perceived support network. This support played a crucial role in fostering subjective well-being, as those with strong support systems reported a greater sense of encouragement and the prospect of a prosperous life. This conclusion is in line with research conducted by Xu et al. (2019), which posits that individuals who cultivate positive social relationships and receive substantial support are more likely to experience high levels of subjective well-being.

In addition to the various achievement processes and factors discussed earlier, this research has uncovered the significance of lifestyle and self-confidence factors that contribute to the attainment of subjective well-being. Nephrotic syndrome sufferers in this study paid careful attention to their lifestyles, with a particular focus on maintaining dietary and sleep patterns, refraining from staying up late, and avoiding unhealthy food and beverages to minimize the risk of recurrence. Research conducted by Martín-María et al. (2020) supports the notion that subjective well-being is closely linked to lifestyle, where adopting a healthy lifestyle can serve as a protective measure for maintaining health and achieving subjective well-being.

However, it's important to note that some nephrotic syndrome sufferers exhibited low self-confidence, which posed limitations on their social interactions due to feelings of embarrassment. This lack of self-confidence stemmed from physical changes experienced by nephrotic syndrome sufferers as a result of the medications they were prescribed, including side effects like moonfaces, stretch marks, acne, facial flushing, and hair loss. This aligns with the perspective presented by Adi et al. (2022), which emphasizes the detrimental impact of physical changes and negative comments from others, such as gossip, on an individual's quality of life and their ability to experience well-being. Given the interplay of these achievement processes and influencing factors, it is evident that participants coping with nephrotic syndrome have not yet fully attained subjective well-being, and many continue to struggle with well-being at a low level. Consequently, this study provides a comprehensive portrait of subjective well-being in individuals living with nephrotic syndrome.

Implications

The implications of this research suggest that healthcare providers and support systems for nephrotic syndrome sufferers should not only focus on medical treatment but also address psychological and social aspects, including self-confidence and lifestyle. Tailored interventions to boost self-esteem and promote healthier lifestyles could enhance the well-being of individuals living with nephrotic syndrome. Additionally, the findings underscore the importance of social support networks in mitigating negative emotions and fostering subjective well-being in these patients.

Limitations and Suggestion for Future Research

The research on subjective well-being in individuals with nephrotic syndrome has limitations, including a potentially small and homogeneous sample, reliance on self-reported data, and a lack of consideration for cultural and societal influences. It may not fully capture the dynamic nature of well-

being over time and could benefit from a more diverse and comprehensive assessment of psychological factors, treatment variability, and external variables. Acknowledging these limitations is essential for a more accurate understanding of the well-being challenges faced by nephrotic syndrome patients and for guiding future research in this area.

Future research in the field of nephrotic syndrome and subjective well-being can benefit from refining participant characteristics by considering factors like age, gender, and duration of diagnosis. Additionally, including self-confidence and lifestyle in qualitative interviews can provide a more comprehensive view of their impact. For quantitative studies, tapping into nephrotic syndrome support communities can yield more precise insights, helping us understand how various factors affect well-being and informing better support strategies.

CONCLUSION

Based on the studies conducted in this research, several conclusions can be drawn regarding the subjective well-being of individuals with nephrotic syndrome. While everyone aspires to lead a healthy and fulfilling life, this can be challenging for nephrotic syndrome patients who grapple with the disease and its treatment-related side effects. Consequently, many individuals with nephrotic syndrome struggle to attain subjective well-being. This struggle often stems from the difficulty in achieving life satisfaction, the prevalence of negative emotions, and low self-confidence among these patients. Consequently, nephrotic syndrome sufferers typically experience low levels of subjective well-being. Nevertheless, the support and relationships offered by those around them play a crucial role in motivating these individuals to embrace life with enthusiasm. Being a nephrotic syndrome patient imparts valuable life lessons, including the importance of adopting a healthy lifestyle.

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All authors have read and approved the final version of the manuscript.

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