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Qualitative Analysis of the Psychosocial Adaptation Process in Children with Chronic Kidney Disease: Toward Effective Support During Transition from Childhood to Adulthood

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ABSTRACT

Background Pediatric chronic renal disease only shows abnormal values in a urinalysis in the initial stage, and subjective signs and symptoms are rare. If adolescents with chronic renal disease face a disease crisis combined with the usual developmental crisis, this may cause psychosocial maladaptation. We analyzed psychosocial adaptation in Japanese children with chronic renal disease in order to identify factors influencing healthy adaptation.

Methods Ten children and adult patients with chronic kidney disease attending Tottori University Hospital, Japan in 2016 participated in a semi-structured interview (a modified version of the grounded theory approach) comprising questions about episodes since disease onset and thoughts/feelings at onset.

Results Twenty-four concepts extracted from the data were sorted into 5 categories. These concepts and categories were expanded on an orthogonal axis with time and self-esteem in order to establish an adaptation model for children with chronic kidney disease. Category names are as follows. (Cat. 1: Emotional impact on being informed of disease, Cat. 2: Social challenges of treatment and resulting identity diffusion, Cat. 3: Emotional conflict on school return, Cat. 4: Resilience and related factors, Cat. 5: Re-establishment of identity).

Conclusion Since pediatric chronic renal disease has few manifestations, it is difficult for patients to accept. Children facing a chronic disease crisis plus adolescent developmental crisis may show identity diffusion. In order for children to re-establish their identity and adapt to society, factors supporting resilience are important. Key factors include school life, interactions with friends, counseling by adult mentors and family acceptance. Healthcare professionals need to provide age-appropriate information on renal disease and support patients.

Key words chronic kidney disease; pediatric nursing; qualitative research; transition

Chronic diseases that develop in childhood require long-term treatment, which often continues until the child becomes an adult.¹ Chronic kidney disease is one of the chronic diseases that often develop during childhood. Studies from the U.S. and Europe published since 2000 indicate that approximately 30% to 40% of children with chronic kidney disease develop recurrence and the disease persists into adulthood.^{2,3}

Chronic kidney disease initially causes few symptoms in pediatric patients and is only detected by abnormal findings in a urinalysis. However, its prognosis is not necessarily favorable. In some cases, kidney function may deteriorate and renal failure that requires dialysis may occur over the course of 10 to 20 years.⁴ In order to prevent chronic kidney disease in children from progressing to renal failure, treatments with steroids or immunosuppressants may be necessary for an extended period during childhood and adulthood.⁵

These treatments may have adverse effects with a negative impact on the body image of patients, e.g., obesity due to increased appetite, moon face, hypertrichosis and short stature. These adverse reactions reduce motivation to continue treatment that is aimed at preventing renal failure associated with disease progression because patients only experience the adverse effects of the treatment and have no symptoms due to the underlying disease. This situation is characteristic of chronic kidney disease in children.

Children have to achieve many developmental tasks during their journey to adulthood. According to Erikson, children in adolescence, a transition period from childhood to adulthood, become more self-aware, come to understand themselves as social beings, and ask themselves what they are now and what their future holds.^{6–11}

During adolescence, children are more likely to be psychologically unstable even if they have no chronic disease (developmental crisis). Children with a chronic disease may also have a crisis associated with the disease (situational crisis). Thus, they have to negotiate

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Abbreviations: Cat., category; Con., concept; CKD, chronic kidney disease; M-GTA, a modified version of the grounded theory approach

double crises, and this sometimes leads to psychosocial maladaptation or the failure to achieve developmental tasks.

How do children with chronic kidney disease overcome these crises during the transition from childhood to adulthood? Some of these children achieve social adaptation and lead a normal social life as adults, whereas others have difficulties in overcoming their issues and develop psychosocial maladaptation. A clearer understanding of the factors that facilitate or interfere with adaptation during the crisis period is very important when we attempt to provide support to children in transition.

The age of onset and severity of the chronic disease may influence the adaptation process, while the child's personality and support from their family and friends may be factors that provide resilience.¹² Rutter et al. stated that important components of resilience are an encouraging school environment, self-control, good planning and good relationships with adults.¹³ Grotberg and Hiew et al. suggested the importance of skills, competence, inner/personal strength (e.g., self-control and matured independent activity) and an encouraging environment (e.g., stable family background and good relationships with parents).^{14, 15} However, these studies did not describe children responding to a crisis caused by chronic disease. There is no established theory on the psychosocial adaptation process of children affected by both a developmental crisis and situational crisis associated with chronic disease.

Therefore, the present study was performed in order to obtain basic information for providing appropriate support to children with chronic diseases in the transition period from childhood to adulthood by analyzing the psychosocial adaptation process of Japanese children with chronic kidney disease and identifying factors that facilitated adaptation.

SUBJECTS AND METHODS

Participants

Among 22 patients (children and adults) with chronic kidney disease who had attended the pediatric outpatient clinic of Tottori University Hospital, Japan between May and August 2016, patients were enrolled in the study if they had no cognitive impairment, no acute physical or psychological illness in the opinion of the researchers, and gave consent to participate. We held interviews with subjects in their chronological order of visiting the outpatient clinic during this period. Theoretical saturation was reached for concepts derived from the interviews after interviews with 10 subjects were completed; therefore, these 10 subjects were included in the analysis. Subjects were 6 males and 4 females aged 17.2 ± 4.1

years (range: 12 to 27 years), and the duration of chronic kidney disease was 8.4 ± 5.9 years (range: 3 to 23 years) (Table 1).

Table 1. Characteristics of participants (n = 10)

	n	Ave.	SD
Sex			
Male	6		
Female	4		
Age (years of age)			
10 to 15	2	17.2	4.07
15 to 20	7		
20 or older	1		
Race			
Japanese	10		
Marital status			
Single	10		
School/work			
Elementary school	1		
Junior high school	1		
High school	6		
Preparing for college	1		
Employed	1		
Underlying disease			
Idiopathic nephrotic syndrome	5		
IgA nephropathy	1		
Purpura nephritis	2		
Lupus nephritis	1		
Chronic nephritis	1		
Duration of disease (years)			
Less than 10	7	8.4	5.87
10 to 20	2		
20 or longer	1		
Family structure			
Only parents and their children			
Parents and their children	3		
Father or mother and his/her children	0		
Extended family [with grandparent(s)]	6		
Live alone	1		
Others	0		
Current treatment			
Oral drugs	7		
Only periodic hospital visits	3		

Ave., average.

Ethical considerations

The details of the present study were explained with reference to documents, including an explanation that the child had the option to choose not to participate in the study or could consent during the study without prejudice, that the results obtained from the study would only be used for investigational purposes, and that the personal information of the child would be strictly protected by de-identification when data were presented

at an academic meeting. Written consent was obtained from the child and from the parents when subjects were < 18 years old, while it was obtained directly from subjects ≥ 18 years old. The present study was conducted after obtaining approval from the Ethical Review Board of the Faculty of Medicine, Tottori University, Japan (Approval No. 1602A116).

Analytical methods

In order to evaluate the psychosocial adaptation process in patients with chronic disease, it is essential to analyze the details of the statements made by participants in the study during their interviews. We used a qualitative research method that allowed theoretical interpretation of the data obtained from the narratives of the study participants.¹⁶ One of the qualitative research methods suitable for the analysis of adaptation processes is the grounded theory approach proposed by Glaser & Strauss.¹⁷ In the present study, we employed a modified version of the grounded theory approach (M-GTA)^{18, 19} that incorporates the “researcher’s viewpoint” in order to allow the application of the results to clinical practice. This analytical method is based on a theory defining that the viewpoints of interviewers or analyzers for qualitative studies influence data evaluation in these studies.

We conducted semi-structured interviews with participants for 20 to 60 min based on the interview guide (interviewers asked the children to recall their feelings/thoughts at the onset of the disease, and when episodes occurred from the onset up to the present, Table 2). The validity of the interview guide was tested in advance on patient with chronic diseases who were not included in the study. In order to provide the researcher’s viewpoint (a characteristic of the M-GTA), a nurse with experience in a pediatric outpatient clinic was selected.

Analytical procedures were performed as follows according to the M-GTA. Verbatim transcripts of the interviews were searched for data apparently related to “the adaptation process of pediatric patients with chronic kidney disease in the transition period from childhood to adulthood” and the findings thus identified were used as examples. Concepts consisting of examples and definitions were then derived from the data by using an analysis worksheet. After each concept emerged, similar or antithetical data related to the concept were examined in order to prevent arbitrary interpretation. Theoretical saturation was considered to be reached when the number of concepts did not increase after repeated analysis. The validity of the analysis was confirmed by ensuring that five researchers with expertise in qualitative analyses reached a consensus in the interpretation of the findings. This is a common method of qualitative research.

Concepts with common features were grouped into categories. Categories and concepts were then plotted with time on the horizontal axis and the level of self-esteem on the vertical axis to establish a hypothetical model of the psychosocial adaptation process of children with chronic kidney disease.

Table 2. Interview guide

About yourself

- Tell me your name and age.
- Did the diagnosis of your disease have any influence on you?
- Do you think that living with the disease will have some influence on your future?

Difficulties encountered during treatment

- Did you have any difficulties, sadness, or hard times because of your disease?
- If you did, please tell me the details.

Who or what supports you?

- Is there anything/anybody supporting your life with the disease?
- If yes, please tell me the details.

RESULTS

Twenty-two concepts regarding the process of adaptation by children with chronic kidney disease were derived from the interviews and grouped into 5 categories (Table 3). These categories and concepts were used to establish a theoretical model of the process of psychosocial adaptation by children with chronic kidney disease (Fig. 1). The storyline of the model was as follows.

Acceptance of chronic renal disease varies widely, from asymptomatic children who deny the illness to those who are depressed (Cat. 1: Emotional impact on being informed of disease). The establishment of a self-image is influenced by issues in daily life and adverse reactions to steroids (Cat. 2: Social challenges of treatment and resulting identity diffusion). Missing school for an extended period due to hospitalization causes isolation and conflicting feelings about school (Cat. 3: Emotional conflict on school return). Patients overcome crises with support by friends and become more positive over time (Cat. 4: Resilience and related factors). Patients become more objective, realizing they have to live with anxiety about their disease (Cat. 5: Re-establishment of identity).

Details of categories 1 to 5 (Cat. 1 to 5), the concepts (‘ ’) constituting each category, and the verbatim transcripts (“ ”) from which the concepts were derived are shown below.

Table 3. Categories and concepts

Category	Concept
1: Emotional impact on being informed of disease	Con. 1: I could not believe that I have a disease Con. 2: I was depressed to learn that I have a disease
2: Social challenges of treatment and resulting identity diffusion	Con. 1: I had to receive difficult treatment Con. 2: I was discouraged because I could not do what I wanted Con. 3: Idle life in hospital Con. 4: Loneliness associated with hospitalization Con. 5: I could hardly think about anything other than myself Con. 6: Inferiority complex about my appearance because of adverse reactions to steroid therapy Con. 7: Forgetting events in the past
3: Emotional conflict on school return	Con. 1: I wanted to return to school as soon as possible Con. 2: I wondered whether I should tell my friends about the disease Con. 3: I was frustrated that I could not do things with my friends because of my disease Con. 4: I felt uncomfortable when my friends gave me special consideration Con. 5: I want a life like that of my friends
4: Resilience and related factors	Con. 1: A little happiness during treatment Con. 2: A positive attitude that grows over time Con. 3: Support from friends Con. 4: Relationships with adults other than parents Con. 5: Support from the family
5: Re-establishment of identity	Con. 1: A positive attitude that grows over time Con. 2: Anxiety about a life with disease Con. 3: Finding things to do despite restrictions Con. 4: Accepting myself and my disease Con. 5: Experiences in hospital have influenced my hopes for the future

Con., concept.

Cat. 1: Emotional impact on being informed of disease

This category consisted of 2 concepts: ‘I could not believe that I have a disease,’ ‘I was depressed to learn that I have a disease.’

Con. 1: Regarding the concept ‘I could not believe that I have a disease,’ participants said that “My doctor suddenly told me that I have a disease, but it is difficult to conceive and I don’t believe that I have a disease.” These statements indicated that the children understood that they had a disease, but were unable to grasp its severity or prognosis.

Con. 2: Regarding the concept ‘I was depressed to learn that I have a disease,’ subjects understood what chronic kidney disease meant, but said that “I had not thought that such a disease would affect me” in order to express their disappointment.

Cat. 2: Social challenges of treatment and resulting identity diffusion

This category consisted of 7 concepts: ‘I had to receive difficult treatment,’ ‘I was discouraged because I could not do what I wanted,’ ‘Idle life in hospital,’ ‘Loneliness associated with hospitalization,’ ‘I could hardly think

about anything other than myself,’ ‘Inferiority complex about my appearance because of adverse reactions to steroid therapy,’ and ‘Forgetting events in the past.’

Con. 1: The first concept was related to the difficulties the children had encountered (‘I had to receive difficult treatment’). The children were hospitalized and received intravenous infusions, and some foods were prohibited. The most difficult procedure for the children with chronic kidney disease was renal biopsy.

Con. 2: The second concept expressed the disappointment of the children (‘I was discouraged because I could not do what I wanted’). The children had to refrain from playing sports in order to prevent the aggravation of their disease. They said “I knew that I could not do what I wanted, and it was frustrating” or “I wish that I did not have the disease. If I did not have it, I could do what I wanted.”

Con. 3: When the children were hospitalized, they spent a lot of time watching TV or reading books (‘Idle life in hospital’).

Con. 4: The children felt lonely because they seldom saw their school friends and their families were only permitted to visit in the evenings (‘Loneliness associated with hospitalization’).

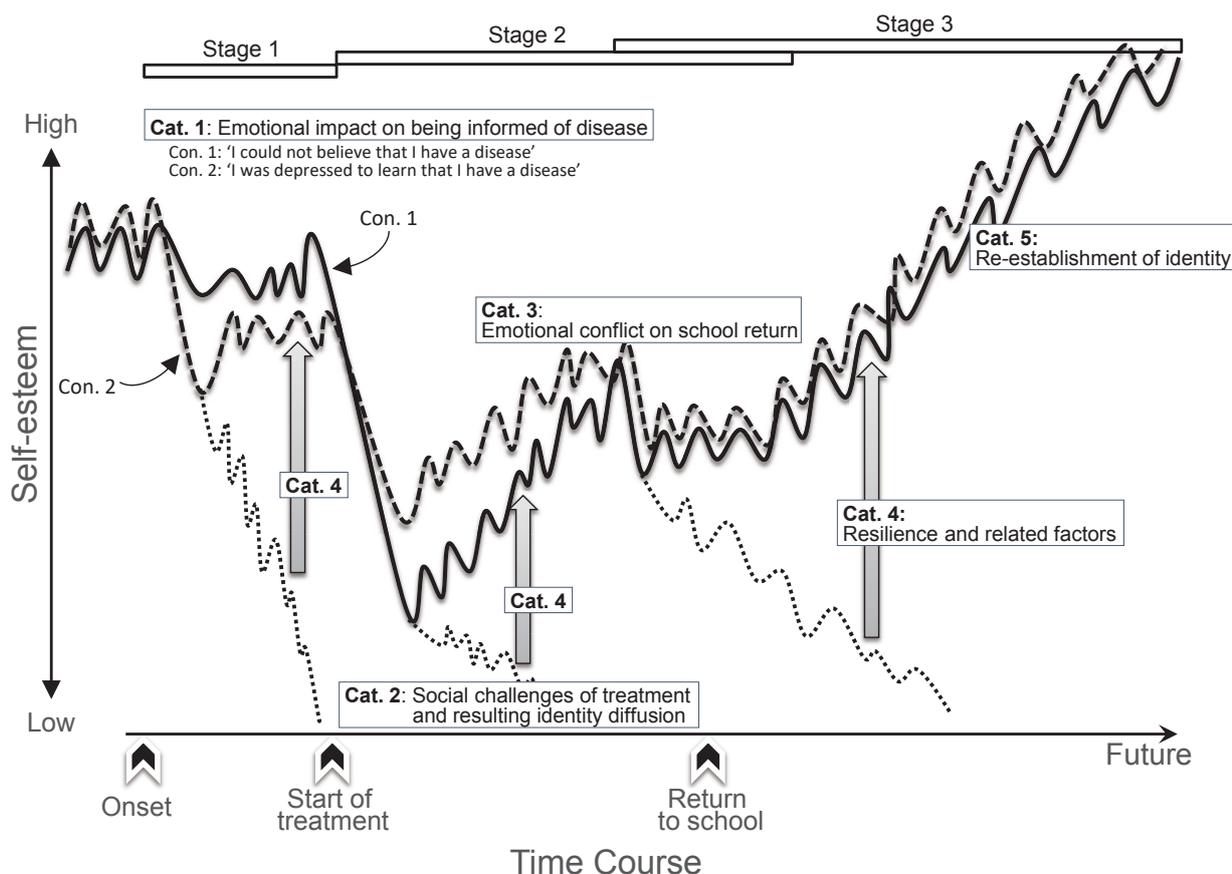


Fig. 1. A model of the psychosocial adaptation process in children with chronic kidney disease. Category and concept names are in the boxes and quotation marks. Curves (unbroken line, dotted line, dashed line) represent changes in self-esteem over time. The unbroken line represents children who answered “I could not believe that I have a disease” and the dashed line those who answered “I was depressed to learn that I have a disease” immediately after being informed of the diagnosis. The dotted line represents children who failed to overcome the crisis. Cat., category; Con., concept.

Con. 5: The children made statements such as “I had to concentrate on myself so I could not be considerate to others” (“I could hardly think about anything other than myself”).

Con. 6: The children could not accept the obesity or short stature that occurred as adverse reactions to steroid therapy (“Inferiority complex about my appearance because of adverse reactions to steroid therapy”).

Con. 7: The children could not recall, or refused to recall, the details of their treatment (“Forgetting events in the past”).

Cat. 3: Emotional conflict on school return

This category consisted of 5 concepts: ‘I wanted to return to school as soon as possible,’ ‘I wondered whether I should tell my friends about the disease,’ ‘I was frustrated that I could not do things with my friends because of my disease,’ ‘I felt uncomfortable when my friends gave me special consideration’ and ‘I want a life like that

of my friends.’

Con. 1: When treatment was successful and the disease went into remission, children started wanting to return to school (‘I wanted to return to school as soon as possible’).

Con. 2: The children wanted to tell their friends about their disease and make their friends understand the difficulties they had encountered, but they were also afraid of not being understood when they explained the situation to their friends (‘I wondered whether I should tell my friends about the disease’).

Con. 3: The children expressed frustration by statements such as “I could not participate in the sports club meets” or “I could not keep up with studies” (‘I was frustrated that I could not do things with my friends because of my disease’).

Con. 4: Some children were embarrassed by receiving special consideration from their friends, for example “I didn’t like my friends caring about my disease” or “I

went to school after a long absence, but it was uncomfortable as if I had been late for class” (‘I felt uncomfortable when my friends gave me special consideration’).

Con. 5: Furthermore, the children wanted a life without disease, saying “I am different from others my age: I have a disease, but they don’t,” “I wish I was a normal child (without disease)” (‘I want a life like that of my friends’).

Cat. 4: Resilience and related factors

This category consisted of 5 concepts: ‘A little happiness during treatment,’ ‘A positive attitude that grows over time,’ ‘Support from friends,’ ‘Relationships with adults other than parents’ and ‘Support from the family.’

Con. 1: The children found a little happiness during treatment, as evidenced by statements like “I had not noticed food was so delicious before, and it tastes very good now” and “I found cute illustrations on the wall that I had not noticed before” (‘A little happiness during treatment’).

Con. 2: Adverse reactions were gradually alleviated over time and the children commented that “The treatment seems to be effective, so I will work on becoming better over time” (‘A positive attitude that grows over time’).

Con. 3: The children also noted the kindness and consideration of their friends (‘Support from friends’).

Con. 4: Encouragement by adults other than their parents, such as teachers or the adults they encountered at part-time jobs, alleviated their depression and facilitated a positive attitude. “My teacher encouraged me when I was worried because I could not keep up with studies” or “Adults encouraged me by saying you are OK just as you are” (‘Relationships with adults other than parents’).

Con. 5: The respondents also had a sense of gratitude to their families (‘Support from the family’).

Cat. 5: Re-establishment of identity

This category consisted of 5 concepts: ‘A positive attitude that grows over time,’ ‘Anxiety about a life with disease,’ ‘Finding things to do despite restrictions,’ ‘Accepting myself and my disease’ and ‘Experiences in hospital have influenced my hopes for the future.’

Con. 1: Over time, the children came to understand that “Everyone has his/her own problems” (‘A positive attitude that grows over time’).

Con. 2: At the same time, their anxiety about chronic disease remained, saying “I am always concerned about recurrence” (‘Anxiety about a life with disease’).

Con. 3: The children found things that they could still do despite the illness, e.g., “Playing sport was restricted after the onset of my disease, but I can watch

sports” or “I have come to regard communication with others as important” (‘Finding things to do despite restrictions’).

Con. 4: Over time, the children came to accept life as it is, e.g., “I understand that what I should do is maintain my current condition,” “I am different from everyone else so it is no use comparing myself with others,” or “I should do what I can, and I don’t have to do what I cannot” (‘Accepting myself and my disease’).

Con. 5: Some children re-constructed their identity through difficult experiences during treatment, and said “I want to go into an occupation related to medicine” (‘Experiences in hospital have influenced my hopes for the future’).

DISCUSSION

In order to facilitate an understanding of the psychosocial adaptation process in children with chronic kidney disease, dividing this process into the 3 stages described below may be helpful. Stage 1 is the early period after disease onset, Stage 2 is the identity diffusion period, and Stage 3 is the identity reconstruction period.

Stage 1 (early period)

In this stage, the children show a change in their feeling immediately after being informed of their disease.

Many diseases have characteristic symptoms/signs; however, children with chronic kidney disease have few symptoms at the initial stage and a characteristic feature is that affected children often do not believe they are ill.⁵ Therefore, they tend to question being ill and face loneliness or difficulties after becoming aware of their diseases, as reported in a previous interview-based study involving children with pediatric chronic diseases.²⁰ In the interviews performed for the present study, some children answered that they became depressed after learning that they had a chronic disease, while others said that they were unable to believe the diagnosis or understand it. Thus, the extent of acceptance of the disease varied widely among the children.

Children who responded that “I could not believe that I have a disease” or “I could not understand what my doctor said” were more likely to have lower self-esteem when treatment was started because they only experienced adverse effects without any evident benefit (see Fig. 1). Lacking an understanding of the disease concept, they were surprised to see these effects, and became confused, as they stated: “I needed to protect myself with all my might, so I could not afford to worry about others” and “I panicked when side effects suddenly occurred, because I had not taken them so seriously.” On the other hand, those who became disappointed at the

initial stage tended to understand their own conditions from the early stages of treatment, as they stated: “I felt frustrated because I could not do what I wanted to do” and “Adverse effects occurred after all.” This is because the children who did not understand the disease or its treatment were surprised to develop adverse reactions and became confused.

Based on these results, it appears to be important to ensure that children understand the details and prognosis of their disease from its onset by providing an appropriate explanation for their developmental stage.

Stage 2 (identity diffusion period)

This stage is characterized by identity diffusion caused by double crises, which are a developmental crisis and situational crisis.

Developmental crisis

Children face various anxieties during the transition from childhood to adulthood, such as “What kind of person am I?,” “I am different from everyone else,” or “I have an ideal image of myself, but I cannot live up to it.” Over time, they overcome this developmental crisis and establish an adult identity (achievement of the developmental task). This crisis involves life events such as entrance to high school/college, getting a job, marriage and birth of the first child. When children cannot overcome this development crisis and fail to achieve their developmental tasks, a condition known as identity diffusion occurs.²¹

Situational crisis

Erikson stated that “when a person feels that he/she is being extensively deprived by the environment, he/she desperately resists the environment. This resistance is similar to that observed in animals struggling to survive at the time of a crisis.¹⁸ This is generally called a situational crisis, and is the protective reaction of a person making efforts to adapt to external changes. In the present study, the situational crisis occurred when the children with chronic kidney disease encountered restrictions or difficulties in daily life associated with the disease and had to cope with these situations.

Double crises

At the time when the children encountered these double crises (developmental crisis and situational crisis), they had little social experience due to prolonged treatment of the underlying disease, their social skills had not matured because they had been protected by their parents, and they were burdened by the requirements of treatment as well as having a feeling of alienation due

to treatment.²² Under these conditions, children may not achieve their developmental tasks or establish their identity, which may lead to identity diffusion. Children with identity diffusion may avoid making commitments and become apathetic, or may be confused because of the disparity between what they were before the diagnosis and what they are now when they have to live with the disease.²³

The children participating in the present study were aware of a discrepancy between their ideal life and reality. They endured painful treatment, felt isolated and became apathetic. They could only think about themselves and were more likely to be aggressive towards others. Statements representing their difficulty in accepting their situation, such as “I did not expect a situation like this,” were particularly frequent among those who answered: “I could not believe that I was ill” at the initial stage after the onset. They were distressed due to the gap more markedly than other respondents. In other words, all of the subjects had identity diffusion without the establishment of their identity at the initiation period of treatment.

Helping children with identity diffusion

Roberta suggested that healthcare professionals who support adolescent patients with chronic diseases have to understand the needs of their patients and provide suitable support for each individual patient.²⁴ However, the children participating in the present study did not directly discuss their relationship with medical professionals. The children did not discuss nurses or physicians because these medical professionals had made the children face a situational crisis by diagnosing chronic kidney disease. However, if medical professionals postpone providing information on prognoses, treatments, side effects, children cannot fully understand the disease and will be shocked when they fully grasp their situation, which may make it harder for them to overcome the crisis. In order to prevent this situation and provide support for children in Stage 1, it is crucial for physicians and nurses involved in managing chronic diseases to provide children with information on the disease and its treatment. In Stage 2, in addition to support from physicians and nurses, it is crucial to receive support from other individuals who are not directly related to the treatment, particularly for the children with identity diffusion and those with self-abandonment or suicidal ideation.

Stage 3 (identity reconstruction period)

This is the stage in which the child shifts from identity diffusion to reconstruction.

When treatment is successful and symptoms are

alleviated, the child's physical needs have been fulfilled. Even when children experience multiple relapses without improvements, they become accustomed to the situation. In addition, children find their place among peers with the same disease, anxiety is reduced, and they have time to address developmental tasks. In order for children to achieve identity reconstruction and adaptation to society, several factors are crucial for enhancing (or assisting the enhancement of) resilience. Factors important for the enhancement of resilience include the alleviation of symptoms, becoming accustomed to the condition over time if symptoms persist, relationships with friends or peers who have the same disease, conversations with friends or counseling by adults other than their parents (talking about the disease, their anxieties and their future outlook), and acceptance as they are by the family. Among these factors, encouragement or acceptance from others is crucial for children to overcome their inferiority complex, which means that "finding someone who appreciates the child" is essential for the development of resilience.²⁵ Chronic disease and long-term treatment are challenging issues, but also provide a person with the ability to overcome difficulties. During this process, the person will come to understand the condition more objectively and will learn to reflect about himself/herself more deeply, leading to self-acceptance and perhaps more profound insights into developmental tasks than peers of the same age without chronic disease. These factors are likely to help children overcome their crises. Medical professionals have a role in providing children with correct information to help them understand their chronic disease more objectively and overcome the challenges imposed by illness, as well as supporting children with affection similar to members of their family.

LIMITATIONS OF THIS STUDY

Identity is established during the transition from childhood to adulthood; however, the detailed process depends on the cultural background. For example, Westerners are more likely to establish an identity based on individualism,²¹ whereas East Asians (including Japanese) establish an identity that harmonizes with their surroundings and is more strongly influenced by tradition or religion. Therefore, generalization of the present results as a model of the process of psychosocial adaptation by children with chronic kidney disease may be limited because this study only analyzed Japanese children.

Furthermore, only subjects undergoing the transition from childhood to adulthood were investigated. Children have a less objective understanding of their condition than adults. On the other hand, they easily recall their

thoughts and feelings and express them more vividly because the disease and its associated challenges were relatively recent events.

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