

# The Experiences of Family Caregiving in a Chronic Care Unit

Myung Ok Cho<sup>1</sup>

**Purpose.** The main purpose of this critical ethnography was to examine the process and discourses through which family caregivers experience while caring for their sick family member in a hospital.

**Methods.** This was achieved by conducting in-depth interviews with 12 family caregivers, and by observing their caring activities and daily lives in natural settings. The study field was a unit for neurologic patients. Data was analyzed using taxonomy, discourse analysis, and proxemics. All research work was iteratively processed from March 2003 to December 2004.

**Results.** Constant comparative analysis of the data yielded the process of becoming a successful family caregiver: encountering the differences and chaos as novice; constructing their world of skilled caregivers; and becoming a hospital family as experienced caregivers. During the process of becoming an experienced hospital family, the discourse of family centered idea guided their caring behaviors and daily lives.

**Conclusion.** The paternalistic family caregivers struggled, cooperated, and harmonized with the patriarchal world of professional health care system. During this process of becoming hospital family, professional nurses must act as cultural brokers between the lay family caring system and the professional caring system.

**Key Words :** Critical ethnography, Family, Experiences of caregiving

## INTRODUCTION

Caring is an essential component of nursing and human survival. Nurses have traditionally claimed their realm of work and responsibility as distinct from that of physicians with an emphasis on patients' comfort and environment. Some nurses have adopted "care" as nurses' particular domain, as distinct from the focus to "cure" that is seen to characterize medicine in the modern era (Poirier & Ayres, 2002). Besides, caring is also an essential component of the human phenomenon. As a human phenomenon, caring is crucial for the continual survival of our species as social and cultural, as well as biological beings (Leininger, 1991).

Since the mid 20th century, Leininger studied caring

and its nature, component, traits, structure, and meaning with many nurses in the world. From many field research, Leininger (1991) postulated that the use of generic and professional care knowledge is a powerful means of promoting healthy, well-being, and recovery from illness or disability, or of helping clients and families. For caring practices to be effective, they must be recognized as caring by patients, viewed through the specific lens of the patient's culture, his or her concerns, and whatever else meaning in the patient's world. In the studies on caring, however, a discrepancy emerged between what the lay caregiver perceived as important, essential, or possible, and what health professionals perceived as optimal (Atwood, 1978). Bowers (1987) found that nurses and other professionals lacked an adequate understanding of the family caregiver's experience, and

1. Professor, Department of Nursing at Donggeui University

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Corresponding author: Myung Ok Cho, Department of Nursing at Donggeui University, 995 Eomgwangno, Busanjinju, Busan 614-714, South Korea

Tel: 82-51-890-1556 Fax: 82-51-890-1554 E-mail: mocho@deu.ac.kr

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this precluded effective nursing interventions. In the study, the professionals' view of the parent role in hospital care was rarely congruent with the parents' model of their role, and this was a source of stress for the parents.

Nurse theorists who claim care to be the traditional and essential domain of nursing offer prescriptions for nursing that can help alleviate this discrepancy. Nurses have sought to involve patients and families in their own health care by teaching and responding to their concerns. Swanson(1991) investigated nurses' caring by asking patients, who received nursing care, about their perception of the care. In the study, skillful caring practice has proven to be a powerful influence on the client's recovery. However, skillful practice as care cannot, it seems, be taken for granted (Kanavagh & Knowlden, 2004). Caring is steeped in nursing ideology, professional constructs, and broader cultural and social discourse. The notion of caring is affective for it evokes images of kindness, compassion, and patience. These behaviors are embedded in practice ideology and normalized in professional nursing models. What is less clear is how the caring ideology intersects with practice realities and how it might be influenced by the imperatives of the managerial health service environment. This leads to speculation about how care may, thus embedded, serve to promote and maintain the health status of the client.

Again, Leininger's work can provides suggestions on how this end may be achieved. According to cultural care theory, there are two health care systems in every society: the generic (lay, folk) and the professional systems (Leininger, 1991). Generic system refers to culturally learned and transmitted, indigenous, folk knowledge and skills used to provide assistive, supportive, enabling, or facilitative acts toward or for another individual, group, or institution with evident or anticipated needs to improve a human way of life, health condition, or to deal with handicaps and death situations. Professional system refers to formal and cognitively learned professional knowledge and practice skills that are taught in professional institutions to a number of multidisciplinary personnel in order to serve consumers seeking health services. As I described so far, and suggested by Anderson (1990), there is a discrepancy between the generic folk and professional systems in the notion of health, illness, and treatment or caring. In this situation, nurses need to attempt to bridge over the cultural gap between professional system and generic system. For the culture care theorist, culturally congruent care is the best

way to obtain the goal. Culturally congruent nursing care can occur when culture care values, expressions, or patterns are known and used appropriately and meaningfully by the nurse. And this culturally based nursing care contributes to the well-being of individual, families, group and communities within their environmental context. As Leininger (1991) concluded, professional nursing must be built upon generic care.

Therefore, we need to study cultural specific care, the generic folk care, to gain an understanding about this system of care. Only after this, can we bridge between the two systems. This study was targeted to explore the family care that is an essential component of the generic care system. As a generic care system, family caregiving has existed throughout history, but it has only recently come to the attention of nursing scholars and health practitioners. As chronic health diseases increase, many patients have their health condition managed in a community by their family. In everyday life, the family takes care of their children and older parents for keeping, promoting, and recovering health. In the social network, family members internalize the interpretation of social reality by significant others. Thereby, they habituated and practiced the cultural value of caring. Thus, generic cultural caring behaviors can be easily observed in a family. In-patient setting, families are the major source for providing financial support for health care in hospitals. Furthermore, in many chronic care facilities in Korea, the family caregiver takes responsibility for the primary care for their ill family member. These family caregivers dwell in the ward and take care of their ill family member. They tend to perform some of the more complicated tasks that are ordinarily performed by skilled nurses. That is to say, professional nursing and generic family care systems co-exist in chronic care hospitals of our society. If these two systems are not in accordance, the quality of caring can not be obtained. The first step towards a goal of good nursing care is an understanding of the caregiving family as a consumer of nursing care and a care partner.

Another notion guiding this study is that caring is a cultural phenomenon. Caring is part of such diverse basic human activities as parenting, counseling, befriending, and healing. All of which activities occur within the socio-cultural context. In the In-patient setting, although nurses and family caregivers may attend to patients in crisis, there is also a concern for the everyday, personal circumstances in which patients experience illness. This

inherent interest in context and lives as they are lived makes theories of nursing relevant to this cultural analysis of family caregiving.

The meaning of caring is interpreted from the behaviors that arise from a particular culture's social expectations about its people and which are approved and rewarded as such. Socialized and enculturated as we are, we learn patterns of understanding and behaving in the world as we know it. Experience of living contributes to new meaning and understanding, amid new and always changing interpretations, caring remains both embedded in and reflective of culture (Kavanagh & Knowlden, 2004). As critical approaches postulate, culture is neither passive nor deterministic but requires active appropriation, perpetuation, and transformation through human participation (Barker & Galasniski, 2001). This involves meditation between, for example already-learned tradition and the situation of the moment. In this way, culture is operative in all acts of understanding and caring. Caring is a classic example of hermeneutic problems, for its meanings are often not apparent and requires interpretation (Kavanagh & Knowlden, 2004). For the interpretation of human behavior, we need to descend to the lowest level. Discourse analysis is a way to fulfill this purpose.

Most of the early studies on family caregiving were surveys of the social supports that family caregivers needed or desired (Bass & Noelker, 1987; McCaslin, 1988; Montgomery & Hatch, 1987), and stress or burden and the ability of family caregivers to cope with that stress (Park & Han, 2000; An, 2002). In these quantitative studies, characteristics such as depression, physical health, social isolation, and financial needs were measured (Cantor, 1983; Sexton & Murno, 1985). The results were helpful in identifying certain aspects of the caregiving experience. However, their focus on the stressors in caregiving fed the stereotype of caregiving as onerous work. We need to find other aspects of the caregiving experience, the positive ones.

A move away from such exclusively quantitative reporting came with some scholars such as Corbin and Strauss (1988). Much of the early qualitative research on family caregiving was grounded in contemporary assumption about the constituency and nature of family caregiving. Human experiences have their various constituents. Exploring the nature of caring is essential to understand clients and in providing client-centered nursing practice. But, it is not enough to find some con-

stituent of certain human behavior. We need to identify the underlying basis of these constituents.

The purpose of this study was to find an understanding of the family caregivers' experiences in a hospital, and focused on the process and discourse by which they become an expert family caregiver. Thus, the question that guided this research was; "what do family caregivers experience during the process of caring for their family member?"

## METHODS

### *Research design*

In this critical ethnography, I adopted an interpretive qualitative approach in which data collection and analysis are processed iteratively. This study was designed with one group of family caregivers.

### *Data collection*

The fieldwork for the study was conducted in a neurology unit of a hospital in B city. This for-profit institution's bed capacity was 400. On the unit used for research, there are two wards and 100 beds. Prior to conducting the study, research permission was obtained from the educational board of the nursing division of the hospital. Participants were self-selected in a purposive, convenience-sampling process after informed consents were obtained. All participants and informant were provided materials and the purpose of the study was explained, including ethical norms of research, and their right to discontinue participation whenever they want. Data were generated from 12 primary family caregivers: 8 were women and 4 were men; 3 daughters, 3 husbands, 5 wives, and the son of a patient. Participants' ill family had the following medical diagnosis: 8 stroke, 2 meningioma, 2 head injury. Ethnographic participants' observation was the major method of collecting and analyzing data. Interviews were the secondary data collection method used in the ethnography.

Participant observation and unstructured interview proceeded from March 5, 2003 to December 21, 2003. During 10 months of fieldwork, I engaged in the field one day a week from 7:00 to 15:00. The fieldwork proceeded with the question: "what and how does the family caregiver care for their ill family?" The focused interviews and mini tour participant observations were conducted between January 2004 and December 2004 after the domain analysis was completed. During this field-

work, I engaged in the field one or two days per week from 6:50 to 15:35 or in the evening. This fieldwork proceeded with the question: "what did they change in their caring behaviors?" "What made the difference in caring patterns among the participants?" The third fieldwork was conducted during the 3rd week of December 2004. The final fieldwork for confirming the rules for caring behavior was continued for 7 days from 7:00 to 17:00.

Interviews to collect data enabled participants to discuss in a safe, confidential space their experience of caring with their family patients. Each family caregiver participated in three or more individual semi-structured interviews that lasted 20–30 minutes. In the loosely structured interview, I asked all participants broad open-ended questions: "Tell me about your experience on how you became a primary caregiver for your family", "Tell me about your experiences in this hospital", and "Tell me the reason why you did such and such activity for your family". The interview was audiotape recorded with the permission of participants. Observation as a participant and participation as an observer approach were selected so as not to disturb the natural behavior and the privacy of research participants. Participant observations were conducted in the patients' room, in a nurse station, and in a lounge on the unit. The researcher participated with the family caregivers' hospital life event such as having a meal, discussing with health personnel, and even struggling against other family caregivers as well as caring for their ill family. Participant observations and interviews were conducted until the final process of family caregiving pattern was identified.

### *Data Analysis*

To make a text, interview data was transcribed verbatim and observation data was recorded in a field note. Because most of the interview and participant observation proceeded simultaneously, interview data were put in the field note. The text was read and reread in order that it could be engaged with as a whole. After this highlighting process of analysis, the data were examined line-by-line. At this preliminary stage of data analysis, two operational domains were selected: the discourse and the process. The second step taken in the study was scrutinizing the data for significant statements that reflected the process of becoming a family caregiver and discourses behind this process. The purpose of this step of analyzing was to find out how the everyday caring practice

is constructed by and within the context and culture of the in-patient environment. Data analyzing was guided by the questions; "What are the dominant discourses that shaped and constrained the family caregivers' daily life and caring behavior?" and "How do they exercise this discourse in the practice of caring?" The process of reading and rereading, noting the whole, the parts, and the parts in relation to the whole, was repeated for each participant's text. Once this process was completed, common themes were sought in all participants' texts. In developing early themes, exemplars from the text were extracted to demonstrate the similarity or contrast of patterns of meaning, common situations, or embodied experiences. They were then coded and situated to develop additional themes. As the result of the second step of analysis, the strategies and patterns and ideas of space were founded as typical cultural themes. These common aspects for all participants and typical exemplars were formed on the basis for discussing the predominant discourse and process that operate in family caregiving. Thus, in the results section, what and how the participant behaves in relation to the use of space and strategy are examined.

For validating contextual data, meaning of the participants' behavior, and analyzing themes, the nurses on the unit were invited to read the text. After description, analyzing theme, and interpreting, the text was returned to their owners for validation. Ethnic norms were preserved so that participants would not feel dishonored. Participants were made to understand that dialogue and observation are means of research and that the data will never be used for any other purposes. The researcher assumed no role of superiority during the participant observation and interview process. In order to safeguard their privacy, caregiver' names and other identifying information have been altered.

Research standards assisted in verifying findings of qualitative research. Three criteria of rigor used in the study are credibility, fittingness, and auditability. The descriptions of findings that are easily recognized by participants in this study, as well as other family caregivers, speak to the credibility of the research. Fittingness is concerned with adherence to research procedure; the findings of this study reflect the purpose of the study and the data generated. The purposes, processes, data and results of this study have been widely shared and the decision trail can be followed. The standard of auditability has been met.

## FINDINGS

### *Becoming a family caregiver*

The findings indicate that family caregivers have experienced in their daily life in the unit as well as caring behaviors which were shaped by discourses. Family centered idea was the factor guiding the caregiver's behaviors. They also recount decisions that were debated within themselves and with others, often repeatedly such, as health condition, economic situations, and family relationships. These inevitably shifted and changed over the month and years of care giving.

### *Encountering the difference and chaos: being alone*

Whether they became a family caregiver by choice or demand, participants entered the care system as a stranger. As every society has its own culture, hospitals have their own rules (patterns for behavior) and patterns of behavior. Hospital culture is a professional one. Participants have been "thrown" into a new-to-them world of machinery equipped with technology and specialized professions. These are cultural alien to the caregivers. Between these two caring cultures, the professional hospital and the lay family one, they must endure the differences and chaos.

There is no space for the scared novice family caregiver in a speedy, complex, rigid, and formidable professional world. In response, novice family caregivers are overwhelmed with this unfamiliar environment:

It was so terrible. I was absolutely overwhelmed. At first I was so afraid because I didn't know anything about my father's condition and what to do for him. He was unconscious. I didn't know whether he was sleeping or dying. A nurse entered the room and talked to me about something. But, I could not hear a word. She demonstrated the procedure of 'expelling the sputum' from my father's mouth and neck opening. I 'd never seen a person with a neck opening and nasal tube. How can I do that!

As reflected in the above statement, without any knowledge, skill, and experiences- the power basis of the caring world- participants were overwhelmed. These novice family caregivers were overwhelmed by the specified and complex professional health care system. There were various health care personnel on the unit. The

health care system specified their role and work. For the novice family caregiver, it was not easy to differentiate among these personnel. Therefore, they didn't know whom to ask for help. An anxious family caregiver wandered around the corridor and came to the nurse's station to ask for help:

Participant: Hello, nurse. Could you let me know where can I find some food? I have been starving since yesterday morning. My husband was admitted yesterday. He had an attack yesterday morning. We were working on a farm.

Nursing student: Well. Um, hum, I don't —.

Researcher: You can get some bread or snack in the supermarket. You can find the supermarket on the 1st floor.

Participant: 1st floor? What floor is this? I am a farmer. I couldn't eat bread or snack. I wish I could have rice and *doengangug* soup for my breakfast.

Researcher: You can have a meal in the hospital restaurant located on the first floor basement. They open 3 times a day. It is 10 now. The restaurant is closed. What room is your husband in? What is the room number?

Participant: 53-Ai. What - Well I — what is it-the last number. Ah I can't remember the last one.

Researcher: Ah Ha. Your husband is staying in the other ward of this floor. It is a ward of this unit. So, you can have a meal in the resting room located at the end of this corridor. But, you should prepare food by yourself in the kitchen.

Participant: It was so sudden. I'd never expected it. I couldn't prepare anything. Clothes, foods—. I am so hungry. Oh. The breakfast is over. Now, I have to wait for lunch.

There were nurses in the corridor. The family caregiver couldn't differentiate between the nurse and the student. On admission day, a nurse gave her an orientation including when and how she could use the dining hall, kitchen, and resting room for meals. On her husband's bedside table, there was a pamphlet entitled, "For your admission and successful hospital life"

Professional dominance, the authority held by the medical profession, might serves in both the therapeutic encounter and in the border public sphere to maintain a social distance between the professional and the patient. By the virtue of "custom centered health care" polices

of the hospital, most of the barriers between the health personnel and the family caregivers were left out. However, the power struggle between the formal caring professional and informal private caretaker made a novice family caregiver bewildered, embarrassed, or confused.

The private caretaker hired by a patient and charged for personal care to their patient such as personal hygiene, clothing, back care, and feeding. They are informal care personnel and included in a lay care system. Often these informal workers tend to act in an unprofessional manner, aggressive towards their patients and other professional staff, and are frustrated in nature. For example, some private caretakers refused to comply with the unit manager's orders such as to wear a gown; keep a report line; to not leave the patient; and practice correct caring methods. In front of the nurse, the private caretaker submitted to the nurses' order. In the absence of nurses, however, they pretended to themselves to be medical professionals and practiced nursing care and medical treatment. They persisted in their procedures even after the nurse announced it was harmful. They tried to destroy a line of order by reporting patient's symptoms and signs to the doctor and requesting a doctor's prescription. These private caretakers recommended to the family caregivers or patient's family a treatment modality such as acupuncture, physical therapy, or folk remedy. Occasionally, these insurgents advise to novice family caregivers "Don't request nurses because they are not productive. The nursing students might be harmful because they know nothing" and suggest that family caregivers follow their technique. Very often, private caretakers ordered nursing students: "You novice! Don't touch my patient. He should take a rest." As a result, family caregivers couldn't differentiate the role and activities of other family caregivers, private caretakers, and formal caring personnel.

Furthermore, these private caretakers used medical terminology such as "saction (incorrect term of suction)" to differentiate themselves from a lay caregiver, family caregiver, and to boost their confidence. The nurse's aids also used medical terminology to differentiate themselves from lay caregivers. On the other hand, nurses tried to use indigenous terms to help the patient's understanding as reflected in a morning care situation:

Patient: Hey! Give me a *jagupbook*(cloth for working). I need one today.

Nurse's aid: Jagupbok? Oh, no! It is *whaneeu*. Not a jagupbok.

Participant: Hi! Nurse! Please give me a zoobong (trousers)

Nurse: Yes. Here is a *zoobong*.

For the nurse's aid and private caretaker, their jargon is a symbol of professional power. The use of medical terms or jargon is a means for keeping a group boundary. As a result, family caregivers are bewildered in a 'word festival'.

These novice family caregivers found themselves powerless and attempted to adapt to this chaotic 'their' world by a passive assimilation strategy. As a participant, family caregivers yield under pressure of vested power:

It was harder for me to endure the complaints of a private caretaker. She complained about noise from suctioning disturbed her sleeping. For a few weeks, my father had a lot of sputum. I need to do suction day and night. Of course I was so sorry for the other patients and caregiver in the room. What should I do? There were many people in the room. But, I felt I was alone in the clouds. I couldn't say a word even though I thought their demand was unfair. I also didn't understand the nurse's admission orientation. But, I didn't ask the nurse to explain once more because I couldn't understand their jargon. I just said "yes", and followed their orders.

The novice family caregivers followed the procedures of the formal health personnel. They even tried to use the personnel's term as we can see in a dialogue:

Participant: please give me a - what should I say-. Ah- Ah. Hum Ah——.

Nurse: Can I help you? What do you want?

Participant: Ah. Ai. Dress? *Utjeogory*? What can I say?

Nurse: Ah ha! Upper wear! Did your wife wet her shirt-waist? Here is a *Whaneeu*(cloth for patient).

Participant: Oh yes. You are right! *Whaneeu*!

He was trying to be involved in the care personnel's group by using the personnel's terminology as the private caretakers did. In the participant's world, there is a formula: "you=right, me=wrong"

In this stage, participants tried to discard 'their world' and depended on every personnel to enter the new

world of the professional caregiver. These novice family caregivers followed the personnel's advice. They requested the nursing student's help for personal care and technical nursing care. They relied on personnel for all the care, including helping the patient to sit up. All the decisions on treatment methods for their patients were delegated to the doctor. Thus, all power for caring was given to the professional.

For getting help, they came closer to the doctors and all caring personnel. They also tried to keep a personal relationship with the professionals. For example, these scared novice family caregivers tried to put their heads together with the doctor or nurse when they talked. On the other hand, they were afraid of getting close to and touching their patient. A few days after admission, family caregivers sat down on a couch or stood far from their patients. Otherwise, they went around searching for help. In an extreme case, a participant failed to assimilate the care and returned to her home.

There were no spaces for a novice family caregivers in a caring world. Family caregivers were 'out-there'. Thus, these novices struggled to blend into this formidable world using a passive assimilation strategy.

### *Constructing the world of skilled caregiver: being-in*

As a result of passive assimilation, participants are accustomed to a new environment and gaining caring skills. This skilled family caregiver encountered caring and daily life "within-the-world". They secured their world and protected it from outer world of hospital step by step by: staying with their patients in the same space, searching for information about the patient's healing, searching for selective help, standing up for their patient, making their patient special, and securing their territory.

When family caregivers gained caring skill, their sights are turned to their family patient from the health personnel. Participants, once they have tried to stay in the personal space of the health personnel, came closer to their patient. They stayed at the bedside of their patient for 24 hours and their daily activities were designated to fit to the patient's treatment schedule. They lived in a space of family caregiving. A participant responded to a researcher's question on a delayed breakfast:

Did you take breakfast, professor? Yes. It is too late to have a breakfast. But, it is usual for us. Morning passed so fast. I am so busy even though I wake up early in the morning, at 5 o'clock. At that time, the

nurses start their work. Check blood pressure, body temperature, and respirations. Ah. They check sugar levels (blood sugar test) for my husband. After that, I start work; expelling sputum, bed bathing, skin care, position change, changing diaper, tube feeding or helping with a meal—. We have so much to do in the morning. [How about a bath at 10 or later?] Bath? At 10 o'clock? Oh no! We can only use hot water from 7 to 9 o'clock. There are several shower booths in an aqua treatment room. All the people in this unit use the room. So, I should do my work fast to complete bathing our patient. After that, I can clean and wash myself for a while. The doctors visit their patients between 9 and 9:30. During the Dr's rounds, we should not leave our patient. We can have a break after that, between 9:30 and 10. That is our time for taking breakfast. If I am going to give our patient a good physical therapy, I should go to the physical therapy room before 9 o'clock.

She continued in her response to the researcher's question, "Why don't you use the resting room for breakfast? It's more comfortable, isn't it?" by saying:

Oh, we certainly know that. There are many convenient facilities in the resting room. But, I feel more comfortable here, near my husband. If I stay there, I might be very afraid of him falling down, wetting the bed, or calling for me. I need to respond immediately to his request.

For the skilled caregivers, the resting room and kitchen in the unit is a barrier to keep near the patient. As such, the skilled family caregiver's daily lives within his or her space are circled as a clock. Participants never quit this 'caring clock' even when they know that the patient has no hope of survival.

I know. He couldn't live. The doctor told me— 'He has no hope'. I think either -. He couldn't get up again. I will continue to do my best nevertheless. There are no other ways. That's my life.

For the participant, family caregiving is a way of daily life, not an extraneous or enforced onerous work. Thus, skilled family caregivers never gave up caring for their patient.

Even though family caregivers are accustomed to tech-

niques for personal caring and a few professional nursing caring techniques, their knowledge and experiences are not enough to evaluate a patient's health condition and make decisions for treatment methods. These skilled family caregivers did their best for their patient's healing. To do their best, they went around actively searching for treatment information. They are open to all treatment methods: herbal medicine, folk medicine, alternative therapy, and even religious healing. Herbal medicine is the most favorable. Very often, family caregivers asked their doctor to refer the patient to an herbal doctor. These alternative therapies may result in an improvement in the health of the patient, but they may also be harmful. For the family caregivers, to adopt diverse alternative healing therapies is an expression that they are doing their best. Thus the negative effects are not considered seriously.

As a participant became a skilled caregiver, they differentiate each personnel's role and work. A professional was not a participant's hero anymore. Very often, they did not place trust in the health personnel's nursing care and treatment. These suspicious caregivers persisted in their methods even though they couldn't understand what was going on with their patient's condition and didn't know what and why a treatment or care was beneficial to their patient. They did not depend on health personnel and requested the professional's help selectively:

Participant: Hi head nurse, my doctor told me that my brother can start wheelchair ambulation now. Could you tell a nurse to help me?

Head nurse: Of course, we will do that. I will be there whenever you call me. How about student nurse?

Participant: Student? E hum-well-I think — it would be— When are you free today? I wish I could start it around 11: 30. I think it would be good for him to exercise before lunch.

For the skilled caregiver, nursing students, once a good caring resource, are not professionals anymore. Within her world, the caring personnel's role and status has changed from that of the beginning: a doctor became 'my' doctor; a head nurse became a care manager for the participant's brother and a co-worker of the family caregiver; staff nurses became direct caregivers and helpers for a newly introduced caring skill. She is not waiting for medical personnel anymore. Rather, health personnel should wait to adjust to her caring schedule. The power

relation in caring between family caregiver and health personnel changed. Family caregivers had the power.

Thus, their caring strategy has changed from passive assimilation to "differentiation". Their strategy is also reflected in a pattern of caring behaviors that differentiates themselves from other caregivers. They tried to make their family special through specific caring techniques. After family caregivers were accustomed to caring skills, they developed patient-specific techniques and imposed a special meaning to it. For example, health personnel and private caretaker used a feeding bag for a Levine tube feeding. But, family caregivers persisted in using a syringe instead of a feeding bag. They needed to hold up the feeding syringe for 15minutes or more to complete a tube feeding with a syringe. Family caregivers confessed the reason:

Others use a bag. They hang a bag filled with formula on a pole. During the feeding, they are not concerned whether the formula dripped or not. Sometimes they leave the patient or do other things such as talking gossip with other private caretaker, swing, or cleaning bedside tables. How they can notice a patient's condition and feeling? I know it is more convenient to use a formula bag than a syringe. But, I will never do it. I think— using a bag is-not sincere. I like to care for my husband with my whole heart. With my tube feeding using a syringe, I can do my best for him. The true heart heals a disease.

For the private caretakers and nurses, tube feeding is a labor. For the family caregiver, on the other hand, tube feeding is a means to express and complete their desire for the best care. Most of the family caregivers washed the patient's clothes that had already been washed in a laundry. To differentiate their caring from others, and thereby making their patient special, these skilled family caregivers requested health personnel to give new and clean linen and clothes. They knew that all patients can have a change of clothes at 10 o'clock. But, they came to the nurses' station early in the morning and requested their patient's clothes so as to get a new or clean one. A participant washed and pressed clothes with her foot for her husband. She explained the reason as follows:

I heard from someone. "All patient's clothes are washed in a laundry factory. The factory gathers patients' clothes and linens from many hospitals." On

several occasions, I found dirty and even blood on laundered clothes. I have kept our priest (patient, her husband) clean-cut. He was always neatly dressed. As I always ironed the priest's cloths in my house, I pressed his cloth with my foot to make it neat.

For the family caregiver, her sick family member is not a patient but the person they have loved and respected. Thus, even though a patient has a pathologic body, the person becomes a social being as a father of a family or a respected leader of a society.

Another pattern of caring behavior of the skilled family caregivers was securing a position to protect them from low quality care. Family caregivers tried to keep the position as a social being as well as a caring consumer. To keep their patient's position, they stood for up for their ill family member. Another means for keeping a position was expanding and keeping their space.

Family caregivers protected the patient's right to have benefits and not to get harmed. Selecting a competent helper and controlling health personnel and novice family caregivers' caring is a means to protect their rights as a caring consumer. Participants requested the nursing personnel to assist with position change, back massage, and moving a patient. But, they were not welcomed to help with tube feeding because of following reason:

I am not strong enough to move my brother. Nurses and students are strong. They can help me. It is a simple and trivial work. But, the tube feeding is a very important task. It is a task to put something in. Inside my brother's body! That's very important for his health. All the diseases came from a disorder of the inside. We can't see inside. Back massage or position change are the work for outside of the body. It can be easily seen and treated. That's not important. Every one can do that. How can I permit others to do such important work! Tube feeding is my job.

The participant imposed a value on the human body. Her folk etiology and caring behavior came from this value. For the participant, the disease of the body is serious and the important work for 'inside' is a work of the 'inside' person, the family.

Thus, the skilled family caregivers refused a vital sign check by the nursing students who became outsiders. They were told, "not to disturb my husband's (or wife's) rest." They prohibited other family caregivers and pri-

vate caretaker's behaviors by saying, "Don't make noise! My patient is sleeping. Don't open the window! My patient is susceptible to a cough. Don't enter my space and don't touch anything! I need it. I have to live here" In an extreme case, a family caregiver angered nurses and nursing students during a nurses' morning rounding, with shouting "Why do you look at my wife? She is not an animal in a zoo!" As thus, these powerful family caregivers push caring personnel out of their world and protect their sick family from a caring they perceived as useless and even harmful.

Family caregivers also keep their territory by securing physical space. As all human society, the family caregiver's society has a proxemics, the rules for use of space. At admission, most of the patients use a bed at the entrance of a room as a new employee is positioned at a desk near the entrance. In this place, patients and family caregivers feel discomfort and are unstable because they are open to all people. Skilled family caregivers have a right to move their patient's bed from near the door to near the window, the 'inside' of the room. In this place, they occupy a wider space than novice caregivers have. They also try to keep a private space by drawing a curtain, covering side rails with a sheet, and blocking the foot side of the bed with a footboard. Very often, there are struggles among family caregivers over the space. A dominant family caregiver occupied another patient's space, and the patient couldn't use the centrally supplied suctioning equipment. This occupier projected this practice to health personnel and blamed them:

What is a nurse for? They never care for the patient. What on earth! Do they even have a thought? A foolish worker might set have one. How clumsy is this! If a person has a brain, they never installed it here. Nurses have responsibility to manage a worker.

All the central supply equipment was set up on the wall over the patients' bed in a regular setting. In the world of these skilled family caregivers, there is a formula 'me = right, you = wrong'.

In their private space, they keep daily necessities such as a washbowl, food, clothes, mirrors, cosmetics, and even a cooking pan and electronic rice-cooker. Within their space, they have their everyday life as a caregiver. Their lives are devoted to the sick family members healing. Skilled family caregivers built their world and confined themselves and their patient in this kingdom.

### *Becoming a hospital family: Being with*

If skilled family caregivers open the door of their world, they encounter 'our world' and 'being with' the hospital family. In this stage of the process of family caregiving, the experienced family caregivers internalized all their experience and the rules of the hospital. Their caring skill, personal knowledge of caring for their family, and the rules for their behaviors are harmonized with professionals and others family caregivers. For the experienced family caregiver, major power resource of caring is not a skill but a wisdom from caring experience and intuitive knowledge.

They do not differentiate themselves from other family caregivers and health personnel any more. Rather, they encompass an all hospital family. There is openness, connection, authentic relations, and amity in the experience of 'being with'. The authentic family caregivers have their sight extended to neighbors. They looked at their situation in the context of the whole environment. For them, health personnel and other family caregivers are not objects to struggle and overcome, but colleagues to share caring, everyday life, and even suffering. At this stage, all members, the family caregivers, their patient, and the health personnel, are in the same boat. Thus the open-minded family caregivers became a hospital family.

These authentic caregivers do not care for their sick family exclusively anymore. They care with the hospital family: his or her family patient, neighboring family caregivers and their patients, and co-working health personnel. A participant talked to his wife who stained her diaper with feces:

Oh, my love! Why didn't you tell me, "Honey, soiled myself" You can say that. I am here with you. It's my life to care for you. If I didn't do it (changing diaper and washing), all the *sikgu*(family) in our room might suffered from a foul smell. It will embarrass you.

His wife couldn't say a word and not even hear his voice because she had been in a permanent vegetate state for 3years. Not a person in the room complained to him. However, his openness to his wife and other people in the room had its eyes toward people's mind. The family caregiver, who once had been stubborn and closed his world to others, became a highly considerate neighbor of the hospital families. This generosity came from the confidence in themselves, as well as in the health personnel.

Their caring skill became more sophisticated through much experience in practical caring. Very often, they find and evaluate the fine changes in the patient's health condition more exactly than the health personnel do.

As they are experienced and sophisticated in caring skills, their roles become extended. They became a coordinator in the hospital family as well as co-workers of the health personnel. There are cultural differences between the caring of for-profit health personnel and the paternalistic family caregiver. The cultural brokers (the experienced family caregivers) connect with the hospital families. As their role changed, their caring strategy also changed from "differentiation" to "internalization". Thereby, they became 'being with' the hospital family. Now, they stand for other family caregivers and health personnel as well as his or her patient. One day, after a doctor's rounds, a participant and a ward manager discussed the following:

Participant: Did our doctor finish his rounds? Ah— ha. I was on the stairs. Just for a second. Ah. I should wait for him in my room.

Nurse: Yes. He returned to his office. He has waited for you for 15 minutes. Do you have anything to talk to him about? May I call him?

Participant: Oh. No! I had something to talk to our doctor about. But-it's Ok. My wife is badgering me -

Nurse: Ah ha! This morning, grandma (participant's wife) looked weak and fatigued, not good. She looked like she needs something—

Participant: Yes, she does. Hum - she lost her vigor. Certainly, there is something wrong in her condition. Something wrong is going on. That's an ill omen. I know it. She wants to have herbal treatment. She coaxed me to talk about it to our doctor. But, I think it is not good for her condition. I had several experiences of admissions. For spine fracture, stomach surgery, appendicitis etc. According to my experience, western medicine is better for her condition. Herbal medicine is not good for such an acute stage of stroke. I know. Is that right? What's your opinion?

Nurse: I agree with you. But, grandma wants to have herbal treatment. I think it is not a bad idea to talk to your doctor. Just talk to him-your wife wants to have herbal treatment.

Participant: You are right. Yes, I will. But, it might upset our doctor. He is our doctor. Who want to transfer his patient to another doctor? I don't want to make him

disheartened—— he might misunderstand — as if we have no confidence in him. Well. It's better to appease her. I will try to make my wife understand the situation.

This experienced family caregiver is standing up for the patient and the doctor. He is a coordinator between his patient and the health personnel. For the hospital family, the health personnel's needs and position are as important as that of his wife. In the world of an experienced family caregiver, there is a formula: "me= right, you= right"

This familiar connection and authentic relation is more frequently expressed among lay caregivers. Patients' family caregivers in a room call each other by kinship terms such as *hyungnim* (elder sister-in-law) or *au* (younger sister-in-law). They shared the suffering and pleasures of their life as well as supplies for daily living. On a patient's recovery such as starting to walk, removing the L-tube, or awakening, they offer a congratulation party with some cake. If a patient's health condition worsened, all the patients' family caregivers involve themselves in caring for the patient. During the absence of a family caregiver, patients' caregivers are ready to share personal caring. One morning, a participant was asking a nurse:

I'm gonna drop by my house and come back this afternoon, around 2 or 3 o'clock. I have to clean up the house and prepare some foods. My daughter and her husband will visit tomorrow. An *au* will feed formula at 10:30. Could you drop by my husband? Would you send some nursing students when he needs help at 12 o'clock for position changing, and at 2 o'clock for formula feeding? The husband of the *au* has to go to the physical therapy room at 2 pm. So, she couldn't feed my husband.

For the participant, the patients' family caregivers and health personnel are all her caring resources. She is willing to involve nursing students in caring personnel. She is coordinating these resources for the caring of her husband. As thus, she held in all people in the hospital to her world. The skilled caregiver who was dedicated only to her or his patient becomes a generous caregiver dedicated to all hospital families.

Since they have become a hospital family, there are no reasons to struggle to build up a formidable boundary.

The experienced family caregivers do not press other patient's family caregivers to give up space. Rather, they protect novice family caregivers from the skilled caregiver. In a struggle among family caregivers, an experienced family caregiver intervenes in the favor of the novice caregiver:

Au, you are skilled in suction and he (patient) is not wet frequently. The young lady should change her father's position and diaper all through the night. A nurse visits frequently and conducts suction for him. How difficult for them in this narrow space! They don't take a nap all through the night.

The experienced family caregivers do not persist in the right to use new and clean clothes and linen anymore. They are pleased to give away their rights to have treatment within a convenient schedule or provided with caring supplies. For the experienced generous family caregivers a caring environment, the hospital space, the material for caring and treatment, and the health personnel are not for special patients only, but for the hospital family.

Even though generous family caregivers didn't enforce and intrude on others to keep their position and space, all persons, including health personnel, respect his or her position and space. The genuineness and openness, not the physical force or technical skill, is the power of the experienced coordinator. With this power, the experienced family caregivers stand on the top of the hierarchy.

Thus, family centered idea confined within a family (patient and his or her family caregiver) expanded its realm to a hospital family.

## DISCUSSION

Family caregivers encountered diverse experiences from when they were newly encountered with professional health care system as a novice to become an experienced caregiver (Figure 1).

There is no space for the novice family caregivers in the world of professional caring system of a hospital. Thus, in the first stage of family caregiving there are two separated families: patient's family and hospital family. The boundary of these two families is differentiated. For the novice family caregiver, the professional caring world is too far and formidable to approach. After family caregivers ap-

proached to and entered into the professional realm, they construct a caring world of their own. In this stage of caring, they try to keep their world by keeping their boundary. Within their caring world, they protect their family from outsiders, the health personnel, and other family caregivers. Finally, family caregivers open their world to outsiders. At this stage, two caring world are combined and harmonized as a hospital family.

To provide good care to their family and to adopt themselves to a patriarchal medical market, family caregivers adopt some strategies: passive assimilation by the novice family caregivers, differentiation by the skilled family caregivers, and internalization by the experienced family caregivers. As the family caregivers go on caring for a devastated family and experience daily life in a hospital, their perspectives also change: 'You are right, I am wrong', 'You are wrong, I am right', and 'You are right, I am right'. In the process of becoming a hospital family, the power relation also changed: health personnel dominants, struggling for equalization between family caregiver and health personnel, and family caregiver dominants.

Most of the early studies on family caregiving were survey focused on the stressors in caregiving fed the stereotype of caregiving as onerous work. In most of early qualitative research, family caregiving described as overwhelming, onerous work done by beleaguered saintly women. According to Poirer and Ayres (2002), part of this image stems from the 19th century, with the unmar-

ried daughter, aunt, tireless wife or mother bringing succor and peace to all within her walls. Taking care of one's family with dedication, competence, and equanimity was seen as natural to women. From the start, this (upper, middle-class, white) image of the intelligent, inspirational, yet totally self-effaced "angel in the house" offered a set of psychological contradictions and double binds that have been the source of much critical revision over the past two decades (Abel, 2000). In Korean society, the image that family caring is the due of a sacrificed powerless woman and thereby might be an onerous work seems to stems from the men-centered patriarchal idea.

In this study, as we can find in some recent studies, this image is changing. Today both circumstance and choice find increasing numbers of men are becoming family caregivers-and adapting with relative ease and willingness (Kaye & Applegate, 1990; Neufeld & Harrison, 1998; Parsons, 1997). In this study, caring for their family might be an overwhelming onerous task for the novice family caregivers and the young daughters forced into family caregiving. However, the skilled family caregivers were strong enough to keep their territory and thereby protected their sick family from health personnel. The experienced family caregivers were respected as a coordinator and a top manager of the lay care system. Their power came from genuineness and openness. The position of an experienced family caregiver is that of the head of a family, the father. The characteristics and images, however, are that of an integrated human being.

Process	Cultural components of family caregiving							Discourse: Family centered idea
	Stage	Caring world	Relation & direction	Basic idea of relation	Major caring resources	Strategies	Major means	
Becoming a family caregiver	Novice	Two separated family	Health personnel dominance: toward profession	You are right	Health personnel	Passive assimilation	Dependence	
	Skilled	My family in hospital family	Struggling against to health personnel: toward my family	I am right	Family caregiver's skill	Differentiation	Protection	
	Experienced	Combined, harmonized Hospital family	Family caregiver dominance: toward both world	We are right	Family caregivers experience and intuitive knowledge	Internalization	Sharing	

Figure 1. Cultural map of family caregiving.

For some family caregivers, caregiving is an onerous work overriding their usual duties and sacrificing their needs. For others, it is the process of human becoming.

As Bishop and Scudder (1991) defined caring as a way of being, the experienced family caregivers arrived at the end station through authentic caring. Caring for others is necessary when they are unable to care for themselves. The necessity for such care gives the caregiver much power over the person receiving care. Care can be given in ways that take self-direction from the one giving care. When we care for others two ways might be taken. In the first way, a person will "leap in" for another and "take over for the other." This form of care can readily foster dependency when the caregiver "leaps in and takes away 'care'". In contrast to dependent care, authentic care occurs when the caregiver will "leap ahead" in his existential potentiality-for-being, not in order to take away his 'care' but rather to give it back to him authentically". Thus, in authentic care the other is helped to care for themselves.

Family caregiving has often been viewed as supererogatory; that is, as dangerous or burdensome work that is above and beyond the expected responsibilities of family membership. This perception was perpetuated by a number of published research reports that described only negative aspects of caregiving. The notion of burden thus became synonymous with caregiving in much of the scholarly and popular literature (Callahan, 1988; Montgomery, 1989). As recent studies have found, however, caregiving is fulfilling to many people, who would not give up its rewards to escape its difficulties (Farran, Keeane-Haggerty, Salloway, Kupfere, & Wilken, 1991; Given, King, Collins, & Given, 1988; Klein, 1989). Most of the participants, except a few sacrificed victims, were willing to become family caregivers. For them, caring for their husbands or wife was a reply to a bestowed favor and a means to fulfill their duty as humans. It is also a means to keep a family structure. The notion that family caregiving is dangerous also loses its voice. Atwood (1978) clearly delineated the ways in which families are effectively organized to meet certain needs of impaired persons in the home, and how they selectively do not meet other specific needs. The participants of this study also organized the family by selecting a primary family caregiver through a deliberative decisional process, and adopted various strategies to give qualified care.

The challenges for family caregivers and the health

professionals who serve them is to accept that this work can be fulfilling and rewarding even when -and perhaps because-it is burdensome while also realizing that the possibility of such fulfillment should not be demanded of or expected of all family caregivers. In other words, the burden of caregiving should be freely chosen by family members, women and men alike, with the acknowledgement that other family members, friends, and health care professionals may be needed to help sustain this decision. Furthermore, family, friends, and health care professionals need to be alert for signals that caregiving must be shared or surrendered, and to help caregivers find the resources necessary to do so.

According to Foucault (1991), a critical cultural theorist, culture can be reproduced or transformed within social relationships. Cultural practices tend to be reproduced when hegemonic forces are in place and when people comply with the prevailing order largely because it has been taken for granted and accepted. The dominant cultural group's agenda goes ahead unchallenged and even unnoticed. Yet culture can also be transformed when peoples' consciousness are raised, and they begin to notice hegemony, to realize how dominant groups have a tendency to silence differences of opinion, and to marginalize groups that do not conform to mainstream ideas. In this view, power is a resource that is accessible to all people within society, not just those in authority, and it can be used to challenge and perhaps transform everyday cultural practice.

These phenomena were exposed in the health care culture within the chronic care unit context in which this study is located. At the beginning of family caregiving, formal healthcare personnel had a dominant power. The novice caregivers complied with the orders of the powerful health personnel, and tried to be involved in the new society through a passive assimilation. The dependent novice became an insurgent when they had a power armed with caring skills and knowledge of the health profession. They began to differentiate the role and activities of each health personnel and to notice the hierarchy. With that power, they tried to gain hegemony and to marginalize the weak, the novice family caregiver and even health personnel. At last, experienced family caregivers construct a new dominant cultural group, the hospital family. As we can see in this process of family caregiving, family-centered ideas was the main force to drive the participants behaviors. They tried to enter, to construct and keep, and to live in a family.

During this process of family caregiving, successful participants became experienced caregivers, who opened their world and maintained authentic relationships, extending their realm to the hospital family, and securing a top hierarchical position in the society. However, not all the family caregivers came to this station and became winners. Maladapted participants, as a novice family caregiver who failed to adopt into the hospital environment, closed their boundaries and stop going through a stage or returned to their world. A formidable skilled participant also stopped along the way and closed his or her boundary. Again, health professionals need to be involved and to intervene in the process, and thereby protect family caregivers and patients from an undue sacrificed by a dominant group. Support and help to find the necessary resources through education and counseling are needed.

The findings in this critical ethnography of family care giving highlights the importance of strong support for the cultural value of the family centered idea in the area of professional nursing and family care giving. During the process of becoming an expert family caregiver, nurses and family caregivers worked together as a family within the hospital. They even struggled with each other to be become accepted amongst their colleagues- the stage of 'being-in'- and found themselves interdependent during most of the process. Nurses need to try to understand the process and final results of the process of family care giving: the process of becoming part of a hospital family. Nurses also need to try to understand the reason and discourse that shape the behaviors of family care giving. Then, nurses can be more successful in caring for their patients and the patient's family members.

Family caregivers need nurses' help during the process of care giving. For the novice family caregiver, nurses are one of strongest of support. During the stage of 'being-in', family caregivers need to accept the nurses' help and use it as a care resource. In the stage of 'being with', the expert family caregiver open to and shared with health personnel and other family caregiver. However, they suffered from burden of many roles in a hospital family. They need to request nurses' help. Family caregivers are also nurses' clients as the patients.

## CONCLUSION

As Kavanagh and Knowlden (2004) declared in their narrative analysis of the caring experience, caring is at

the heart of nursing. Today, nurses and family caregivers engage in the work of caring in the clinical setting and the community. Considering that the primary caregiver takes on much of the patient's care in a hospital, nurses in Korea should understand the family caregiver's caring experience and daily life in a hospital setting. We can observe how the lay caring and professional nursing care interact in this situation. This study aimed to explore the experiences of family caregivers in a hospital setting.

Patients and their families are devastated by chronic illness, hospitalization, and the loss of their job. At the entrance of the professional caring territory, they were novices who didn't know what to do. Family caregivers should adapt themselves to this stressful and chaotic environment and care for their family patient in a crisis. As they developed caring skills, family caregivers construct a boundary and confined themselves in the caring world to protect their patient. As they became experienced caregivers, they opened the boundaries and maintained authentic relations with their patients, health personnel, and other family caregivers. For the experienced family caregivers, caring is a way of 'human becoming'. During the process of caring, they tried to assimilate, differentiate, internalize and coordinate the discourses of domain culture. As thus, paternalistic family caregiving and utilitarian professional caring are harmonized in the world of the hospital family.

To remain strong and viable, the nursing profession must not only utilize scientific knowledge but must also learn the lay care knowledge in order to truly understand the patient's meaning of caring behavior. Only in this way, the culturally congruent nursing care that based on scientific knowledge can be practiced. The results of this research can serve as a cultural knowledge of family caring.

During the process of family caregiving, the relation between family caregiver and health personnel, basic ideas of these relation, caring resources, strategies to adaptation, major means of caring are changed. Nurses who work with family caregivers should adopt and provide different caring strategy according to the stage of becoming family caregiver.

Not all participants in the study go through the same step of family caregiving. Some are return to former stage others are lagged in a stage. Probably, they might continue the way to the goal if more opportunity and help were given. Nurses can intervene for these staggered family caregivers.

To produce more detail and useful knowledge for clinical nursing, studies focus on why some family caregivers lagged in a stage or return to former stage are needed. Every caregiver, every ailing family member, and every family is unique. Their personalities, ages, values, income, housing, and countless other dimensions influence their family relationships and their ability or desire to take care of ailing or injured parents, spouses, or children. It is important for all people involved in family caregiving to understand, appreciate, and respond to these complex dynamics.

There is no one right way to understand family caregivers and their experience. Professional nurses who work with families need to develop a theoretical flexibility to accommodate the diverse personalities and situations that they will encounter. Family caregivers need to find ideas and support in the experiences of others in ways that will enable them to think creatively about themselves and their own circumstances. The understanding of generated discourse analysis is bound by context. As any other interpretative qualitative research method, post-structural approaches to inquiry are grounded in the notion that truth, rather than an objective reality, is local, multiple, and intersubjective. This study aimed to explore aspects of context-specific family care practice in what is certainly a partial way. We need more diverse approaches based on different perspectives, such as feminism or phenomenology.

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