

Compassionate Care Among Iranian Nurses Caring for Candidate Brain Death Organ Donor Patients: A hermeneutic study

Atención compasiva entre las enfermeras iraníes que cuidan a los pacientes candidatos a la muerte cerebral por órganos: un estudio hermenéutico

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Abstract

A part of cares provided at the end of life of patients in intensive care units is allocated to the care of brain death patients, which is considered under title of one caring unit. Many nurses tend to provide high-quality and compassionate care. However, studies indicated that almost all patients do not receive compassionate cares. This research was carried out to explain the living experiences of nurses in intensive units providing care for brain death patients.

In this hermeneutic phenomenological study, van Manen's methodology was used. Ten nurses (9 women and 1 man) working in Intensive Care Units were interviewed using semi-structured interviews. The data derived from the interviews was analyzed after recording and transcribing.

The main theme of this study, which manifested the important and innovative aspect of caring the brain death patients, was "compassionate care". It included two sub-themes of commitment and devotion with sub subthemes of responsible caring and kindness in caring and sympathetic support with sub subthemes of providing emotional support to family and emotional influence.

According to the results of this research, it can be concluded that providing care for brain death patients, who were candidate for donation, despite imposing psychological burden on nurses, has provided a compassionate care for patient and family. This care is due to commitment, professional responsibility and deep emotional effects in them. The research results provide the conditions for educational planners to train nurses in order to improve their care provided for the patients and support the nurses.

Keywords: Nurse, Brain death, Organ donation, compassionate care

Resumen

Una parte de los cuidados proporcionados al final de la vida de los pacientes en unidades de cuidados intensivos se asigna a la atención de pacientes con muerte cerebral, que se considera bajo el título de una unidad de cuidados. Muchas enfermeras tienden a brindar atención de alta calidad y compasiva. Sin embargo, los estudios indicaron que casi todos los pacientes no reciben cuidados compasivos. Esta investigación se llevó a cabo para explicar las experiencias de vida de las enfermeras en unidades intensivas que brindan atención a pacientes con muerte cerebral.

En este estudio fenomenológico hermenéutico, se utilizó la metodología de van Manen. Diez enfermeras (9 mujeres y 1 hombre) que trabajaban en Unidades de Cuidados Intensivos fueron entrevistadas mediante entrevistas semiestructuradas. Los datos derivados de las entrevistas se analizaron después del registro y la transcripción.

El tema principal de este estudio, que manifestó el aspecto importante e innovador del cuidado de pacientes con muerte cerebral, fue el "cuidado compasivo". Incluía dos subtemas de compromiso y devoción con subtemas de cuidado responsable y amabilidad en el cuidado y apoyo comprensivo con sub subtemas de proporcionar apoyo emocional a la influencia familiar y emocional.

Según los resultados de esta investigación, se puede concluir que el cuidado de pacientes con muerte cerebral, que fueron candidatos a donación, a pesar de imponer una carga psicológica a las enfermeras, ha proporcionado una atención compasiva para el paciente y la familia. Esta atención se debe al compromiso, la responsabilidad profesional y los profundos efectos emocionales en ellos. Los resultados de la investigación proporcionan las condicio-

nes para que los planificadores educativos capaciten a las enfermeras a fin de mejorar la atención brindada a los pacientes y apoyar a las enfermeras.

Palabras clave: Enfermera, muerte cerebral, donación de órganos, cuidado compasivo

Coping with death is always one of the expected outcomes in intensive care units (Jones 2011 and Mobley 2007) and care at the end of life is considered as one of the important tasks of nurses (Pearson 2001). A part of cares provided at the end of life of patients in intensive care units is allocated to the care of brain death patients (Sprung 2003, Moraes 2015). It is considered in the care plan of these patients and families in an intensive care unit (Bloomer 2013).

The care needs of brain death patients are different from those of other patients since they have no therapeutic aspect. However, this care has special professional, ethical, and cognitive aspects (Cavalcante 2014). In fact, the appearance of a brain death patient, whose organs are survived for transplantation, is different from that of other death patients (Pearson 2001, Vincent 2011). The important task of nurses is protecting the patient and family in a death process through various interventions (2010 Abbasi Dolatabadi). The families of these patients are usually very sensitive and fragile and they require special care and support by the health team due to facing with death of their loved people (Afrasiabifar 2003, Bocci 2016). Studies suggest that the family of the patient, who is at the end of his or her life, like that sensitive and compassionate staff to care of their patients (Abedi 2012). Compassionate care is an important aspect of nursing and it is considered as a value in the practical code and standards of nursing (2017 Henderson, Akrami 2004, Zamanzadeh 2017).

Studies indicate that there has been a public concern on reduced compassion in health care systems in developed countries since early 2000 (Haw 2007 Maxwell, 2017). Formanenk and Schoffski (2010) state that 41% of hospitals with potential donors suffer from problems such as low quality of care and low sensitivity of staff (Formanenk & Schoffski (2010). A comprehensive review of studies suggests that the health team has inadequate empirical perception of compassion (Sinclair 2016). In fact, many nurses tend to provide high-quality and compassionate care, while studies revealed that almost all patients do not receive compassionate cares (Bradshaw 2011). Thus, while paying attention to concept of compassion is not so new concept, it is growing globally (Grimani 2017).

The results of studies have indicated that the ability to spend adequate time with the patient family, answering their questions and managing family requires the knowl-

edge, skills and experience of nurses (Masoumian Hoseini2015, Oroy 2013). Hence, the sympathetic behavior of the nurse with the family of these patients can provide great support for them (Cavalcante 2014). Unfortunately, in health professions, including nursing, some characteristics related to compassionate caring have been nowadays ignored (Bradshaw 2011, 2011 Cole-King). It seems that it is due to development of specialized skills and its effects on evidence-based performance and sometimes due to lack of time, personnel and work pressure. Various studies have been conducted on the care of brain death patients who are candidate for donor, which each of them has examined different aspects of this phenomenon. However, given the need to discover the new and unknown insights of this complex phenomenon in the current context and in order to gain deep understanding of it, this research was carried out to explain the experiences of nurses in intensive units providing care for brain death patients.

This qualitative research was carried out using hermeneutic phenomenology method (Van Manen) to discover the meaning of nurses' living experience of caring brain death patients. Six Van Manen methodology steps (2014) were considered to guide, reflect, and interpret the meaning of participants' living experiences as the main framework of research (Van Manen 2014). In the first step, given the empirical background of the researcher and the concern of working with these patients, we developed the phenomenological question of the research. Then, by writing personal experiences, we determined the epistemological viewpoint and our understanding of the phenomenon of caring brain death patients. In the second step, an ontological search was conducted on the nature of the care through the process of data collection. For this purpose, semi-structured interviews were performed with open questions with 10 participants, who were nurses of the intensive care units and it was conducted in a quiet place. The research inclusion criteria included having experience on caring the brain death patients, willingness to participate in the research, having at least 6 months of work experience in intensive care unit. The main question of the research is "What are the meanings of nurses' living experiences of brain death patients who are candidate for donation?"

The research context included intensive care units in the Neurosurgical Hospital of x in city of xx. The city was a major center of transplantation in the south of the country, and participating nurses had a rich experience on brain death patient who were candidate for donation. The duration of the interviews was between 40 and 70 minutes, and all of the interviews were recorded and immediately implemented word by word. The goal of research was explained verbally and in writing for all participants before

the interview and the informed consent was obtained and all ethical considerations were observed.

In the third step, reflection was performed on the inherent themes, characterizing the care phenomenon. Accordingly, thematic analysis method was used to determine the thematic dimensions in describing the participants. Then, we separated the thematic expressions and by linguistic transformation, we determined the inherent and subsidiary themes through the free imagination technique.

In the analysis steps through the hermeneutic conversations among the members of the research team and experts, we conducted collaborative analyses to create deeper interpretive insights and more understanding on this care phenomenon. In the fourth step, care description through art of writing and rewriting was performed to provide a deep and rich description of the experience of caring brain death patients.

In the fifth step, by maintaining a strong relationship with the phenomenon and adhering to the main question of the research, we described the nature of the meaning of the living experience of caring patient, who was candidate for donation, by considering the non-effect of their preconceptions. Finally, by balancing the research context and considering the elements and whole simultaneously, we depicted the meaning of this experience. To achieve the accuracy and strength of data using Van Manen (2014) criteria, we developed the phenomenological question based on empirical descriptions and initial resources free of any viewpoint. In addition, parts of the descriptive notes were confirmed by participants.

Results

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Participants of this research included 10 nurses (9 females and 1 male) with mean age of 36.3 ± 7.34 and a professional background between 2 and 25 years. In this research, an important and innovative aspect of caring brain death patients emerged under the title of main theme of "compassionate care", which included two subthemes of "commitment and devotion and sympathetic support". Commitment and devotion included two subthemes:

Responsible care

One of the ethical principles considered by nurses providing care for brain death patient who were candidate for donation was adherence to a commitment and professional responsibility, required them to take care of these patients. Not only they were obliged to professional oaths, they were also responsible for the patient and his family, and the disappointing condition of the brain death patient did not cause to neglect the care. For example, participant 4 did not consider caring these patients less than that of other patients and he referred to importance and paying more attention to these patients and stated:

Caring this patient is more important than caring the conscious patient. I am feeling that I have more sense of responsibility to him. He might die a few hours later. All disappointedmuch work might not be done for him... there is a sort of more sense of responsibility for this patient, since we are obliged to do for this patient as we can, and if it fails, we should do our best.."

In this regard, participant 10 stated that: "Anyway, I do my work accurately. I am nurse and I must to do my work accurately until patient is alive..."

Compassion in care

Based on the participants, nurses try to provide relaxation for patient over time and provide care for him as he deserves. Nurses provided care because of their compassion and kindness and could not be indifferent to brain death patients. The nurses were feeling responsibility for families and had compassionate and kindly behavior to them.

Participant 5 said that:

" I feel piteous, let me do anything I can do it. This patient has fallen alone on the bed and there is nobody to help him, but I am with him so that he does not feel alone and we are indifferent to him ..."

An effort to maintain the dignity of the patient was also considered as paying attention to his family. In fact, providing care of the brain death patient was providing care for normal patient and his family. Paying attention to family emotional needs was major part of caring the brain death patients, who were candidate for donation. Our nurses in this crisis recognized the psychological state of the patient family and their efforts were to make their family more relaxed, an understanding beyond the feeling, which was leading to sympathetic behavior in the nurses. "Providing emotional support for family" and "emotional influence" were the sub-subthemes of the sympathetic support.

Providing emotional support for family

Our nurses also paid much attention to emotional needs of the patient family. They recognized that in this situation, the best possible work for family was paying more attention to them and their requests. Thus, they tried to respect the family values, meet their emotional needs as much as possible, support the family, and answer to their questions as possible. Providing care behind the closed door created a world of question and need for the patient family, the questions that were sign of denial, bargaining, and concern of family. Participant 7 said:

I allow the patient's family to go the patient bedside and pray for him. I do this for their need and relaxation.... I know it has no effect on survival of their patient, but I respect, I like to satisfy them, make them more relaxed, I want to make the family more satisfied and comfortable at these moments ...".

Expressing their sympathy with family, participant 8 stated:

"We cannot understand the patient family feeling com-

pletely and imagine our situation in their situation; we can only understand them I understand them, both the families and the patients, and I am really piteous for them ..."

Deep emotional influence

In the current research context, according to expressions of the participants, nurses provided their compassionate care to the patient under the influence of the patient's disability, non-defense, and loneliness and they thought that patients were observing and monitoring the care. The feeling of the nurses of caring the brain death patients, who were candidate for donation, implies that patient is observing and monitoring their caring behaviors. In addition, they always imagined themselves or their families in the situation of the patient and his family.

For example, participant 3 in this regard stated: When I suction the patients, I am always feeling that the patient has stood here and looking at me. It might be funny, but I am feeling that if I miss a work, he sees me, for example, his soul is here. While it has not been proven, I have such a feeling ...".

Two subthemes of "commitment and devotion" and "sympathetic support" formed the main theme of "compassionate care" and clarified an aspect of care of brain death patient, who were candidate for donation. In the current research, nurses provided sincere and compassionate care for the patient and his family. The negative outcome of care (patient death) did not affect the quality of nurses' performance, and they see still themselves responsible for the patient and his family.

Undoubtedly, providing compassionate care is considered as an ethical dimension in nursing cares (Von Dietze 2000 Henderson 2017, Zamanzadeh et al 2017,). Colegard (2011), (Cingel 2011), Crowther et al (2013) and Sand & Olson (2010) referred to the key characteristics of compassion, such feeling of existence, sympathy, commitment, empathy, attention, understanding, helping, and altruism (Cole-king 2011, Cingel 2011 Crowther et al 2013 Sand & Olson 2010). In the current research, based on the expressions of participants, many of the key characteristics of compassionate caring are evident, and these expressions are in fact confirm the nature of this care. However, Ball et al (2014) have shown that 86 percent of nurses failed in providing compassionate care by "overlooking the patient, neglecting, failing in providing care, and failing in establishing the required relaxation" (Ball 2014). In the current research, commitment and devotion showed the responsible aspect, combined with compassion and kindness, in compassionate caring of nurses (Ball et al, 2014). Sand & Olson (2010) stated that devotion and affection to others cause care providers to be motivated al-

truistically to accept responsibilities, since they feel love, concern, and responsibility to others (Sand & Olson 2010). Moreover, Gustine et al (2012) referred to responsible action as one of the aspects of compassionate care (Gustine et al 2012). The expressions of these researchers also confirm the analysis of the current research on theme of compassionate care.

Providing emotional care for patient and family can make uncomfortable situations tolerable for them and the families of patients view the nurses, establishing respectful relationship with patient and family, as "good staff" (Reid 2012). In a research conducted by Manzari et al (2012), Sque et al (2007), and Wu (2015), the brain death patients' family needs to emotional, empathic and sympathetic support have been shown (Manzari et al 2012, Sque et al 2007, Wu 2013). However, Mc Millen (2008) and Oroy (2013) referred to difficulty of providing the appropriate conditions to support the families of the patients who are at end of their life and non-relaxation feeling of nurses in providing care in these conditions (Mc Millen 2008, Oroy 2013). In Iran's cultural context, Iranian families have deep emotional bonds. In the current research, paying attention to emotional needs of families was important part of caring the brain death patients, who were candidate for donation, and participants made their efforts to meet the emotional needs of the family of the patients. Regardless of family decision to donate the body organ of their patients, they support them and made their effort to moderate the routine of the intensive care unit for relaxation of their family and respect for their values and beliefs. In this regard, Hinkle et al (2015) and Bocci et al (2016) emphasized on the sympathetic communication and emotional support of the patient's family during the care process, stating that patient family seeks for support (Hinkle et al 2015, Bocci et al 2016). Although Cingel et al (2011) stated that the two concepts of compassion and sympathy show a feeling of grief and discomfort caused by understanding the pains of others, a distinction should be made between sympathy and compassion. Sympathy is a negative description of compassion and in fact represents a feeling of powerlessness (Cingel 2011). Thus, if we accept the descriptions of these sympathy and compassion, it should be stated that in the current research, the participants felt sympathy to patient and they were feeling weak and powerless to conditions of the brain death patient. However, they solved this problem by paying attention to the patient's family and sympathizing with them and meeting their emotional needs.

With regard to emotional effects of brain death patients, who were candidate for donation, on nurses, Wu (2015) in his study on the experiences of male nurses in end-of-life care realized that nurses paid more attention to emotional needs of the families and made an effort to resolve them by providing emotional support to patient. In this research, it was reported that nurses felt sorrow due to loneliness of the patient and allowed the family to attend at the patient bedside (Wu 2015). In the current research,

in line with results of Wu (2015), nurses were affected by non-defensiveness and loneliness of the patient and family, and while appointment in ICU had been banned based on the rules, flexibility and moderation were applied by nurses on the rules of this unit, indicating emotional influence of the family of brain death patients on them.

Limitations and Recommendations

Based on the theme of "compassionate care", it is recommended that studies to be conducted on the outcomes of compassionate care in nurses and on developing the tool assessing the compassionate care in patients who are at the end of their life. In addition, there was no specific limitation in this research, except for the non-generalizability and the small sample size, which are considered as nature of qualitative studies.

Conclusions

According to the results of this research, it can be concluded that providing care for brain death patients, who were candidate for donation, despite imposing psychological burden on nurses, has provided a compassionate care for patient and family. This care is due to commitment, professional responsibility and deep emotional effects in them, the care which is provided completely without neglecting, despite leading to patient death. The research results in addition to providing a deep insight on the phenomenon of caring brain death patients, who were candidate for donation, provide the conditions for educational planners to train nurses in order to improve their care provided for the patients.

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Conflict of Interest

The authors declare that there is no conflict of interests regarding the publication of this paper.

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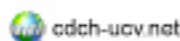
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