



## Original Article

# Gender-based experiences on the survival of chronic renal failure patients under hemodialysis for more than 20 years



Mi-Kyoung Cho, PhD, APN<sup>a</sup>, Gisoo Shin, PhD, RN<sup>b,\*</sup>

<sup>a</sup> Eulji University, Gyeonggi-do, Republic of Korea, 1315

<sup>b</sup> Chung-Ang University, Seoul, Republic of Korea, 06974

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## ABSTRACT

**Background:** Chronic kidney disease (CKD), which causes reduction in kidney function, is a common public health problem worldwide. Among patients who have received hemodialysis for 20 years, the survival rate in first 5 years is merely 39.9%. Such rate is lower than that of cancer patients.

**Objectives:** In an effort to understand and develop helpful realistic nursing interventions, we interviewed hemodialysis patients of different genders, who have survived more than 20 years, regarding what their survival experiences meant for them.

**Methods:** While the phenomenological research method was used, the data were analyzed by Colaizzi.

**Results:** We found that the essential meaning of survival experiences was as follows: the stress of hemodialysis patients is similar to that of late-stage cancer patients, and the patients of each gender go through different experiences due to the country's specific cultures. However, regardless of genders, the positive supports from their families and nurses were important influences in their 20 years long survival. The results imply that an in-depth understanding of hemodialysis patients' experience is an essential element for developing effective nursing interventions.

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## 1. Introduction

Chronic kidney disease (CKD), which damages and hinders the function of kidney, is increasingly recognized as a major health problem worldwide. CKD has been identified as a predictor of lower quality of life. The estimated prevalence of CKD is 8–16% worldwide, and prevalence rate of CKD seems to be high in both developing and developed countries (Meuwesen, Plessis, Burger, Lubbe, & Cokeran, 2016). The number of CKD patients in Korea was about 28,000 in early 2000s, but it tripled to about 80,000 in 2014. Moreover, about 73% of the CKD patients are receiving hemodialysis (Korean Society of Nephrology, 2014). Among the number of hemodialysis patients in Korea, number of CKD patients is higher than other numerous countries like Japan or the United States. The increase rate of incidence and prevalence of hemodialysis patients in Korea was also higher than global average (Park, Baek, & Jung, 2016).

The application of hemodialysis in CKD patients allows a longer lifespan, but the patients also suffer from accompanying physical and

psychological pain. During each round of dialysis, the patients have to endure the pain caused by vascular perforation and stay in bed without moving for 4 hours, 2–3 times a week. Therefore, the treatment does not cure the disease completely, but it is continued throughout the patients' lifetime until death to extend their lifespan (Murtagh et al., 2007). Furthermore, hemodialysis patients need to control their eating and drinking habits, manage their medications, and should be aware of the potential complications (Grva et al., 2013). These conditions lead to their loss of job, poor financial stability, reduced social activity, resultant isolation from society, and mental problems such as helplessness, depression, anxiety, and frustration (Macaron et al., 2014). Thus, compared to the patients with other chronic diseases, such as hypertension and diabetes, hemodialysis patients complain about psychogenic symptoms more frequently, and many of them are unable to adjust themselves to hemodialysis treatment, eventually dropping out of the treatment (Cukor et al., 2008). As hemodialysis patients fear that they might die as soon as the treatment is stopped and witnessed the death of other peer patients who received the same treatment, they tend to think about death more often than cancer patients do (Russ, Shim, & Kaufman, 2007). Although the long-term survival rate among hemodialysis patients has increased since the past, their survival rate in the first 5 years after the diagnosis has been merely 39.9% for the last 20 years, lower than the survival rate of 45.9% among cancer patients. It was also noted that the first 5 years survival rate was higher among male patients (The Korean Society of Nephrology, 2014).

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\* Corresponding author at: Red Cross College of Nursing, Chung-Ang University, 84 Heukseok-ro, Dongjak-gu, Seoul, South of Korea, 156-756. Tel.: +82 2 820 5975; fax: +82 2 824 7961.

E-mail address: [gisoo@cau.ac.kr](mailto:gisoo@cau.ac.kr) (G. Shin).

Different from male counterparts, female hemodialysis patients encounter additional problems related to their appearance, sex, pregnancy, childbirth, and role in their marital life (Peng et al., 2005). Moreover, it has been reported that they suffer from more severe mental conflicts and show a higher rate of suicide ideation or attempt than the male patients. Especially, since child birth and parenting are emphasized for sexual roles of women in Korea, having the illness is equivalent of losing their female roles and identities as wife and mother (Chen et al., 2010).

On the other hand, male hemodialysis patients experience stress due to sexual dysfunction induced by hemodialysis, which leads to negative emotions in terms of their masculinity (Turk et al., 2004). Furthermore, in Korean society, the generations from the 1960s through the 1980s perceive gender roles that are clearly distinguished between a father and a mother, usually considering the father as a breadwinner who plays an economic role and assumes a strict patriarchal attitude (Lee & Janey, 2002). For this reason, male hemodialysis patients are daunted by their economic incapability and sexual dysfunction during the hemodialysis procedure.

Most of the previous studies on hemodialysis patients were quantitative researches that assessed the factors influencing nursing interventions and quality of life for providing the optimal quality of life to the patients after considering the chronic and incurable characteristics of the disease (Cleary & Drennan, 2005; Krings & Crane, 2009; Tasy & Healstead, 2002). However, quantitative research has limitations in assessing hemodialysis patients as a whole, because it simplifies and reduces the meaning of their experiences. In an effort to understand and develop more helpful and realistic nursing interventions, we need to examine the meaning and essence of subjective experiences from male and female hemodialysis patients who have different gender roles based on social cultures.

Therefore, the following study aims to explore the survival experiences of hemodialysis patients based on genders by using a phenomenological method among CKD patients who have survived for more than 20 years in Korean society.

## 2. Design and method

### 2.1. Methodology

Using the phenomenological research method, this study collected data on gender-based experiences of Korean hemodialysis patients who had survived for more than 20 years through in-depth interviews and analyzed the data by using the method proposed by Colaizzi (1978). In the process of data collection through in-depth interviews, involvement of the participants was voluntary, and we tried to understand their empirical world through conversations. By holistically approaching the gender-based survival experience phenomena for more than 20 years among hemodialysis patients, we made efforts to find the meaning of the experiences and gain an insight into their empirical world.

### 2.2. Participants

The participants of this study were six hemodialysis patients who had been diagnosed with CKD and received hemodialysis for more than 20 years in the hemodialysis room of a university hospital in South Korea. Only the patients with normal cognitive and memory functions were selected for the study. The participants were provided with the explanations about the purposes and the method of the study and were those who gave their consent for voluntary participation. Among six participants, one participant died of complications during the research, and the data of other five participants were analyzed in this study. The five participants consisted of two females and three males, ranging between 37 and 67 years old with the average age of 53. The causes of their CKD included glomerulonephritis, polycystic kidney, and IgA nephropathy.

### 2.3. Data gathering

Based on the previous studies related to the research topics and the researchers' experiences and through researchers' discussions, this study developed open questions that could comprehensively and thoroughly reveal the phenomena experienced by Korean hemodialysis patients who had survived for more than 20 years. The following questions were asked: 'How did you live while receiving hemodialysis?'; 'While receiving hemodialysis, what problems did you experience as a woman or a man?'; and 'How did you solve these problems and adjust to them?' Before conducting in-depth interviews for data collection, we met the participants and built trust with them. The interviews were conducted in the hemodialysis room, which was comfortable for the participants, after hemodialysis. Each interview lasted about 30 minutes, with each participant having 3–7 interview sessions. Thus, the total interview time was 1.5–3 hours per participant. There were two interviewers in each session, one to conduct the interview and the other to tape-record the conversations and monitor the participant's state. If the interviewee complained of fatigue, the interview was stopped at that point and the next interview was scheduled. All the interviews were tape-recorded, and noteworthy contents were recorded.

This study was approved by the institutional review board of the university. Concerning the ethical issues, we explained to the participants about the purposes and intentions of the research before each interview and the fact that the interview would be tape-recorded. They were also ensured that the recorded contents of the interview would be transcribed anonymously and confidentially and all the records would be discarded at the end of the research.

### 2.4. Data analysis

For data analysis, tape-recorded data were transcribed as they are. The transcripts were cross-checked with the records for confirming the reliability of data. Data collection and analysis were performed cyclically as data were analyzed immediately after they were collected, and the method proposed by Colaizzi (1978) was used for data analysis. We read the transcribed data repeatedly and extracted meaningful phrases or sentences directly related to the phenomena. During the course, we focused on the context, the participants' response, and etc. in the data. Through careful examination of the extracted meaningful statements, redundant expressions were removed and the statements were refined into more general and abstract forms. The reconstructed meaningful statements were grouped by the theme based on their contents, and for higher abstraction, those with similar themes were categorized and the main themes were derived.

For ensuring higher reliability and validity of this study, the identified themes were described and the contents were cross-checked with the participants' experiences through a feedback process. Through cross-checking and discussions, we derived consistent results. Moreover, new insights, prejudices, etc. found in this study were recorded for comparison with the interview data and relevant literatures.

## 3. Findings

In order to understand the essence in the experiences of Korean hemodialysis patients who had survived for more than 20 years, this study performed an analysis by using the Colaizzi's (1978) method and derived four themes (Table 1).

### 1. Lifelong nasty disease beginning with 'Surely not'

For both, male and female participants, the reasons for starting hemodialysis were not clear, and the time of diagnosis of renal disease varied from the period of elementary school to adulthood. All the participants answered that they started dialysis by denying the reality and thinking that 'Surely, I will not have such disease like this.' They mostly started hemodialysis due to unexpected happenings, as

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