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Original Article

The lived experience of family caregivers caring for patients dependent on life-sustaining technologies

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ABSTRACT

Purpose: The purpose of this study was to describe the meaning of the lived experience of family caregivers caring for their loved ones who were dependent upon life-sustaining technologies while in the hospital.
Methods: This study followed van Manen's hermeneutic phenomenological approach to generate and analyze data to describe the experience of ten family caregivers who met the following inclusion criteria: a family member who participated actively in caring for the loved one who was dependent upon technologies for human care. Data were collected using individual in-depth interviews. The interview transcriptions were analyzed using van Manen's phenomenological approach, while Lincoln and Guba's criteria were used to establish trustworthiness of the study.
Findings: Four thematic categories structured the meaning of the experience: *Being an invisible person; supporting patients' wholeness; struggling to trust technologies for human care; and living in uncertainty.* These thematic categories were reflective of Van Manen's four lived worlds of body, relation, space, and time.
Conclusion: Understanding the experience of family caregivers challenges nurses to express their technological competencies in caring more fully in their human care. Locsin's theory of *Technological Competency as Caring in Nursing* was used to explain and describe the meaning of the experiences of family caregivers caring for patients who were dependent upon technologies for human care, and foster nursing practice as caring in nursing.

1. Introduction

Technologies have been increasingly used to save and sustain human lives. These technologies include such mechanical devices as ventilators, and other devices that increase the continuity of patients' living. Some of these technologies, especially in high-technology arenas, include various oxygen devices, defibrillator, temporary pacemaker, intra-aortic balloon pump, bedside portable hemodialysis, electrocardiography monitor, pulse oximeter, and infusion pumps. Locsin described in his theory of "*Technological Competency as Caring in Nursing*" that in nursing persons who are dependent on technologies for human care, nurses need to be competent in the use of care technologies and of the persons. In caring for persons, this theory gives significance to knowing the person - a continuous process in which the nurse and the nursed have understanding, while at the same time affirming, celebrating, and supporting each other. The person being nursed is a health care partner who is not seen as an object of care. Technologies of health and nursing are aspects of care that assist nurses to know the nursed more fully as a whole and caring person [1].

Family members are significant when it comes to getting involved in care when the patients are dependent on technologies. Recently, the conceptual model of family-centered care and participation in care has been found significant and has been

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implicated in the nursing practice [2,3]. The patient's family is encouraged to have a role in caring for their hospitalized kin. Family caregivers become one with the healthcare team [4]. As can be seen from reviewing relevant literature, some of the studies explored the experiences of family members in intensive care units where they have access to various life-sustaining technologies as is now the case in many countries [4–7]. These studies provided some understanding about the needs of family members, such as the need for information [5,7], the need to be with the patients [5] and the need to be supported by healthcare providers [5,7]. In addition, the family members wanted to feel as a whole person [5] and be dignified [7]. Family members would experience psychological symptoms including post-traumatic stress, anxiety, and depression [8].

In Thailand, family caregivers participate in caring for their loved ones who depend on technologies for human caring while in a hospital. From the literature review, only one study was found that explored experiences of family caregivers while participating in the care of patients who used mechanical ventilators in a hospital center [9]. The findings of this study revealed that the family caregivers needed to be supported about accessibility in participating in care. They needed clear information about the patients' signs, professional help in educating them to care, and they needed someone to assist them in care [9]. However, little is known about the lived experiences of family caregivers caring for their loved one who is dependent on technologies in a hospital. Understanding this phenomenon is necessary in assisting nurses to improve their competency by acknowledging family caregivers as partners of their care. This can be beneficial in providing a good quality of nursing and human caring in the technological environment of the hospital.

Accordingly, this study purposed to describe the meaning of the lived experience of family caregivers caring for their loved ones dependent on life-sustaining technologies in a hospital in Thailand.

2. Background

The Theory of Technological Competency as Caring in Nursing [1] is a middle range theory grounded in *Nursing as Caring* [10]. There are five theoretical assumptions:

- Persons are caring by virtue of their humanness [10]. All human beings are caring. Caring in nursing is the substantive focus of the discipline. It is not an act or emotion that one may direct towards another person.
- The ideal of a person's wholeness is a perspective of unity [1]. Human beings as persons are whole, complete beings, regardless of composite parts. The nurse will focus on nursing as shared lived experiences between the nurse and the person being nursed, rather than focusing on fixing the person's deficiencies or missing 'parts.'
- Knowing persons is a multidimensional process [1]. The nurse and nursed focus on appreciating, celebrating, supporting and affirming each other, while continue mutually knowing each other.
- Technologies of health and nursing are aspects of care [1]. Nurses know human beings more fully as persons who participate in their care, rather than simply recipients and object of their care.
- Nursing is a discipline and a professional practice [10]. Nurses use knowledge of nursing in their caring for persons.

The theory of Technological Competency as Caring in Nursing is used in explanations of the findings of the study.

3. Methods

3.1. Design and setting

A qualitative research design informed by hermeneutic phenomenology was used for the study. In the hermeneutic phenomenological approach, the meanings of the lived experience are discovered through the interpretive findings of the text of life [11]. This study was conducted in a hospital in Hat Yai city, southern Thailand. The hospital provided the opportunity to the patients' family members to participate in caring for the patients in ward units during the visiting time and would allow the family members extra time to be with the patients. The care activities provided by the family caregivers included cleaning the patient's body, giving massages, providing psychological and spiritual support, feeding, etc.

3.2. Ethical considerations

The Institutional Review Board and Ethics Committee of Faculty of Medicine, Prince of Songkla University approved this study. After receiving permission from the hospital to collect data, a purposive sampling method was used to recruit and interview participants. Details of the study were explained to each participant before signing an informed consent form. Participants were guaranteed confidentiality.

3.3. Participants

The participants were family caregivers. Inclusion criteria included: being an active family caregiver (one person/one family) who participated in caring for his/her loved one who was dependent upon technologies of human care while being in a hospital in southern Thailand. An exclusion criterion was family caregivers in pediatric units.

3.4. Data collection

The family caregivers who met the criteria were invited to participate. Interviews were arranged mutually in a small meeting room in the hospital or the researcher's office.

Individual interviews were conducted using the following interview guide questions.

- Please tell me your experience of participating in caring for your family member who was depending on life-sustaining technologies in the hospital?
- Please tell me what you felt/thought when you were participating in caring for your family member who was depending on life-sustaining technologies in the hospital?

Each interview duration was from 45 to 90 min with audiotape recorded. A code number was assigned to each participant for identification and confidentiality of data. To analyze the data, audiotapes were transcribed verbatim. The number of participants depended in the repeated data in the interview transcriptions.

3.5. Data analysis

Van Manen's hermeneutic phenomenological approach was used to analyze and interpret the interview data. Words, phrases and statements describing the experiences of family caregivers caring for their families' members who were depending on life-sustaining technologies in a hospital were highlighted and identified from the interview transcriptions. These statements were

isolated thus forming themes reflecting descriptions of the family caregivers' experiences. All themes that had the similar meaning were grouped together as a thematic category [11].

All thematic categories were reflected within Van Manen's four lived worlds of corporeality or lived body; relationality or lived relation; spatiality or lived space; and temporality or lived time [11]. Corporeality is the feeling to body relative to the phenomenon. Relationality is the connection between the patients, family, and healthcare providers. Temporality is the feeling of time in the experience of the phenomenon. Spatiality describes as environment or distance space while the family caregivers were caring for their loved ones who were depending on life-sustaining technologies in a hospital. The analyzed data were translated from Thai language to English language by the researcher. The translated language was validated by a bi-lingual nursing professor who was expert in both languages.

3.6. Trustworthiness of the study

Lincoln and Guba's criteria of credibility, transferability, dependability, and confirmability were used to establish the trustworthiness of this study [12]. Credibility was required by recruiting and interviewing participants who had the experience of caring for their loved ones who were depending on life-sustaining technologies in the hospital. Transferability was reached by providing rich in-depth descriptions of the lived experience. Dependability was verified by another researcher following the process of the study and findings without contradiction. Confirmability was accomplished through journaling.

4. Findings

Ten family caregivers were the participants in this study. Nine participants were Buddhists, one was Christian. The mean age was 44.4 years old, with a range from 31 to 58 years old. Seven participants were women and three were men. Five participants had a baccalaureate degree, while two participants had diploma degrees, one had graduated from high school, and two participants had graduated from primary school. Regarding the relationship between the participants and the patients, it was found that two participants were sons and three participants were daughters. Two participants were wives, one was a husband, one was a mother, and one was a niece. The time duration that the participants were engaged in caring for their loved ones who were dependent upon technologies for human care was from 1 week to 1 month.

There were four thematic categories that structured the meaning of the participants' experiences. These are:

- being an invisible person;
- supporting patients' wholeness;
- struggling to trust technologies for human care;
- living in uncertainty.

These thematic categories were reflective of Van Manen's four lived worlds of lived body, lived relation, lived space, and lived time.

4.1. Being an invisible person

Being an invisible person while caring for their loved one, this thematic category describes the participants' feeling of themselves that they were not shown interest in a significant way by the nurses and physicians. They were at the patients' bedside and the nurses or physicians hardly greeting them, talked to them, or had any interaction with them.

The family caregivers experienced difficulty in sharing their knowing about the patients to the healthcare team because the opportunity to discuss this was not offered. The nurses focused on their own work and gave priority to technologies. The nurses rarely took care of the psychological aspect of the family caregivers.

> *"The nurses talked less, did their own work, and gave a lot of significance to technologies, especially in the ICU. It is like we are staying in their house and the hosts don't talk to us. We are not sure that they are welcoming us or not. The nurses should greet us and give some information. They should begin talking to us first, like open up an opportunity, ask us. We're stressed. It is like the nurses are not interested in us or to talk to us. It is like we are air, not to be seen."*(P6)

4.2. Supporting patients' wholeness

Supporting patients' wholeness, this thematic category describes that the participants were being with the patients depending on life-sustaining technologies in a hospital and helping them as they are a whole person. The participants provided comfort care to their loved ones following their needs and wishes, and protected them to be safe in the technological environment. The care activities included massaging, limb movement, cleaning the body, and praying.

The participants revealed that they were able to communicate caring genuinely to their loved ones. "*Relatives (family caregivers) can communicate through their sincere heart to the heart of our family members (the sick).*" (P9) The participants could relieve their loved ones' psychological suffering. They honor their loved ones as they were normal human beings while they were depending on life-sustaining technologies. A son who was a family caregiver explained that:

> *"In the beginning, I thought that my mom wasn't in much pain. When the tube was removed from her throat, I saw it was quite long. It was for her good but my mom wasn't familiar with it. Her breathing showed she was frightened by the mechanical ventilator and she had hyperventilation. I encouraged her not to fear and be calm. I touched her chest and guided her to slow down her breathing. I told her to think of Buddha Dharma. I touched her chest until she fell asleep. When she woke up she attempted to pull out the tube and lines, I hugged her and was with her at the bedside."* (P10)

4.3. Struggling to trust technologies for human care

Struggling to trust technologies for human care, this thematic category describes that the participants felt fear and unsure about the safety of the technologies intended to save their loved ones' lives while understanding the benefits of these technologies.

The participants feared the alarms and complexity of the technologies used would harm their loved ones' lives. They understood that the alarm noises were the signals of problems related to the proper functioning of the machine. They were not educated to deal with these alarms.

> *"I was afraid. The physician told me that there were many lines and technologies, and not to fear. I feared his heart would be stopped. I always looked at the graph to make sure that he was still alive. I felt good that there was a nurse. When I heard the alarm noises, I felt scared every time. I thought that it wasn't a good sign. The ventilator was giving an alarm; I don't know what was happening. I called the nurse. But I knew that he had many technologies to*

measure his conditions. I realized that it would be better to have them, instead of having nothing to monitor his life." (P3)

4.4. Living in uncertainty

Living in uncertainty, this thematic category describes that the participants were living uncertainty of time. They had doubt and did not know what would happen each day while being with and participating in the care of their loved one who was depending on life-sustaining technologies in the hospital. The participants lived in the shadow of their loved ones' conditions that might be changing moment to moment or day by day. The conditions could improve or get worse.

The participants experienced difficulty about what exactly to expect regarding their loved ones' signs and symptoms because their vital signs were unstable. The participants feared to know about the death of their loved ones.

"We didn't think that mom would get better. First 2–3 days, I saw a patient die and be transferred from the ward. I was frightened. I was relieved that the dead person wasn't my family member. I was waiting for her condition to improve for a week. I thought that technologies could save her life and the doctor would take care of her closely. I was worried about her and wanted to know and see her all the time. When the doctor was calling my name, I was scared because I thought about bad news or not good things happening to her. "(P9)

When their loved ones were weaning off the mechanical ventilator or other life-sustaining technologies, the patients' vital signs would be changing. The participants were suspicious of the changes. In addition, the patients would have some complications from their diseases and from using life-sustaining technologies such as infections, pneumothorax, or bleeding. The participants felt they could not arrange and plan their lives since they lived in uncertain situations because of their loved ones who were depending on life-sustaining technologies. A participant who was a son whose mother was post-arrested and depending on a mechanical ventilator and was hooked up with many lines inserted in her body described his experience as follows:

"My mom had many complications. She also had urinary tract infection. When the catheter was removed, we had to wait to see if she could urinate by herself or not. And then wait again to see if other things would happen with her or not. Today she was better but about tomorrow we couldn't expect anything. She could have sepsis. They checked her blood every day. Today she could be better but tomorrow might be worse, who knew. I couldn't manage my life. I could only stand by and observe her changing." (P10)

5. Discussion

The findings revealed that the participants in this study felt as if they were invisible persons while caring for their loved ones' depending on life-sustaining technologies in the hospital. This is because the nurses and physicians were busy with other tasks and technologies of care. Sharing experiences of caring between the nurses and the family caregivers were not valued. Even though family-centered care and the participation in care model was integrated in nursing practice in Thailand, the nurses might not understand their roles regarding this model. The family caregivers in this study did not feel they were also a center of nurses' caring and their partner in caring. The context of culture care in the hospital settings mainly focuses on patients-centered care and dependency on technologies. Fifty percent of family caregivers had an educational level of less than a bachelor's degree. This may have influenced the nurses' consideration that these family caregivers might not have the competency to care for the patients who are dependent on technologies for care. In addition, nurses and other healthcare providers may have believed that it was their responsibility as care providers to do everything for the patients, to prevent any risks if family members participated in the care of their loved ones. Therefore, the family caregivers were not invited to participate in the care of their loved ones or to share in any of the knowledge and experience with the nurses and other healthcare providers. This is different with the study of Michell and Chaboyer in Australia, who found that the family members shared partnership with nurses in caring for the patients, as they knew each other, and were being seen as helpful [4]. According to the theory of Technological Competency as Caring in Nursing [1], the family caregivers will be seen as caring persons and a partners of nurses caring. The shared experience between the nurse and the family caregiver is significant in order to know and support each other in caring.

The "invisible" phenomenon in this study is similar with the phenomenon of patients who were depending on life-sustaining technologies or in a technological environment. The relatives of patients being cared for were invisible persons or not shown interest by healthcare providers as the latter rather concentrated on the persons in their care focusing on technologies, patients' diseases, and documents [13,14]. However, the finding in the study of Agard and Harder in Denmark showed that the relatives put self aside. They wanted the nurses to have most focus on the patients although they appreciated when the nurses instructed them how to take care of the patients and supported them to participate in caring for the patients [15]. While a study by Frivolda, Dalea, and Slettebøa described that the families received the experience of welcoming from the nurses and healthcare providers and felt included and participating. This experience made the families feel appreciative and safe, and provided increased confidence in the healthcare system [16].

The relationship between the participants and their family members depending on life-sustaining technologies was important to support the patients' wholeness. In this study, the participants continued knowing their loved ones' depending on life-sustaining technologies and communicated caring holistically. Locsin viewed that knowing a person as whole in the moment was necessary to their well-being and preserve their wholeness [1]. This finding of supporting patients' wholeness is congruent with the study by Plakas, Cant, and Taket in Greece in which the relatives were with the patients and provided physical care, emotional care and spiritual care. They gave massage, and offered courage, cheerfulness, hope and love [7]. Michell and Chaboyer argued that allowing family members to be involved in caring for the sick relatives enabled them to be physically close and help holistic caring [4].

The participants were struggling to trust technologies for human care. They were scared of the technologies because they were not educated regarding the technologies used in care. This finding is congruent with the study by Locsin and Kongsuwan that explored the experiences of patients being cared for in intensive care units in Thailand. The findings of the study revealed that the patients who were depending on technologies for human caring feared the alarms of technological equipment and experienced insecurity. Not knowing about the problems of technologies saving their lives created lack of trust in technologies [17].

Living in the time of uncertainty was a relevant issue for the participants in this study. The main cause of uncertainty derived

from the unstable patients' signs and symptoms and not knowing what was happening to the patients. Uncertainty is consistent with the findings from other studies [15,18]. The families lived through times of uncertainty regarding the unexpected patients' situation and whether or not they would survive. The families' questions and requests for information about medical or technical aspects of the patients' treatment were not responded to. Not knowing made them feel no reassurance [15].

6. Conclusion and implications

This study provided understanding regarding the experiences of family caregivers while caring for their loved ones who were dependent on technologies in a hospital as *being an invisible person and living in uncertainty with struggling to trust technologies for human caring while supporting patients' wholeness.* The understanding of these experiences of family caregivers can challenge nurses to develop their technological competency in caring more fully as these caregivers are partners in the care of patients. Locsin's theory of "Technological Competency as Caring in Nursing" is used to foster the understanding of the experiences of family caregivers caring for patients dependent on technologies.

The findings of this study can be used to suggest some implications for nursing practice.

- Nurses should support the family caregivers and share experience of caring with them as they are caring persons and partners of nurses caring.
- Nurses can promote reciprocity between family caregivers and the patients to achieve caring for the whole person.
- Nurses should educate the family caregivers about the benefits and harm of life-sustaining technologies, the alarm signals and how the family caregivers can assist the nurses to care about these technologies used in saving their loved ones' lives in the hospital.
- Nurses should give information according to patients' conditions to the family caregivers continuously and include the family caregivers in advance care planning. This will assist the family caregivers to obtain assurance and manage their living.

Conflicts of interest

None declared.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ijnss.2018.09.011.

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