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CONCEPT ANALYSIS

Family caregiver: Caring on family carers

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Abstract

This study was conducted to clarify the idea of caring for non-professional family caregivers and identify their vulnerabilities while caring for their patients. This concept was developed because of the non-availability of structured caregiving programs for non-professional family caregivers in the hospitals and community. This issue might lead to potential health and safety hazards for patients and caregivers. Nurses and non-professional family caregivers can co-create a safe and loving environment ideal for patient care. Nurses are essential to upholding the health and safety of non-professional family caregivers while developing their confidence and care performance. Moreover, training the non-professional family caregivers in the hospital and communities would promote safe and effective nursing practice in preparation for a smooth patient transition at home.

Keywords: *family caregiver, non-professional family caregivers, nursing, caring, work-related hazards, collaboration*

Background

Harvey Picker (1987), as cited in Rawson & Moretz (2016), has listed eight principles of patient-centered care: (1) respect for patients' values, preferences, and expressed needs; (2) coordination and integration of care; (3) information, communication, and education; (4) physical comfort; (5) emotional support and alleviation of fear and anxiety; (6) involvement of family and friends; (7) transition and continuity; (8) access to care. Articles agreed that the patients are always at the center of care. However, direct carers should also deserve to share a space in the center too. The manifestation of close family ties among Filipinos is seen from birth to death (Miralao, 1997). Reinhard et al. (2008) and Henson (2020) referred to a Family Caregiver as an *unpaid non-professional Family Caregiver, either a family, friend or neighbor willing to provide care to a family member.* A Family Caregiver may act as a direct carer, a decision-maker, and a liaison between the multidisciplinary team. Family Caregiver is one of the significant people who could influence a patient's ongoing and future treatments; hence, a potential entity that would realign the patient back to the center of care (Li, Hu, Dong, & Arao, 2013).

Despite the challenges, there is no known taste of caring for Family Caregivers in most articles. Not everyone could acquire good vitality forever. Being selfless for a long time makes their body weak in addition to physical strain and emotional challenges they have experienced, like moral distress and compassion fatigue (Henson, 2020). These factors could gravely affect the tasks expected from them (Schulz & Beach, 1999). However, despite various articles related to such a topic, the following questions have not been answered yet: Are all non-professional family caregivers capable physiologically and mentally to become such? How could they provide quality care when nobody cares for their health and safety at work? This concept analysis brings the idea of integrating love and care for Family Caregivers because patient safety starts from them. The principal objective of this paper is to enlighten the concept of caring for Family Caregiver and understand their vulnerabilities through Walker and Avant's concept analysis methodology.

Definition

Walker and Avant (2019) included the analyses of each terminology to understand the conceptualization process of Family Caregiver Focused Care.

The Merriam-Webster dictionary defines family as a *"basic unit in society traditionally consisting of two parents rearing their children."* The Medical online dictionary described the family as *"a group of people related by blood or marriage or a strong common bond, such as those descended from a common ancestor, or a husband, wife, and their children."* Moreover, Dictionary.com defines the term according to the family type—traditional and single-parent family. The traditional family is *"a basic social unit consisting of parents and their children, considered a group, whether dwelling together or not* ."While the single-parent family is *"a social unit consisting of an adult with the children they care for."* Family is the relatedness of individuals not merely in the consanguinity of blood but also in social relationships (Miralao, 1997).

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On the other hand, the Cambridge Dictionary defines a caregiver as "*someone who takes care of a person who is young, old, or sick.*" Also, the NIH National Cancer Institute (2012) deeply defined the term as "*a person who gives care to people who need help taking care of themselves. Examples include children, the elderly, or patients who have chronic illnesses or are disabled. Caregivers may be health professionals, family members, friends, social workers, or clergy members. They may give care at home or in a hospital or other health care setting.*"

To fuse the two terminologies, the Family Caregiver is "*informal, unpaid family member, friend, or neighbor who provides care to an individual who has an acute or chronic condition and needs assistance to manage a variety of tasks, from bathing, dressing, and taking medications to tube feeding and ventilator care* (Reinhard, Given, Petlick & Bemis, 2008)." Family Caregivers in a clinical setting have to be selected accordingly to maximize their role (Feinberg, 2008).

The expression of tender loving care is usually associated with Nursing; hence, the only way to raise the value of a Family Caregiver is to collaborate their work with Nurses. The term nursing is defined as *"the duties of a nurse* (Merriam-Webster, n.d.) *that concerned with the provision of services essential to the maintenance and restoration of health by attending the needs of sick persons* (MedicineNet dictionary, n.d.)." Furthermore, the International Council of Nurses (2002) added, "*Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups, and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled, and dying people ….*" For the Family Caregivers to function well, a collaborative nursing pathway must exist to pursue the Family Caregiver role. The Covenant Health (2019) deciphered six interdependent competency domains of a Family Caregiver Competency Framework, which would allow functional collaboration between the Nursing Team and Family Caregiver. Firstly, Nurses would guide a Family Caregiver to recognize their roles (indicators: understanding their value and contribution; knowledge of caregiving; identifies their roles and responsibilities on patient care). Secondly, nurses to have direct communication with a Family Caregiver (indicators: communicate with respect, empathy, and compassion; listen actively; convey information in a timely and straightforward manner; support care coordination/engagement). Thirdly, Nurses partner with a Family Caregiver (indicators: understand benefits; create a collaborative environment; recognize their assessments and planning; spot conflict and countermeasures). Fourthly, Nurses foster resilience among Family Caregivers (indicators: assess their needs and daily goals; understand relationship dynamics between nursing-caregiver-patient; educate to enhance skills and abilities; promote health and wellbeing). Fifthly, Nurses help navigate the health and social systems and find accessible resources (indicators: access social support timely; make referrals if needed; work on overcoming obstacles). Sixthly, nurses and Family Caregivers enhance the culture and context of care (indicators: recognize stigma and discrimination; introduce caregiving models; assist in self-reflection). In addition, the seventh dimension might include Nurses ensuring Family Caregivers promote safety on their patients and themselves.

To promote a loving and caring atmosphere towards the Family Caregivers, nurses must identify and resolve the intrinsic and extrinsic vulnerabilities in the workplace (Reinhard, Given, Petlick, & Bemis, 2008). *Lexico defines vulnerability as the "quality of being exposed an active or possible attacked or harmed, either physically or emotionally.*" Meriam-Webster dictionary referred to as "*capable of being physically or emotionally wounded" and "open to attack or damage.*" Furthermore, Vocabulary.com added to the definition as "*susceptibility to criticism or persuasion or temptation.*" Relating to the concept, these vulnerabilities in Family Caregivers include being susceptible to the effect of physical and mental hazards such as moral distress and compassion fatigue that may cause medical errors, poor work performance secondary to declining health behaviors such as not taking maintenance prescriptions, no exercise and healthy diet leading to further sickness (Reinhard, Given, Petlick, & Bemis, 2008; Lynch & Lobo, 2012; Rodrigo, 2005). Social isolation is a hazard that confuses a Family Caregiver's life priorities over their role as a mother to her children and a wife to her husband or vice versa (Lanier and Brunt, 2017). A safety hazard is the number one risk among them because they are untrained non-professionals prone to self-injurious activities in the work environment such as issues in body mechanics related to patient care or equipment, the unfamiliarity of hospital set-up, and with little less idea of general guidelines on workplace safety (McNeill, Schuyler, & Ezrachi, 1997; Wardell, 2007).

Defining Attributes

Defining attributes are characteristics of a concept that frequently appears in the literature, distinguishing one from the other related concept immediately bringing the concept to mind (Walker & Avant, 2019). There are three defining attributes of a *Family Caregiver: Caring on Family Carers* concept analysis. Firstly, the Family Caregiver has little or no known knowledge of basic patient care. Secondly, the Family Caregiver is vulnerable to health hazards such as physical, mental, social, and safety. Thirdly, Family Caregiver needs a collaborative effort from the nursing team to avoid work-related hazards and optimize their role potentials. Finally, a Family Caregiver needs to be loved and cared for by the family support system and people around them-they need to be treated with dignity and respect both as a family member and a caregiver.

Model Case and Analysis

A model case comprises all defining attributes integrated into the concept (Walker & Avant, 2019). Below is an example of a model case for caring for Family Caregivers. This model of care involves Nurse Kessa, who is working on a project about Caregiving Program intended for adult cancer patients with functional disabilities. She asked for the help of Nursing Education, Quality Improvement, Patient Relations, Social Worker, Nursing, and the Medical teams. After brainstorming, the Nursing Education representative voiced out, "How can we take care of our Family Caregivers while maximizing their potentials?" All have participated in the brainstorming activities and started drafting a structured program. The team's ultimate goal was to maintain a caring and supportive environment for Family Caregivers to attain patient safety and quality care. There was a strong collaborative partnership between Family Caregivers and the nursing team, including classroom-based and actual patient care demonstrations. Another member suggested, "we need to do light class sessions for Family Caregivers for them to spend more time with their patients." The team then developed a new virtual education platform for Family Caregiver and set a schedule for a practical demonstration on basic care and the elimination of workplace-related hazards.

The example shows a strong collaborative partnership between Family Caregivers and the nursing team to uphold the caregiving role. The nursing team has expressed their care and love for the Family Caregivers by understanding their burdens and making them their strong points. When Family Caregiver has received these attributes, they could empower themselves even more.

Additional Cases

The cases under this category are the borderline and contrary cases. Walker & Avant (2019) defined a borderline case as the existence of most defining attributes, but not all of them. Meanwhile, the contrary case is the reciprocal of a model case where all listed attributes are not present. The following examples below are formulated as a sample scenario.

a) Borderline Case and Analysis

A patient is hemiplegic caused by Cerebrovascular Accident. He is undergoing physical therapy twice weekly, and tomorrow is his last session in preparation for his discharge. The Physical Therapist taught the patient's brother Kellan on the previous courses and advised him to coordinate with the nurses whenever he needed further teaching and assistance. On that day, Kellan asked the nurse to call the therapist for some clarifications in bed turning, but the nurse said, “the Physical Therapist will be coming here today.” Four hours had passed, but the Physical Therapist still had not come. He followed up with the nurse again and said with a loud voice, “I already called the therapist!” despite not doing so. After a few minutes, Kellan shouted for help because of severe pain in his back. Diagnostic investigation revealed spinal fracture due to wrong body mechanics.

This event is an example of Family Caregiver neglect. As nurses, we need to empower the Family Caregivers to get involved in the care required for the patient (as long as they are assisted), making them active participants in inpatient care. The multidisciplinary team should identify possible hazards to caregivers. Institutions should not tolerate neglect and cancel culture in the workplace.

b) Contrary Case and Analysis

A patient is about to transfer from full code to do not resuscitate (DNR) status. Before making this decision, the medical team needs a patient and family meeting (PFM) to comply with the hospital policy. Nurse Joshua informed Dr. Paul, the primary consultant, that the Family Caregiver B would be coming tomorrow. He suggested rescheduling the PFM as the current Family Caregiver A is working 24/7 for five days. But because Dr. Paul's schedule will be hectic starting tomorrow, he decided to conduct the PFM on that day with the presence of Family Caregiver A though the person appears sleepless and exhausted. After the PFM, the multidisciplinary team accepted and signed the DNR form in the presence of Family Caregiver A. Family Caregiver A left the hospital and could not update the rest of the family and Family Caregiver B about the DNR status because of complete exhaustion. The family noticed that no medical interventions were given to their gasping patient on the same day. They clarified to nurse Joshua and responded, "patient is placed on DNR, weren't you informed?" The family became hysterical and violent after hearing the statement.

That event is an example of communication failure secondary to the mishandling of family meeting sessions. Dr. Paul is not considering the impact of his abrupt decision even he knew that Family Caregiver A appeared sleepless and exhausted. Also, he underestimated the family's participation and decision-making capabilities, which led to aggression. Also, he should have pondered the suggestion of Nurse Joshua, as this is shared care, and Nurse Joshua's reason is valid. The multidisciplinary team must carefully assess the Family Caregiver and family representative's ability to decide though they are legally competent.

Antecedents and Consequences

The antecedents are the triggering events or attributes before forming a concept, and the consequences are the outcome that occurred as a result.

Selecting the Family Caregiver is the primary antecedent of this concept analysis. Family Caregivers tend to present themselves

because of family and a financial burden (Collins & Swartz, 2011), but selecting a Family Caregiver should not be voluntary but appointed with careful deliberation considering the level of resiliency (Collins & Swartz, 2011). The absence or incomplete family caregiving direction is another antecedent. There are few institutions not embracing contemporary caregiving programs, and it leaves the non-professional Family Caregiver to "do it yourself" activities Reinhard, et al., (2008). Another antecedent is the lack of professional supervision among medical teams.

Meanwhile, one of the consequences is impaired wellbeing. Reinhard et al., (2008) and Schulz and Beach (1999) conclusively linked death from physical and emotional exhaustion and common for aged spousal caregivers. As evidence, health behavior issues such as forgetting maintenance medication, vices, and an unhealthy diet are typical for the aging population (Reinhard, et al., 2008). One of five Family Caregivers even described their health as fair and poor in a study. Also, mental and physical exhaustion among Family Caregivers affects decision-making. It compromises the safe care and self-care process, leading to medical errors and work-related hazards (National Academies of Sciences, Engineering, and Medicine, 2016).

Empirical Referents

Walker & Avant (2019) propounded empirical referents to provide a way to observe and measure the concept.

The lack of knowledge on basic care can be measured concurrently through examining their knowledge and skills through practical demonstration. Practical demonstration is the best knowledge retention activity (Lanier and Brunt, 2017). Vulnerability from a work-related hazard can be assessed through risk assessment results conducted by Risk Management for both work environment and employee-related factors. A collaboration between nurses and Family Caregivers can be measured through observation and focused group discussion. The initial aim is to initiate professional openness between two different entities. The love and care felt by the Family Caregivers can be evaluated by a satisfaction survey. At the same time, absenteeism reports and the number of incident reports are some indirect parameters of nursing support.

Nursing Implications

Nursing is an art of caring, loving, and sustaining. Being compassionate for the patients and their Family Caregiver is another paradigm to be studied in-depth. Family Caregiver can harness collaborative activities with the nursing team as their professional guide to maximizing potential. Once performed independently or with supervision, they could also provide safe care to patients and safeguard themselves against work-related hazards (Henson, 2020). Also, the family's drive to cooperate in-home care transitions would improve. Family Caregiver is the best co-partner for nurses when maximizing potentials and the caring, loving, and sustaining culture are worthy for them.

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