Illness Representations and Coping Processes of Taiwanese Patients With Early-Stage Chronic Kidney Disease

Chiu-Chu Lin1 • Mei-Chun Chen2 • Hsiu-Fang Hsieh3 • Shu-Chen Chang4*

1PhD, RN, Associate Professor, College of Nursing, Kaohsiung Medical University • 2PhD, RN, Assistant Professor, National Tainan Institute of Nursing • 3PhD, RN, Associate Professor, College of Nursing, FooYin University • 4MSN, RN, Director, Department of Nursing, Changhua Christian Hospital, and Doctoral Candidate, College of Nursing, Kaohsiung Medical University.

ABSTRACT

Background: Chronic kidney disease (CKD) is a public health problem worldwide with an increasing incidence and prevalence and high cost. The role of illness perceptions in understanding health-related behavior has received little attention in patients with early-stage CKD.

Purpose: This qualitative study aimed to describe the illness representation and coping process experience of patients with early-stage CKD in Taiwan.

Methods: A qualitative content analysis approach was used to analyze semistructured, open-ended, one-on-one interviews with 15 patients with early-stage CKD. Purposive sampling was used to recruit patients diagnosed with early-stage CKD from the nephrology departments of two medical centers in Taiwan. Trustworthiness of the study was evaluated using four criteria suggested by Lincoln and Guba.

Results: Six themes emerged from the analysis: experiencing early symptoms, self-interpreting the causes of having CKD, realizing CKD as a long-term disease, believing CKD could be controlled by following doctors’ orders, anticipating the consequences of having CKD, and adopting coping strategies to delay the progress of CKD.

Conclusions/Implications for Practice: Findings from this study compared with previous studies reveal that education can effectively change patient illness representations as an approach to improve coping behavior. This finding offers healthcare professionals insight into the health education necessary to assess patient illness representation to provide culturally sensitive interventions.

Key Words: chronic kidney disease, coping, illness representation, qualitative study.

Introduction

Chronic kidney disease (CKD) is increasingly recognized as an emerging worldwide public health problem with increasing prevalence and high costs (Levey et al., 2009). The result of a systematic review including 26 studies found the prevalence of CKD around the world to be high, especially among Caucasians, Chinese, and Japanese populations (20.4%–49.9%; Zhang & Rothenbacher, 2008). In the United States, CKD has increased 20%–25% during the last decade (U.S. Renal Data System, 2009). The incidence and prevalence rate of end-stage renal disease (ESRD) in Taiwan has risen to become the highest in the world (U.S. Renal Data System, 2009). CKD is a progressive chronic disease divided into five stages. Untreated CKD can progress to ESRD, requiring lifelong dialysis or kidney transplantation. In 2007, 61,866 dialysis patients in Taiwan accounted for 0.26% of the total insured population, but their medical expenses for dialysis treatment consumed 8% of total insured expenditures (Bureau of National Health Insurance, Taiwan, ROC, 2008). Thus, CKD has become a public health epidemic and a financial burden on healthcare systems.

In traditional Chinese culture, kidney disease is often perceived as punishment for sins committed in previous lives (i.e., karma) and a source of male impotence. Thus, patients with CKD often experience social stigma (Lin, Lee, & Hicks, 2005) that is greater than most other diseases. Often, patients are unwilling to accept a CKD diagnosis and will seek alternative treatments through herbal medicine, folk remedies, and secret treatments introduced by others (Lin et al., 2005). Denial and additional treatment-seeking behaviors are because of fear of stigmatization. Patients with CKD often struggle to accept and adjust to their disease (Lin et al., 2005). Obviously, patients’ behaviors toward treatment relate closely to their interpretation of their disease...
and treatment. A patient’s response to his or her disease and symptoms is known as illness representation (Leventhal, Brissette, & Leventhal, 2003).

Leventhal believes that the illness representation process occurs on two parallel pathways, namely the emotional and the cognitive, which interact with and affect each other. Emotional illness representation refers to an internal emotional response to illness stimuli such as fear, anxiety, worry, or anger. Such responses prompt people to adopt emotion-oriented coping behaviors (Hagger & Orbell, 2003; Leventhal et al., 2003). Cognitive illness representation consists of five components (Heijmans, 1998; Leventhal et al., 2003; Leventhal, Nerenz, & Steele, 1984; Moss-Morris, Petrie, & Weinman, 1996; Shiloh, 2006) including (a) identity: patient acknowledgement of their illness through number and type of symptoms that relates to patient knowledge of their symptoms and illness development; (b) cause: patient’s view of what may have caused the illness; (c) timeline: patient’s view about his or her illness being acute or chronic, long- or short-term, and whether it will recur; (d) consequences: patient perception of the severity of his or her illness regarding its physical, psychological, social, and economic impact; and (e) controllability/cure: patient perception about whether the illness can be cured or effectively controlled.

Patient illness representations relate closely to a patient’s decision to seek healthcare (Leventhal et al., 2003; Lin et al., 2005) and compliance with medical advice (Kim & Evangelista, 2010). Empirical data have indicated that an individual’s illness representation can predict how well patients cope with disease (Harwood, Locking-Cusolito, Spittal, White, & Wilson, 2005; Karamanidou, Clatworthy, Weinman, & Horne, 2008; Meyer, Leventhal, & Gutmann, 1985; O’Connor, Jardine, & Millar, 2008). Individuals with a positive attitude toward their illness have been found to achieve better outcomes, and those with negative attitudes have achieved relatively worse outcomes (Hart & Grindel, 2010; Kimmel, 2000; Shiloh, 2006).

In the CKD field, illness representation was mainly studied in patients with ESRD, where it influenced patients’ emotion, self-care, quality of life, compliance with dialysis treatment, medication use, diet, and fluid regimen control (Covic, Seica, Gusbeth-Tatomir, Gavrilovic, & Goldsmith, 2004; Fowler & Baas, 2006; Harwood et al., 2005; Kim & Evangelista, 2010; Kimmel, 2000; O’Connor et al., 2008; Velez & Ramasco, 2006). Most CKD research has focused on medical treatment, with recent studies indicating that self-management intervention can effectively retard CKD progression (Brown, Garcia, Kouzekenani, & Hanis, 2002; Chen et al., 2011; Costantini et al., 2008). However, patient willingness to perform self-management behaviors largely depends on how patients perceive their disease and treatment (Gaston, Cottrell, & Fullen, 2012; Kaptein, Klok, Moss-Morris, & Brand, 2010; O’Connor et al., 2008). To our knowledge, no studies have yet explored the illness representations of patients with early-stage CKD and how these representations affect individuals’ coping behaviors. Furthermore, because most research on illness representation and coping behavior are conducted in Western cultures, it is essential to explore such phenomena in other cultures and populations. The purpose of this qualitative study was to describe the illness representations and coping processes of Taiwanese patients with early CKD.

Methods

Design

A qualitative content analysis approach was used to analyze semistructured, open-ended interviews.

Participants

Participants were selected using purposive sampling via physician or case manager referral from the outpatient departments of two CKD prevention centers at medical centers located, respectively, in central and southern Taiwan. Participant inclusion criteria included stages 1–3 CKD, verbal communication ability in either Mandarin Chinese or Taiwanese, and aged 20 years or older. In line with the saturation principle, participant recruitment stopped at the point when no new information was collected.

Fifteen participants participated in this study. Participant ages ranged from 25 to 77 years. Twelve (80%) were men and three (20%) were women; one was educated to the elementary school level, four were educated to the junior high school level, four were educated to the high school level, four were educated to the university level, and two had completed graduate school. Most were married (n = 13).

Data Collection

Data were collected using one-on-one, in-depth interviews. Interviews took place in either a small discussion room at the hospital or a quiet place selected by the participant. Data were collected between July and December 2008. Interview guidelines for illness representations for patients with CKD were developed for this study based on Leventhal’s self-regulation model (2003). Interview questions addressed three main topics: (a) How did you feel after being diagnosed with the kidney disease? How do you perceive the illness? (specific questions regarding this topic included as follows: What do you think CKD is? What kinds of discomforts or symptoms were induced by CKD? What was the reason for your contracting CKD? Do you think that CKD can be cured or controlled effectively? How do you control your CKD or symptoms? Do you perceive your CKD as a long- or short-term problem, and why? How does CKD influence you? How does CKD impact you emotionally?) (b) How did you deal with problems brought by the disease? (c) Is there anything about CKD you would like to share with newly
diagnosed patients? Each interview lasted 60–90 minutes. All interviews were recorded and later transcribed verbatim.

Ethical Considerations
The study was approved by the institutional review board of the study hospital (CCH-080601). Participants were informed that the interview was anonymous and personal information would be encrypted. Interviews were conducted after written consent had been obtained.

Data Analysis
Content analysis was used to analyze all interview information (Hsieh & Shannon, 2005); the procedures for which were as follows: (a) transcribe entire interview verbatim; (b) read the transcript while listening to the recorded interview from beginning to the end; (c) highlight all statements that, on first impression, appear to represent illness representation and coping response; (d) code all highlighted passages using predetermined codes including illness representation and coping response; (e) assign new codes to any text that cannot be categorized using the initial coding scheme; and (f) present supporting evidence by showing codes with exemplars and offering descriptive evidence.

Rigor and Trustworthiness
Rigor and trustworthiness of the study were evaluated using Lincoln and Guba’s (1985) criteria. To ensure credibility, all researchers had experience in qualitative research or had been trained for conducting qualitative research. Three had both practical nephrology experience and published multiple qualitative studies. Data were analyzed with each researcher separately then discussed together. Transferability was enhanced by the second author, a nurse with 7 years of practical experience in dialysis care, who collected all data. During the interview, she maintained a sensitive and objective attitude as the participants described their illness experiences without prompts. She then transcribed the participants’ subjective experiences into written form. The exhaustive description ensured that results were applicable to other clinical scenarios. Dependability was ensured by recording the entire interview and transcribing verbatim into written form. After transcription, the interviewer checked the transcription word by word to ensure its accuracy. Conformability was achieved without strain after credibility, transferability, and dependability were achieved. File recoding, original transcription, content analysis, and study documentation processes were retained on file for future review to confirm study neutrality.

Results
Data analysis identified six themes, the final two of which contained several subthemes.

Experiencing Early Symptoms
Anemia, proteinuria, and edema are common for patients with early-stage CKD. Symptoms experienced by participants with early-stage CKD were not obvious, but participants associated their kidney disease with these symptoms including dizziness, tiredness, flank pain, foamy urine, and puffiness. Many participants experienced symptoms related to anemia including fatigue and lack of physical stamina. Some experienced edema symptoms including puffiness, joints stretched, and indentation. For example, Participant J said: “I always feel dizzy. My doctor said that I was anemic and he thought it was caused by CKD…. I feel tired easily as well as flank pain. I feel tired whenever I play with my children. I was not like this before!” Participants experienced proteinuria and edema. Participant A said: “I got foamy urine. It’s quite foamy and lasted for a long time. I read it on newspapers before. It said that if your urine is somewhat (or moderately or exceedingly) foamy, then you might have proteinuria. I did a physical check-up and found that I had CKD.” Some participants experienced edema. Both Participant K and Participant J said: “My symptoms are puffiness, edema, and my joints become big and stretched. When I press my finger down onto my skin, I see an indentation. My both legs are swollen, and I can’t even wear my shoes.”

Self-Interpreting the Causes of Having CKD
Participants reported a variety of causes that they believed contributed to their illness, including heredity, other chronic diseases (e.g., hypertension or diabetes), personality, prolonged medication use (e.g., analgesics and antibiotics), poor lifestyle habits (overworking, overstressed, poor eating habits), and karma.

Many participants thought that their kidney diseases were inherited from parents. For example, Participant A said: “My mom got CKD because of her diabetes. I got CKD from my mom.” Participant B believed that he had come down with CKD because of too much work pressure and said: “I am not happy, and I have been under so much stress my entire life…. I think I got CKD because I have high blood pressure, am too tired, and am overstressed. I know that stress affects kidney function…. ” Participant M used karma to interpret the cause of illness and said: “It must be karma. I definitely did something bad that hurt my kidneys in my previous life. That’s why I have CKD this life.” Participant B opined: “I got CKD because of Buddhist karma. That is to say…I did something in my previous life that gave me this disease in this life.” Many participants linked CKD to improper use of medication or dietary habits; for example, Participant H said: “I had taken pain killers for my bone problem for a long time. Later, my doctor told me that pain killers might damage my kidneys. So, I got CKD maybe because I took pain killers for a long time.” Participant A reported: “I believe I have CKD because I used to eat like a horse. I loved fried food, which has so many chemicals…. They damaged my kidneys.”
Realizing CKD as a Long-Term Disease

Participants stated that, if CKD was not well controlled, renal function would decrease gradually, and they would have to go on dialysis. Therefore, they believed CKD to be a long-term disease that would accompany them for their entire lives. For example, Participant C expressed: “CKD is a long-term disease. Once you get it, there is no cure. The only way is to control it and prevent it from worsening.” Participant D repeated: “CKD is a long-term disease. My doctor has already told me that. My doctor told me clearly that CKD would not go away. There is no medicine that will cure it. It could be a long road to fight. I will never get better. I can only maintain my present condition. So once you get the disease, you have to deal with it for the rest of your life.”

Believing CKD Could be Controlled by Following Doctors’ Orders

Most participants believed that the best way to control the disease and prevent renal function from worsening was to follow their doctor’s advice. This included taking medication on time, following a proper diet, not taking unknown medications, and adopting a healthy lifestyle. Participants stressed the importance of not taking over-the-counter medications. For example, Participant A remarked: “My dad believed those ads on radio and bought me some folk remedies. He spent like ten thousand dollars for those Chinese herbs. I went online to check out those remedies, and I found they hadlead and heavy metals in them. I didn’t take any. I went to see doctor because I was sick.” Participant C declared: “I have bad kidneys. That’s why I never take unknown medicine. If you take those things, you will soon need a hemodialysis. Do not take unknown medicine.” Many participants emphasized the importance of following orders. They acknowledged, “I am aware that CKD is controllable. I follow my doctor’s instructions when taking any medication. I am leading a lifestyle recommended by my doctor as well. No need to think twice, just do as your doctor says,” said Participant D. “It would be a blessing if my kidney disease would stop worsening. If you want to survive, you have to do whatever you can to control the disease. You have to listen to your doctor,” advised Participant H. “If your doctor tells you not to eat a certain food, then you can’t. Or you will end up on dialysis,” said Participant C.

Anticipating the Consequences of Having CKD

The perceived consequences of illness focused on dialysis. Participants’ impressions of the consequences derived mainly from the experiences of others. Some study participants believed that understanding other patient experiences helped them to mentally prepare for the possibility of dialysis treatment. However, other participants had negative emotional responses to the experiences they had heard about.

Anecdotal dialysis experiences

Anecdotal dialysis experiences refer to dialysis experiences told to participants by relatives, friends, and others. Some participants had relatives who had received dialysis treatment or were currently receiving dialysis treatment. Others had directly or indirectly heard about the negative influences associated with dialysis treatment. Participant B described that his uncle was a dialysis patient and reported: “My uncle looked quite healthy when he first started on dialysis. But later on, he looked very weak and a bit clumsy.” Participant P thought that his friend’s condition was not good after starting dialysis treatment, and he expressed: “A friend of mine just began receiving dialysis treatment recently. I found that he was in bad mood. He was so worried about the fact that he had to receive dialysis. He felt his life was ruined because of this. I feel bad for him when I know that he needs dialysis. I may end up just like him. I wonder if I can avoid it.” Participant K said: “I know that most people need hemodialysis three times a week. In the end, they will have terrible complexion. Many of my coworkers’ husbands need hemodialysis. Therefore, I know the pain of hemodialysis. They have to receive hemodialysis three times a week and be injected with big needles. I think that’s just too cruel.”

Being prepared for dialysis treatment

Although others’ negative experiences affected participants’ views about dialysis, they also realized that dialysis was essential if their illness progressed to ESRD. Some decided to let the illness run its course and mentally prepared themselves for future dialysis. For example, Participant F responded: “I asked my doctor, and he said the illness cannot be cured. I am prepared that, at the point where my kidneys are not functioning properly, I am going to need hemodialysis.” Participant P shared the same thought: “Now, everything is in control, and I am taking medication as well. Anyway, if someday, my kidneys are not functioning properly…and I need hemodialysis, then I will receive it in order to survive.”

Emotional responses to the possibility of dialysis treatment

Anticipation of the inevitable course of dialysis provoked negative emotional responses from participants. The possibility of dialysis and its accompanying negative effects made participants feel afraid, anxious, and uncertain. Their emotional reactions to future dialysis were complicated. Participant K said: “When I was first told that I had CKD and my doctor gave me a Catastrophic Illness Card, I was very sad, and I was afraid that I would end up needing hemodialysis one day. What if bad things happen to me after I receive hemodialysis? Who is going to take care of my mom? I am worried about others, not myself. . . .” Participant J related: “Having CKD is just like walking in the valley of the shadow of death, and I can see no hope.. . .”
My children are still so young. Death has cast its shadow over me, and I am very affected.” Participant F was scared and filled with uncertainty: “After having CKD, I am so scared because I may need hemodialysis in one or two years…. Sometimes, I would think about finding a new job, but I would remind myself that I have CKD. I didn’t have this disease before, and everything was okay for me. But now, I am not as healthy as before. I always feel that my development is restricted. I am so worried about the future.”

Adopting Coping Strategies to Delay CKD Progress

Although clinical signs for stages 1–3 CKD were not obvious, participants had different interpretations about the causal relationship of the illness. Participants developed their own coping strategies in an attempt to delay illness deterioration and its psychological impact.

Change in lifestyle

Change in lifestyle refers to participants adjusting their previous lifestyle and adopting new strategies (such as changing daily schedules, quitting smoking, exercising regularly, considering a lower-pressure job, and changing their and their families’ eating habits). They hoped these changes could delay disease-related deterioration in their health. Participant F revamped his lifestyle completely, and he relayed: “After having CKD, I adjusted my lifestyle in terms of food, sleep, and exercising. I record all the information and pay special attention to them. I take my bodyweight everyday. Recently, I have been trying to eat less and lighter. I must go to bed before midnight. I also do exercises. Exercise makes you feel good.” Participant H quit smoking and drinking; he stated: “After getting CKD, I have quit smoking for more than one year. My doctor told me that, if I want to live longer, I have to quit smoking. Nicotine may damage blood vessels.” Participant M reported: “After having CKD, I keep doing exercises. I do walking on a treadmill for 130 minutes and 10 kilometers everyday. It’s about 110 steps a minute, a total of 14,300 steps. This is my third treadmill. I find that my blood creatinine has gradually dropped.”

Use of complementary therapy

The use of complementary therapy refers to treatments other than routine Western treatments. Participants tried alternative and complementary therapies (e.g., Chinese medicine or folk remedies) to enhance their health. The most frequently used therapy was Chinese herbal medicine; for example, Participant K said: “I asked people what you can eat if you have bad kidneys. And then, I found an unlicensed doctor who was an old lady and very good at Chinese herbs. I am aware that Western medical doctors discourage their patients from taking folk remedies and medication introduced on radio. I know it clearly. But I took the old lady’s remedy twice. I peed a lot. I think the old lady’s remedy is better than Western medication.” Participant O stated: “Apart from medication given by my doctor, I also take Chinese medicine to treat my kidney disease. The drug I am taking is ‘Shen Chi Pill,’ which is for diuretic use. If someone tells me that a certain Chinese medicine is good for my disease, I will go and find it; even it is in a remote mountain area.” Participant G also tried Chinese medicine: “I cook my Chinese medicine to 1000c.c. and drink it like water. It is probably because I drink more water that protein and uric acid in my urine has decreased. After taking Chinese medicine, I have a better renal index.” Participant K sought natural therapy in combination with Chinese medicine: “After getting CKD, I went to the steam spa at least twice a month. The purpose is to sweat out Western medicine I took in order to reduce the burden of my kidneys. I have bad kidneys, so I study Chinese medicine. Chinese medicine suggests eating black foods such as Judas’ ear fungus, black sesame, and so on. I try to eat lots of them.”

Seeking religious support

In the process of coping, apart from external interventions, many participants sought the internal power of religion to cope with the impact of disease and to gain serenity and peace. Participant B said: “From the perspective of religion, I think my disease is Karma. I did bad things in my previous life; consequently, I got sick this life. I try to do more religious practices. After getting CKD, I read the Repentance Verses for 40 minutes at 6 A.M. and 7 P.M. I feel calm.” Participant O asked for the gods’ help when he felt uncomfortable: “When my condition worsens, I ask for Bao-Sheng-Da-Di’s help to make me healthy. I burn incense stick and pray so that my kidney may not get worse.” Participant J explained: “After I got sick…When I came back to God, I know that He controls everything. There is a fixed time to be born, and a time to die; time for laughing, and time to be sick. He is the one who created me, and He will also look after my kidneys. Give yourself to God, and there is no need to worry.”

Discussion

Illness representations are dynamic and changing. The six themes deduced from the interviews reflected Leventhal’s self-regulation model. That is to say, illness representations change as the illness progresses, treatments are received, and more information is received, which affect individuals’ responses to illness and coping behaviors (Leventhal et al., 2003; Shiloh, 2006). Participant experiences of the illness process are discussed below.

Illness Identity

Participants in this study were patients with stages 1–3 CKD who perceived no specific symptoms at onset. Many
Participants sought medical help because they felt uncomfortable (dizziness, fatigue, general weakness) or had abnormal symptoms (foamy urine, edema). Most participants did not identify their CKD until healthcare staff explained it to them, and only then did they connect their symptoms to CKD. This finding is consistent with Leventhal’s self-regulation model that states that a patient’s illness identification relies on the presence of physical symptoms and information from different channels such as healthcare professionals, other peoples’ illness experiences, and health information received via the mass media (Diefenbach & Leventhal, 1996; Leventhal et al., 1984; Shiloh, 2006). Correct identification of symptoms and early treatment are important factors to prevent CKD progression.

Taiwan has the highest incidence and prevalence of ESRD in the world. This may be because of multiple causes. Evidence-based data suggest that it is related to insufficient illness cognition. Studies have indicated that 11.93% people in Taiwan suffer from CKD but that only 3.54% of sufferers are cognizant of their condition (Wen et al., 2008). In terms of prevention, people must have the ability to self-identify abnormal symptoms to achieve early diagnosis and early treatment. Otherwise, they might misinterpret as abnormal symptoms and not spur the individual to seek medical help. Once people feel uncomfortable or notice obvious symptoms, CKD will have progressed into irreversible ESRD. Therefore, to prevent CKD effectively, competency to recognize abnormal signs and symptoms must be improved. Furthermore, annual medical examinations should be established to identify early patients with CKD to initiate treatment.

Causes
A few participants believed their illness as related to karma, implying that their CKD is related to sins and transgressions committed in previous lives (cause); therefore, their illness is a punishment to be endured in their present lives. Most participants, however, believed that their illness is because of inheritance, chronic diseases (e.g., diabetes and hypertension), use of contrast media, or prolonged use of antibiotics or analgesics. Some participants also connected their CKD to inappropriate lifestyle. The causes and types of illness described by participants were consistent with those reported in earlier studies (Haroun et al., 2003; Schaeffner et al., 2003; Shankarp, Klein, & Klein, 2006; Stengel, Tarver-Carr, Powe, Eberhardt, & Brancati, 2003; White & Grenyer, 1999). Public understanding of CKD has been greatly enhanced through the efforts of Taiwan’s Chronic Kidney Disease Prevention Project sponsored by the Bureau of Health Promotion. Improving understanding shows that illness representations can be changed through education.

Consequences
Because early CKD presents no specific symptoms, patients find it hard to imagine the severity of CKD’s later stages. During interviews, when talking about illness consequence perceptions, most participants stated that, if CKD was poorly controlled, they would eventually have to undergo dialysis. On the basis of that premise, participants coped with the illness and avoided dialysis treatment by reducing stress, changing their diets, and exercising more. Yet, we found that some participants, especially those affected by other persons’ negative dialysis treatment experiences, adopted negative coping strategies because of fear of dialysis. When they learned that they had CKD and might need dialysis, they became anxious, depressed, and fearful. The only question they had was regarding the potential for folk remedy to prevent the need for dialysis (Lin & Yen, 2003). In addition to emotional overreactions limiting their cognition, the deep-rooted concept of “Never receive dialysis treatment; once you receive dialysis treatment, you will need it for the rest of your life” prompted their seeking complementary therapy or religious support with the hope that the illness could be controlled or miraculously cured.

Time line/Control
Health education provided by healthcare professionals and listening to others’ experiences informed participants that CKD could not be cured but could be controlled. They also knew that poor CKD control might culminate in dialysis. On the basis of this cognition and beliefs, most participants believed that following their doctors’ advice was the best strategy to control CKD, and they proactively changed their lifestyle (e.g., regular exercise, better diet, quitting smoking and drinking) to delay disease progress. Apart from changing their lifestyle, many participants adopted complementary therapies such as aromatherapy, traditional Chinese herbal medicine, or yoga to enhance their health and lessen illness-related deterioration. Data from interviews showed that, when individuals cognitively believe their illness to be incurable, they adopt coping strategies that are more positive (Moss-Morris et al., 1996; Scharloo et al., 2000).

Coping
Results found that participant cognition of CKD differed significantly from 20 years ago. Most participants were correct about the causes, time line, and control of CKD; thus, they adhered to medical advice and proactively changed their lifestyle. Findings regarding coping strategies from this study differ from those of previous studies (Lee, Lin, Wu, & Hsu, 2004; Lin & Chang, 1985; Lin, Chin, Liang, & Lai, 2000; Lin et al., 2005; Lin & Yen, 2003) in which patients would seek medical help from wherever they could and use herbal medicine and folk remedies immediately after learning of their CKD diagnosis. The different perception and coping behaviors found in this study might be attributed to the success of the Bureau of Health Promotion’s CKD Prevention Project. Study findings also echo Leventhal’s self-regulation model, which holds that an individual’s
coping behavior is directly affected by his or her interpretation of the event (Diefenbach & Leventhal, 1996; Leventhal et al., 2003; Shiloh, 2006). Accordingly, healthcare professionals should emphasize the impact of illness on patients to lessen the emotional overreaction on their illness cognition, which may further impede effective coping strategies. In brief, healthcare professionals should use culturally sensitive educational information to educate patients about CKD and help them identify effective coping strategies to cope with stress.

Limitations

Study participants were recruited from two medical center CKD prevention units in which nurses provided specialized education. Therefore, results may not be applicable to patients who receive treatment at clinics or hospitals without a CKD prevention unit. Because of the lack of literature on the application of illness representation theory on patients with early-stage CKD, we used patients with ESRD for comparison. Future research is needed to determine whether the implication derived from the comparison properly reflects the current situation.

Implications for Practice

The CKD interpretations and coping patterns of participants in this study differ significantly from those highlighted in previous studies (Lin & Chang, 1985; Lin et al., 2000, 2005; Lin & Yen, 2003). Two decades ago, Chinese people still held highly negative attitudes toward CKD, which was considered a “kidney deficiency.” The public perception was that kidney insufficiency would lead to impotence, thus emasculating male sufferers. Previous studies indicated that many people applied the concept of karma to interpret the etiology of CKD and attributed a related cause (previous sins) and effect (punishment). Traditional culture stigmatized patients with CKD, thus causing them to hide their illness, avoid regular treatment, and try a variety of complementary therapies (Lin & Chang, 1985; Lin et al., 2000, 2005; Lin & Yen, 2003). Misconceptions about CKD have made the coping process particularly difficult for patients. Fortunately, the Taiwan CKD Prevention Project has improved public perceptions of CKD. CKD illness representations and coping processes identified in the current study indicate that a change in public attitude has occurred. Results show that illness representations are indeed affected by local culture; however, these representations can be effectively changed through education and improved patient coping behaviors. Thus, healthcare providers should carefully assess disease understanding and expectations when caring for patients who react overly emotionally or present ineffective coping behaviors. Information provided should be tailored to patient needs to prevent intervention failure and maximize results. To summarize, we can use Leventhal et al.’s (1984, 2003) self-regulation model to evaluate the correctness of patient illness cognition and the effectiveness of patient coping strategies. Doing so will change the original illness structure. Changing patient interpretations of their disease will change coping behaviors accordingly.

Acknowledgments

This study was supported by a Changhua Christian Hospital Research Fund grant (97-CCH-KMU-018). The researchers would like to thank all the participants for sharing their life experiences.

References


Hart, P. L., & Grindel, C. G. (2010). Illness representations, emotional distress, coping strategies, and coping efficacy as


早期慢性腎臟疾病病患之疾病詮釋與因應過程

林秋菊1 陈玫君2 謝秀芳3 張淑真4*

1高雄醫學大學護理學院護理學系副教授 2國立台南護理專科學校護理科助理教授
3輔英科技大學護理學院護理系副教授 4彰化基督教醫院護理部主任
高雄醫學大學護理研究所博士候選人

背景 慢性腎臟疾病（chronic kidney disease, CKD）之盛行率及發生率不斷增加，醫療花費亦高，已是普遍存在的公共衛生議題。個人對於疾病的詮釋會影響其健康相關的行為，然早期慢性腎臟疾病患者對其疾病的感受表現卻鮮少受到關注。

目的 本質性研究旨在描述台灣的早期CKD患者疾病詮釋與因應過程之經驗。

方法 本研究以立意取樣，從台灣兩家醫學中心腎臟科門診中，招募15位確診為早期CKD之病患為研究對象。採半結構、開放式之一對一、面對面訪談，訪談結果以質性內容分析方法進行分析，並以Lincoln與Guba所提的嚴謹度之四個準則進行評核。

結果 從質性分析中得出以下六大主題：經歷到早期症狀、自我詮釋其罹患CKD之原因、體認CKD是一種慢性疾病、相信遵從醫囑就可以控制CKD、預料罹患CKD的後果、以及採取因應策略來延緩CKD之病程。

結論／臨床應用 本研究發現，健康照護專業人員對於患有腎臟疾病此族群病患，對其疾病的解讀與因應有更進一步的瞭解。相較於過去所發表之研究結果顯示，個人的疾病詮釋可以透過教育改變，繼而改善個人的因應行為。此發現使健康專業人員更體認到，進行衛生教育前，必須先評估個案對其疾病的解讀為何，如此方能提供具文化敏感性的介入措施。

關鍵詞：慢性腎臟疾病、因應過程、疾病詮釋、質性研究。