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## Caregiving: A Qualitative Concept Analysis

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## Caregiving: A Qualitative Concept Analysis

### Abstract

A common definition of caregiving does not exist. In an attempt to define the concept of caregiving, the authors used a hybrid qualitative model of concept development to analyze caregiving. The model consists of three phases: (a) theoretical, (b) fieldwork, and (c) analytical. The theoretical phase involves conducting an interdisciplinary literature search, examining existing definitions, and developing a working definition of caregiving. In the fieldwork phase, six participants were interviewed using a structured interview guide. Qualitative data analysis led to the development of two overarching themes: Holistic Care and Someone in Need of Help. Responses from participants were compared to the extant literature and a new definition of caregiving was thus formulated.

### Keywords

Caregiving, Concept Analysis, Hybrid Model of Concept Development, Definitions, Qualitative Research

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*A common definition of caregiving does not exist. In an attempt to define the concept of caregiving, the authors used a hybrid qualitative model of concept development to analyze caregiving. The model consists of three phases: (a) theoretical, (b) fieldwork, and (c) analytical. The theoretical phase involves conducting an interdisciplinary literature search, examining existing definitions, and developing a working definition of caregiving. In the fieldwork phase, six participants were interviewed using a structured interview guide. Qualitative data analysis led to the development of two overarching themes: Holistic Care and Someone in Need of Help. Responses from participants were compared to the extant literature and a new definition of caregiving was thus formulated. Keywords: Caregiving, Concept Analysis, Hybrid Model of Concept Development, Definitions, Qualitative Research*

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The act of caregiving is not unfamiliar, but the term “caregiving” is relatively new, with the first recorded use of the word in 1966 (Caregiving, 2010). The etymology of the word “care” comes from the Old English term “wicim,” meaning “mental suffering, mourning, sorrow, or trouble.” “Give” is also Old English, from “*ðeo-, ðiofan, ðiaban,*” meaning “to bestow gratuitously” (Caregiving, 2010). When the two root meanings are assimilated, caregiving is the action/process of helping those who are suffering.

Sixty-five million Americans, which comprise 29% of the United States (U.S.) population, have served as unpaid family caregivers to an adult or a child (Caregiving in the United States, 2009). Caregiving is multi-dimensional. For example, family caregiving, one dimension of caregiving, is on the rise with an estimated 14% of family caregivers (16.8 million) caring for a special needs child under the age of 18. Parental caregiving, another dimension of caregiving, refers to caring for one’s parent(s). Fifty five percent of families are currently providing parental care, while caring for their own children (Caregiving in the United States, 2009).

Caregiving estimates continue to escalate, and, as the population ages, the number of persons requiring care will subsequently increase. These estimates will no doubt have an unprecedented effect on the economy. Notably, the economic impact of informal caregivers was estimated to be \$350 billion in 2006 (Arno, 2006).

### Hybrid Concept Analysis

The development of the concept of caregiving for use in research lacks consistent conceptualization and operational definitions. The purpose of this manuscript is to report the results of our analysis of the concept of caregiving in an effort to promote conceptual clarity. This study employed a hybrid model of concept development which is based on three bodies of thought: philosophy of science, sociology of theory construction, and

participant observation (Schwartz-Barcott & Kim, 1993). Both authors have extensive nursing experience as practicing RNs and current nurse educators as well as researchers studying chronic illness to advance the nursing profession. Additionally, the authors are caregivers and have a passion for further exploration of the concept of caregiving, hence the impetus for this concept analysis. From our experience, we have noted differences in how both caregivers and care recipients perceive caregiving. Beth stated, “This played a role for me in the inspiration to conduct this study. I remember a care recipient participant in a previous study who eloquently described different providers, those that engaged with him as an individual and those that sat in the corner reading a magazine, doing paperwork or talking on the phone.” Melinda also shared a similar experience with a care recipient, stating that the caregiver who talked to her and saw her as a “person” and not a just “diagnosis” provided the best care. This led us to wonder: “What is caregiving?” Also, are there other concepts that more accurately represent a situation whereby one person is assisting another?

We selected a qualitative inquiry using a hybrid model as the most appropriate level of inquiry in the exploration of caregiving because this process combines theoretical analysis with empirical observation which is helpful since few empirical definitions have been written about caregiving. This allows for “a focus on the essential aspects of definition and measurement, . . . is applicable to applied sciences . . . and is especially useful in studying significant and central phenomena in nursing” (Schwartz-Barcott & Kim, 1993, p. 108).

This model consists of three phases: (a) theoretical, (b) fieldwork, and (c) analytical. In the initial theoretical phase, a concept is identified and the literature is reviewed for definitions, essential elements of the concept, as well as measurements related to the concept. A working definition is developed (Schwartz-Barcott & Kim, 1993). In the second phase, empirical observations and continual review of the literature are conducted (Schwartz-Barcott & Kim, 1993). The final analysis involves combining definitions derived from the first two phases and may result in possible changes to the definition and refinement of the concept (Schwartz-Barcott & Kim, 1993). As a result, several potential outcomes may occur: A new concept may emerge, or, the findings may not support the concept as it was initially conceived. As a result, the concept may become more clearly defined, refined through the process, or a new way to measure the concept may emerge.

### **Theoretical Phase (Defining Caregiving)**

The term “caregiving” is widely used and has been studied from a variety of scientific perspectives, including nursing, sociology, and psychology (Connell, 2003; Mendez-Luck, Kennedy, & Wallace, 2009). As discussed and illustrated in the literature review below, definitions of caregiving typically contained elements related to the act of caregiving or tasks performed of caregiving, making the concept difficult to identify (Swanson, Jensen, Specht, Johnson, Maas, & Saylor, 1997). “Caregiving” appears to follow the logic of *monens ponens* as illustrated by the following series of statements showing circular logic:

If my caregiver gives care, *then* my caregiver is caregiving.

My caregiver *gives* care.  
Therefore, my caregiver *is* caregiving.

The act of the caregiver (precedent) is described by caregiving (antecedent). Subscribing to this logic, caregiver and caregiving equate to the same, when in essence, the terms may represent two entirely different concepts. Therefore, a distinction between the use of the terms, caregiving and caregiver, in the extant literature is warranted. This concept analysis paper will focus solely on the term *caregiving* for the purpose of analyzing the concept of caregiving, using a hybrid concept analysis approach, to promote conceptual clarity.

### Literature Review

We initially chose to search the academic literature published between 2005-2010; however, we found few definitions and thus expanded our search to become more date inclusive (1990-2010) using the following databases: Information Systems Integration (ISI) Web of Knowledge, Science Direct, Psychology and Social Sciences, Business, Management and Accounting, PubMed, and The National Agricultural Library of Agriculture and Allied Disciplines. The authors identified the search terms “caregiving,” “concept analysis,” and “definition” which yielded four results. We then limited the search terms to “caregiving” and “definition” and the results elicited 90 articles. Ninety-four articles were reviewed and 23 were included in this concept analysis. The inclusion criteria identified by the authors was if a definition of “caregiving” appeared. Articles that did not define “caregiving” and, articles that defined “caregiver” were excluded from this review.

The following questions guided the literature search: (a) What is caregiving and (b) Is there a universal definition of caregiving? To differentiate from the individual, that is, the caregiver, and for a more focused definition of, the search term “caregiving” was used.

### Definitions of Caregiving

The etymology of caregiving defined by the Oxford English Dictionary (2010) is as follows:

caregiving *adj.* and *n.* (a) *adj.* characterized by attention to the needs of others, esp. those unable to look after themselves adequately; professionally involved in the provision of health or social care; (b) *n.* attention to the needs of a child, elderly person, invalid, etc.

The Merriam Webster dictionary (2010) defines caregiving as “a person who provides direct care, as for children, elderly people, or the chronically ill” (§2). Drentea (2007) refers to caregiving as “the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological or developmental needs” (§1). Furthermore, Drentea (2007) differentiates caregiving from caring for children, which is parenting; however, if activities performed on behalf of another person are

outside of normal expectations, such as caring for an adult child with cancer, then it is considered caregiving. Conversely, Pearlin, Mullan, Semple, and Skaff (1990) defined caregiving as the “behavioral expression of (one’s) commitment to the well-being or protection of another person” (p. 583). Caregiving is, in and of itself not a role, rather it entails identified actions within the context of a relationship (Pearlin, Lieberman, Menaghan, & Mullan, 1981). The definitions presented speak to the activities involved in aiding another individual who is dependent in some way. Pearlin et al.’s definition (1990), on the other hand, underscores a specific intent behind the activities, that is, an emotional component and commitment to the relationship as the basis for actions. This intent is supported by some caregivers. Specifically, African Americans identified love or affection as reasons for fulfilling caregiver responsibilities (Nkongho & Archbold, 1995), while other groups did not report similar reasons for providing care (Chao & Roth, 2000; Wallhagen & Yamamoto-Mitani, 2006).

The process of caregiving was originally proposed by Bowers (1987) and includes five categories of roles that provide meaning or purpose for the caregiver: anticipatory, preventive, supervisory, instrumental and protective. Swanson et al. (1997) ultimately defines family caregiving as: “Provision by a family care provider of appropriate personal and health care for a family member or significant other” (p. 68), a definition consistent with those presented above.

### **Caregiving among the Disciplines**

Specific aspects of the concept of caregiving related to several disciplines are addressed below, based upon the findings of our literature search.

#### **Nursing**

Swanson, et al. (1997), researchers in the College of Nursing, conducted a concept analysis on family caregiving. This concept analysis focused on the role of the caregiver. Caregiving was conceptualized as having four characteristics: tasks, transition, roles, and process. Tasks identified include activities of daily living, instrumental activities of daily living, the amount of care provided, and direct and indirect care. Transitions focused on care management, delegation, and transfer from family to institutional care. Caregiving roles recognized the extension of normal, family care and involved “mutual nurturing behaviors” (p. 68). Their ultimate goal was to evaluate the effectiveness of nursing interventions in family caregiving.

#### **Sociology**

Sociologists narrowly define caregivers as unpaid workers such as family members, friends, and neighbors as well as individuals affiliated with religious institutions (Drentea, 2007). Whereas early caregiving (Luecken & Lemery, 2004) refers to “immediate family environment and is broadly defined to include disruptions in parenting (e.g., as may occur with high family conflict or with parental death or divorce), along with characteristics related to the quality of parenting received by the child, e.g., caring, abusive” (p. 172), the focus of sociologists has been on examining the global

perspective of a caregiver in various countries: identifying the caregiver and recipient characteristics, such as the most common gender of the caregiver, as well as the caregiver role, including time spent caregiving, and caregiver burden (Ferrante, 2008; Drentea, 2007).

### Psychiatry/Psychology

In the disciplines of psychiatry/psychology, the psychological ramifications of the act of caregiving, i.e., caregiving burden and stress have been studied, but caregiving is not explicitly defined in this arena. The studies located (Stambor, 2006) focused on caregiver-related characteristics or the effects of caregiving on the caregiver, such as caregiving demands (Roepke et al., 2009), caregiver stress or burden (Pioli, 2010), coping strategies, challenges, and the rewards of caregiving (Rapanero, Bartu, & Lee, 2008).

### Conceptualizing Caregiving

There is a pressing need for a conceptual framework of caregiving that may help to guide research and clinical practice. The literature review highlights the lack of a universal definition for this concept. This lack of a generally accepted definition of caregiving makes it difficult to assess the concept of caregiving as well as compare the results of caregiving research. Disease-specific requirements (i.e., treatment), developmental issues (i.e., illness cognition), and contextual factors (i.e., formal versus informal care, home versus hospital setting) also complicate the establishment of an all encompassing definition.

The lack of a generally accepted definition of caregiving also makes attempts to operationalize and measure the concept difficult. While a number of instruments related to the concept of caregiving are available (see Table 1; 44 tools listed), these tools do not measure caregiving itself. Rather they attempt to measure the effects of caregiving, i.e., management of caregiving tasks: burden, demands, impact, and distress.

After reviewing the literature and following the process outlined in the theoretical phase of this hybrid concept analysis, the authors developed the following working definition: Caregiving is made up of actions one does on behalf of another individual who is unable to do those actions for himself or herself. This definition formed the basis for the fieldwork we conducted as the second stage of the qualitative concept analysis.

*Table 1. Caregiving Instruments*

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| <ul style="list-style-type: none"> <li>• Caregiving Competence Scale (Pearlin, L. I., Mullan, J. T., Semple, S. J., &amp; Skaff, M. M., 1990).</li> <li>• Appraisal of Caregiving Scale (Kinsella, G., Cooper, B., Picton, C., &amp; Murtagh, D., 1998).</li> <li>• Caregiving Burden Scale (Schumacher, K. L., Stewart, B. J., Archbold, P. G., Caparro, M., Mutale, F., &amp; Agrawal, S., 2008).</li> <li>• Caregiver Demands Scale (Siefert, M. L., Williams, A., Dowd, M. F., Chappel-Aiken, L., &amp; McCorkle, R., 2008).</li> <li>• Caregiver Mastery Scale (Sherwood, P. R., Given, B. A., Given, C. W., Schiffman, R. F., Murman, D. L., von Eye, A., Lovely, M., Rogers, L. R., &amp; Remer, S., 2007).</li> <li>• Caregiving Role Demands Scale (Mui, A. C., 1992).</li> <li>• Beliefs About Caregiving Scale (Hepburn, K. W., Lewis, M., Narayan, S., Center, B., Tornatore, J., Bremer, K. L., &amp; Kirk, L. N., 2005).</li> <li>• Caregiving Activities Scale (Hancock, K., Chang, E., Chenoweth, L., Clarke, M., Carroll, A., &amp; Jeon, Y-H., 2003).</li> </ul> |
|--|

- Caregiving Role—Preplacement (Gaugler, J. E., Zarit, S. H., & Pearlin, L. I., 2003).
- Caregiving Learning Goal Achievement and Satisfaction Measure (Rosswurm, M., Larrabee, J. H., & Zhang, J., 2002).
- Caregiver Competence Measure (Rosswurm, M., Larrabee, J. H., & Zhang, J., 2002).
- Caregiving Consequences Inventory (Sanjo, M., Morita, T., Miyashita, M., Shiozaki, M.; Sato, K.; Hirai, K., Shima, Y., & Uchitomi, Y., 2009).
- Impact of Caregiving Scale (Cousins, R., Davis, A. D. M., Turnbull, C. J., & Playfer, J. R., 2002).
- Caregiving Distress Scale (Cousins, R., Davis, A. D. M., Turnbull, C. J., & Playfer, J. R., 2002).
- Ways of Coping Scale (Billings, D. W., Folkman, S., Acree, M., & Moskowitz, J. T., 2000).
- Burden Scale (Ruiz, J. M., Matthews, K. A., Scheier, M. F., & Schulz, R., 2006).
- Caregiving Stress Measure (Martire, L. M., Keefe, F. J., Schulz, R., Ready, R., Beach, S. R., Rudy, T. E., & Starz, T. W., 2006).
- Caregiver Stress Scale (Worcester, M. I., & Quayhagen, M. P., 1983).
- Caregiving Management Scale (Phillips, L. R., Rempusheski, V. F., & Morrison, E., 1989).
- Zarit Burden Scale (Gaugler, J. E., Kane, R. L., Kane, R. A., & Newcomer, R., 2005).
- AIDS Caregiver Stress Interview (Wight, R. G., Aneshensel, C. S., & LeBlanc, A. J., 2003).
- Role Submersion Scale (Chang, B. H., Noonan, A. E., & Tennstedt, S. L., 1998).
- Respondent's Decision Strategies Scale (Pratt, C. C., Jones-Aust, L., & Pennington, D., 1993).
- Relatives Stress Scale (Wood, J. B., & Parham, I. A., 1990).
- Caregiver Competence Scale (Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S., 2001).
- Caregiving Perceived Control Measure (Sistler, A. B., & Blanchard-Fields, F., 1993). Finding Meaning Through Caregiving Scale (Hunt, C. K., 2003).
- Enmeshment in Caregiving Measure (Braithwaite, V., 1996).
- Caregiving Hassles Scale (Stephens, M. A. P., Ogrocki, P. K., & Kinney, J. M., 1991).
- Caregiving Hassles and Uplifts Scale (Kinney, J. M., Stephens, M. A. P., Franks, M. M., & Norris, V. K., 1995).
- Caregiver Questionnaire (Krach, P., & Brooks, J. A., 1995).
- Caregiving Satisfaction Scale (Kramer, B. J., 1993).
- Picot Caregiver Rewards Scale (Picot, S. J. F., Youngblut, J., & Zeller, R., 1997).
- Caregiving Involvement Scale (Chou, K. R., LaMontagne, L. L., & Hepworth, J. T., 1999).
- Preparedness for Caregiving Scale (Cummings, S. M., Long, J. K., Peterson-Hazan, S., & Harrison, J., 1998).
- Caregiver Burden Measure (Dew, M. A., Goycoolea, J. M., Stukas, A. A., Switzer, G. E., Simmons, R. G., Roth, L. H., & DiMartini, A., 1998).
- Preparedness for Family Caregiving Measure (Bull, M. J., Hansen, H. E., & Gross, C. R., 2000).
- Family Caregiving Responsibilities Questionnaire (Fredriksen, K. I., 1999).
- Willingness to Caregive Scale (Jewell, T. C., & Stein, C. H., 2002).
- Positive Aspects of Caregiving Scale (Narayan, S., Lewis, M., Tornatore, J., Hepburn, K., & Corcoran-Perry, S., 2001).
- Role Strain Scale (Tirrito, T., & Nathanson, I., 1994).
- Caregiving Assistance Scale (Manne, S. L., Lesanics, D., Meyers, P., Wollner, N., Steinherz, P., & Redd, W., 1995).
- Intention to Caregive Scale (Jewell, T. C., & Stein, C. H., 2002).
- Beliefs About Parental Caregiving Scale (Jewell, T. C., & Stein, C. H., 2002).
- Caregiving Strategies Scale (Phillips, L. R., Brewer, B. B., & de Ardon, E. T., 2001).
- Caregiver Appraisal Measure (Matthews, J. T., Dunbar-Jacob, J., Sereika, S., Schulz, R., & McDowell, B. J., 2004).

### **The Field Work Phase**

Schwartz-Barcott and Kim (1993) consider fieldwork an essential element in concept development. In a hybrid concept development, qualitative data gained by participant observation and in-depth interviews are used to develop insight into the nature of the concept. In this study, the fieldwork phase was conducted in both East and South East Texas. Individuals caregiving for a variety of care recipients were recruited (see Table 2) by the researchers. (Ethics approval was obtained from the university and nongovernmental organizations that agreed to permit us to recruit participants prior to conducting the study.) Purposive sampling was used to recruit potential participants for the interviews who met the inclusion criteria of English speaking adults (≥21 years old) who are current or previous caregivers. Purposive sampling is a common approach in qualitative studies. This type of sampling permits the selection of participants whose qualities or experiences permit an understanding of the phenomena in question (Polit & Tatano Beck, 2003).

Table 2. Demographics of Participants (n=6)

Age	Gender/Ethnicity	Whom they Provide Care/# of Years
52	Female/Caucasian	Caring for Aunt with anemia, diabetes, arthritis, and osteoporosis/2 years
79	Male/Caucasian	Caring for wife with Parkinson's disease/21 years
40	Female/Latino	Caring for mother with diabetes, heart disease, pacemaker, and arthritis/10 years
41	Female/Caucasian	Caring for disabled son with Trisomy 5/7 years
64	Female/Caucasian	Animal caregiver
31	Female/Asian (Chinese)	Registered Nurse

Given that the research question in a qualitative concept analysis is focused on one concept determined before data gathering commences, a large number of participants is not necessary (Schwartz-Barcott & Kim, 1993). Six self-identified caregivers participated in semi-structured interviews which lasted on average 45 minutes (see Table 2). Participants were asked about their caregiving experiences, what caregiving means to them, and reasons for caregiving. The interview schedule is presented in Table 3. The participants were ethnically diverse (Caucasian, Asian, and Latino) and both genders were represented. The participant caregivers included individuals who were either currently caring for or previously caring for a variety of care recipients including spouse, parent, a child with disabilities, and animals.

Table 3. Interview Schedule for Caregiving Concept Analysis

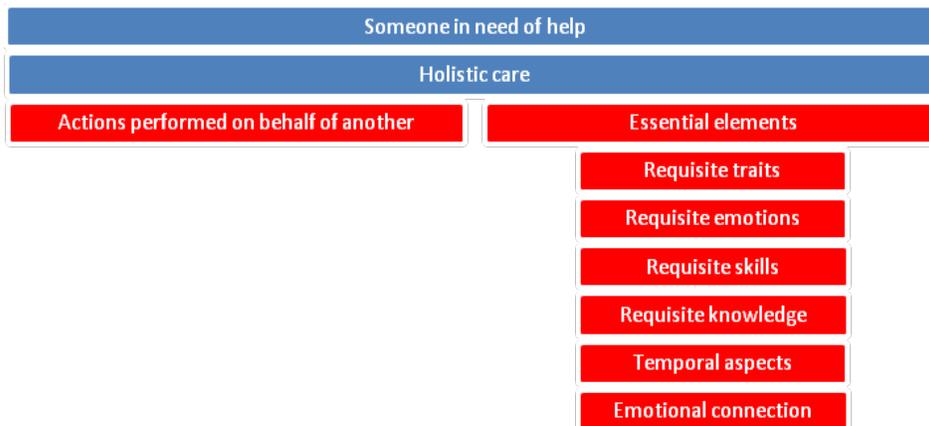
<p>For whom do you provide care?          What is your relationship to him /her?          Tell me how it is you became a caregiver.          What types of things do you do for the person him/her?          Describe a typical day.          How has caregiving impacted your life?          Give me an example of a time when you felt you were caregiving.          Give me an example of a time when you were doing something for ____ and you felt you were NOT caregiving.          What are the cultural values or beliefs associated with your background that impact the caregiving process?          According to your cultural values or beliefs, who should provide caregiving for an older person?          What does caregiving mean to you?          Some caregivers have told us they have family members that do not participate in caregiving activities for their loved one. If this describes your experience, how do you think you are different from them?          If you could draw a picture of you doing caregiving, what would it look like? OR If could author a book, what would be the title of your book? OR Can you think of a metaphor or something that describes your care giving relationship or the caregiving process?</p>
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In this concept analysis, all interviews were tape-recorded and transcribed verbatim by the researchers. After transcription, both researchers reviewed the transcripts and compared them with the audio recordings to ensure accuracy. The process of coding involves segmenting the data into units and rearranging that data into categories which facilitate insight and comparison (Miles & Huberman, 1994). Codes serve as organizing devices that allow rapid retrieval and clustering of all the segments related to a particular question, concept, or theme (Miles & Huberman, 1994). The researchers identified relationships, patterns, themes, and categories related to the phenomena of study developed theme-based tables. An iterative process continued throughout the entire analysis process to ensure that data were authentically represented.

## Results

The research question that guided the analysis was, “What is caregiving?” Analysis of the data led to two overarching themes: Holistic Care and Someone in Need of Help and the identification of two categories: (a) Actions Performed On Behalf of Another and (b) Essential Elements. The sub-categories are: Requisite Caregiving Character Traits, Requisite Caregiving Emotions, Requisite Caregiving Knowledge/Skills, Temporal Aspects, and Emotional Connection emerged (see Figure 1).

Figure 1: Schematic Presentation of Findings



### Theme 1: Holistic Care

The participant caregivers talked about caring for their care recipient’s physical, mental, and spiritual needs. The actions performed and the care delivered was identified as holistic. A female caregiver who currently cares for her disabled son stated that she witnessed nurses doing “scheduled maintenance, not holistic care.” She wholeheartedly believed caregiving was delivering holistic care, “the holistic care of the person, not just seeing to their medical needs, not just seeing their physical needs, but to their mental needs, their spiritual needs, you know...to make them a whole person.” Another participant enthusiastically shared that caregiving is “the strong desire to make things better . . . to give a voice . . .” While another participant did not explicitly use the term

“holistic,” he talked about the importance of attending to his wife’s physical, emotional, and spiritual well-being. He passionately defined caregiving as:

It’s care to keep the patient functional and keep their spirit up so that they can function as good as they can under the circumstance. ...It’s so important to keep them physically and mentally as high as you can... We don’t really know how tough it is because we’re not locked in a body that doesn’t perform, you know. And so we, I guess, we’re just happy that we are able to help the people, you know, the patient.

A participant who is a registered nurse (RN) also talked about delivering holistic care, attending to the physical (reducing pain, giving medications), but also addressing the emotional issues and being understanding by making sure that all needs are met. She further described the importance of holistic care in her delivery of nursing care.

Caregiving...I think the caregiving includes a lot of layers, a lot of levels. Most basically, you have to make sure that everything is okay with the patient physically, make sure they don’t develop any infection after the surgery, make sure they understand the importance of meds, make sure their pain level is under control and they’re taking...like their blood pressure, blood sugar is, you know, within acceptable level. And also, this is the physical part and also the emotional parts. When they feel anxious, nervous, if it’s possible spend more time with them.

Additionally, the RN reinforced the holistic component of caregiving as the “physical caregiving, emotional caregiving, there’s family caregiving that has elements of education in that you need to keep them informed of everything that’s going on and know what’s going to happen.” When participants were asked to identify a time when they felt that they were not caregiving, the RN shared a situation where a colleague was not delivering holistic care. A nurse was fired because she was supposed to straight catheter her patient every four hours. While the nurse charted that she performed the straight catheter procedure, she in fact, had not. The nurse participant stated,

I think she didn’t have the patient interests and feelings in her mind. Even when you’re not a professional nurse, you should know that those kind of feelings, like distended bladder or pain is not something that somebody should bear for 12 hours. ...You need to have those, you know, the patient interest in your mind. Not just a passive care giver, you only wait when they call you.

## **Theme 2: Someone in Need of Care**

All of the caregivers were providing care for someone in need of care. The care recipients had a variety of diagnoses or multiple illnesses from a birth defect to surgery. Many of the participants talked about how their care recipient needed care. One participant passionately illustrated the theme, “Someone in Need of Care,” through her

statement, “An illness, a surgery, a point that they come to where they can’t do certain things themselves.” While the majority of the caregivers did not have any healthcare experience, they were committed to learning how to perform the duties needed to provide care for their care recipients. Additionally, all of the participants were committed to delivering the *best* possible care to their care recipients. All of the participants in this study, with the exception of the nurse, fell into the caregiver role by default (as the mother or spouse), or life circumstances of the caregiver and other family members. Regardless of how they evolved in the caregiver role, all participants were willing to learn, and subsequently learned specific actions/duties necessary to better care for the individual needs of their care recipients. The specific actions will be discussed in the following paragraph.

### **Category 1: Actions Performed On Behalf of Another**

The dictionary definition of caregiving--actions that one person does on behalf of another--guided the interview question, “What kind of things do you do for your care recipient?” All of the caregivers assumed the role of an advocate; advocating for the *best* possible care for their care recipient. Many shared stories/examples of when they assumed the role of an advocate for their care recipients. Participants also openly discussed the actions they routinely performed. Tasks varied according to the care recipient’s individual needs and diagnosis, ranging from activities of daily living, such as bathing, toileting, and feeding, to instrumental activities of daily living, i.e., medication administration, accompanying to doctor visits, ambulation and routine household chores (Table 4). A participant in her fifties caring for her aunt stated, “I was fixing all her evening meals...I drive her everywhere.” The male participant stated, “Before the deep brain stimulation, I had to help her with everything. Now, I help her dress, help her to the bathroom.” The actions that the RN participant routinely performed were as follows: taking vital signs, assessing intake and output, completing physician’s orders, educating patients and family as well as ensuring patient safety. The tasks performed by the caregiver of a pet were involvement in end-of-life care and ensuring a safe environment. All of the participants talked about providing comfort and safety while attending to the care recipients’ needs.

### **Category 2: Essential Elements**

The key characteristics identified in the essential elements of caregiving were as follows: having the “ability to care,” “adapts to situation,” “the ability to communicate,” wherein “the lack of ability to communicate was identified as a barrier to care.” Other caregiving characteristics expressed were: “the caregiver is a good listener,” “affectionate,” “patient,” “well-grounded,” “responsible for someone other than self,” “is strong,” “protective,” “organized,” “understanding,” “want to be the best I can be” and an advocate --“have to become part of the other person.” The sub-categories of Essential Elements are as follows: requisite caregive character traits; requisite caregiving emotions; requisite caregiving knowledge and skills; temporal aspects; and emotional connection. A description of specific character traits identified in each sub-category follows.

Table 4. Physical Tasks Identified by Caregivers

<b>Tasks</b>		
Bathing	Dressing changes	Toileting
Accompany to doctor visits	Ambulation	Help with dressing
Meal preparation	Exercise / Physical Therapy	Transfers & Positioning
Feeding / prepare special meals	Mental stimulation	Disease management (seizures)
Shopping	Check on CR	Advocate
Provide safety	Provide comfort / nurse provided	Transport
Household chores / laundry / change light bulbs	Medication administration	
Assistance with medical equipment (G-tube, walker)	Attend to all the CR's needs ( mental, spiritual, all needs// "holistic, not scheduled maintenance") "a lot of layers, a lot of levels . . . physical . . . emotional parts"	
<i>Nurse:</i>		
Vital signs	Intake and output	Complete medication orders
Patient & family education	Bridge between family & doctor	Patient safety
Assessment	Care coordination	Entertainment/ keep spirits up
Maintain function	Nurse was holistic because parents not around	Holistic: physical (reduce pain, give meds) / must address emotional issues and be understanding Make sure all needs are met
<i>Pet caregiver:</i>		
End-of-life care & decisions	Ensure a safe environment	

### Requisite Caregiving Character Traits

One of the most commonly identified requisite caregiving character traits was the caregivers' commitment to make the care recipient better; "the drive to make that person better." The psychological responses by the caregivers varied, but centered around their "the desire to make a difference, alleviate pain and suffering and make things better;" "the goal of improved quality of life." Patience was a recurring theme shared by all of the participants in the fulfillment of the caregiving role. The animal caregiver further exemplified the notion of patience, as she shared her sentiments of caregiving, stating that it has made her more tolerant, forgiving and understanding of what was asked--"Just the desire to make a difference, alleviate pain and suffering and make things better"... "the goal of improved quality of life."

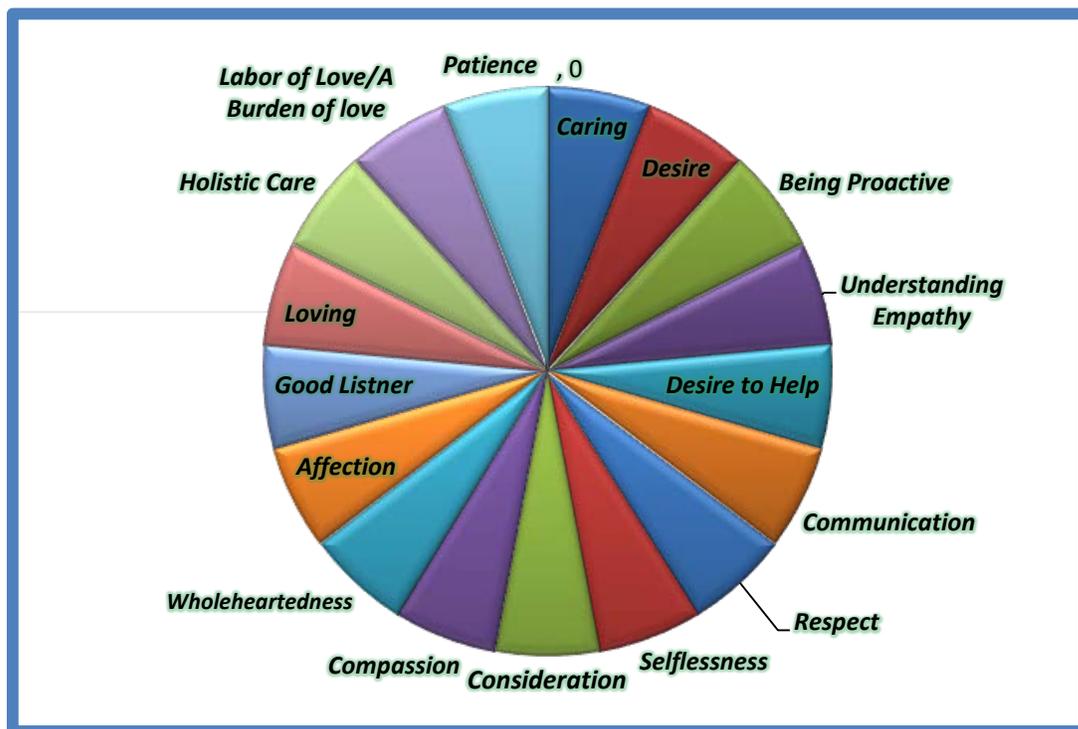
Caregiving is being responsible for someone other than self. Participants talked about the fact that they do not solely focus on their own needs, rather they exert all of their energy on their care recipient's interests and feelings. As one participant stated, caregiving requires, "putting aside own problems and differences" and "not being selfish or self-centered." For example, the mother of a disabled son talked about how her son requires 24-hour care, yet she passionately stated, "I wouldn't do anything else..., everything we do is just about him."

Another family caregiver shared similar thoughts. "Caregiving, to me, is something that you go into wholeheartedly. In my situation, it's kind of like I fell into it,

but then, at the same time, that's my parent, and I'm going to do whatever it is that I need to do to make my parent, or any family member of mine, feel comfortable. Take care of them in any way that I possibly can, and make them feel better."

As one caregiver eloquently said, the desire is to "want to be the best I can be," a desire to "give back." The caregiver is understanding of the care recipient's situation and must try not to "bring yourself to the same level." "It is understanding what the care recipient's needs are as best you can." Similarly, another caregiver conveyed the importance of setting aside the fact that one is caring for a loved one and *do* what needs to be done.

Figure 2. Seventeen Attributes of Caregiving



### Requisite Caregiving Emotions

The requisite emotions identified with caregiving were love, affection, empathy, and compassion. Three of the participants defined caregiving as loving. More specifically, one of the caregivers talked about her Christian beliefs and that she provides care under the premise of "love one another":

"I would do whatever I need to do and that's more out of a sense of duty."  
 "But it is love, too . . . it's like the right thing to do."  
 "I love her and she loves me."

The RN also talked about dealing with one's own emotions, stating, "It's just like you have to know how you deal with the work, the emotion." The caregivers' emotional

responses about caregiving included feeling a sense of satisfaction and fulfillment in caring for their care recipient stating, “it’s priceless,” and “get rewards too...they thank you...makes you happy.” Additionally, others talked about “the importance of setting aside the fact that one is caring for a parent,” “the seriousness of caregiving, “the stress” as well as the feeling of being “sandwiched.” Another participant stated, “you must understand everything to relax, otherwise you can be overloaded. You can be burned out...must deal with work, the emotion.” The male caregiver shared his feelings of inadequacy when his “wife couldn’t get to toilet in time and wet herself.” Affection and compassion were evident in all six participants’ caregiving stories. Additionally, seventeen attributes emerged from the participant interviews, all of which reflect the participants’ caregiver emotions (see Figure 2).

### **Requisite Caregiving Knowledge/Skills**

One of the categories that emerged from the participant interviews was the requisite caregiving knowledge and skills inherent to providing care. The basic knowledge that caregivers use to make decisions and solve problems provides the foundation for developing and improving skills. The RN stated that “the skills and knowledge of a nurse goes beyond changing bed pans, nurses must have knowledge.” Furthermore, she shares, “to acquire knowledge, the caregiver must ask questions in order to learn.” The participant caring for her disabled son had no prior healthcare experience, until her son was born and required 24-hour caregiving assistance. She talked about having to be knowledgeable about seizures and how to prevent them as well as “making sure that he’s gaining weight, so he gets fed 5 times a day through a G-tube.” She states, “We’re on a special formula because he is allergic to coconut oil, which is what they use in all the medium chain triglyceride. And in the medium-chain triglyceride, they use 3 oils. And the primary oil is coconut oil. She goes on to say,

. . . You have to make sure that you’re paying attention to every need, because he’s not verbal. He can’t come up and tell you, ‘Hey Mom, I want a drink....like yesterday just out of the blue he hadn’t had anything to drink in 3 or 4 days, he kept going after my tea glass. And so, I finally said, “Do you want a drink of it? And he had it all over him.

Her testimony beautifully illustrates the importance of knowledge and skills in providing caregiving to her special needs son. Others shared similar stories, many revealing personal testimonies of the knowledge and skills required for performing specific caregiving for their care recipient.

### **Temporal Aspects**

Caregiving takes time. The temporal aspects of caregiving were shared by all of the six participants. For example, one participant shared, “There was a time when I would have to get up and go early over there and take care of her, then go back home. Even though she’s close, it’s still just the time issue and the rest and stress and everything.” Others expressed similar sentiments in terms of the time required to deliver

care/caregiving, as many worked full-time while caring for their care recipient. The RN pointed out that “time management decreases stress and provides time for a break.”

### **Emotional Connection**

Emotional connection between the caregiver and care recipient characterized caregiving situations and were described in various ways. One participant compared two caregiving situations that she personally witnessed. In the first situation, the caregiver /care recipient relationship was strained and this strain had a negative effect on the recipient’s health. A new caregiver was assigned and the relationship between the recipient and the new caregiver was “like family” and the recipient’s health actually improved. Neither caregiver knew the recipient, but the difference was in communication. With the new caregiver, she stated,

...just the way she talked to her, the way she handled her made all the difference. And the lady was willing to work with her. And now, they treat this lady like she’s part of their family....even if they’re not family, there has to be some kind of connection so that the patient is comfortable with that person physically doing things to them or doing things for them in order to make them comfortable.

The animal caregiver described the characteristics of caregiving in this way:

Patience, which sometimes runs thin because of the ability to imagine what they’re going through and there’s the desire to help and probably some degree of selflessness. Some degree of not being totally self-centered there.

### **Unexpected Finding**

An unexpected finding surfaced from the 79-year-old male participant in this study. Currently, he is the primary caregiver for his wife, who has suffered from Parkinson’s disease for the past 21 years. While the sentiments of caring for his wife were positive, his experience differed from the female counterparts. For example, when asked how caregiving has affected his life, he stated, “You become X’s (wife’s name) caregiver...you lose a little more of your own identity.” This contrasts with the female participants, who did not associate caregiving with a loss of their personal identity.

All participants were asked if they wrote a book about their caregiving role, what the title would be. For the male participant, his book title, “Me and My Shadow,” this further illustrated his feelings of losing a sense of his own identity. Despite his feelings of losing a sense of his own identity, he stated that if he were the type of person who played golf, etc., then having to care for someone else would be difficult.

Well, if I were someone who did have golfing, hunting, fishing, thing like that, I think I’d be in a lot of trouble because I’d have to give up a lot of things, or else we’d have to hire someone, you know, to watch after her. It

doesn't bother me, but...I've learned a long time ago that there are only two people, two kinds of people: patients and care givers, and I was the lucky one. I ended up being a care giver.

### **Discussion**

The identification of a working definition of caregiving is vitally important, as the act of caregiving is a reality for many. A revision of the definition of caregiving is suggested based on the field work. The affective component in the revised definition supports Pearlin et al.'s (1990) description of caregiving in that it involves an emotional connection between caregiver and care recipient.

The theoretical phase illuminated definitions of caregiving as well as a working definition that served as a foundation for this hybrid concept analysis. The holistic care in caregiving is supported by the works of Pearlin et al. (1990), who explicitly stated that one must possess the affective component of caring to provide caregiving. Emotional connection and holistic care are closely related, both extending beyond attending to "the physical" being. Both characteristics refer to relating to and caring for a person on an emotional level-being able to share your feelings with them, being open and vulnerable, and trusting that person not to hurt you emotionally. All of the participants in this study, except for the nurse, "fell into the role" of caregiver role by default (as the mother or spouse), or due to life circumstances of the caregiver and other family members. Regardless of how the caregiver evolved into the caregiving role, their approach to caregiving was similar to the indicators identified by Swanson et al. Swanson et al.'s study (1997) alluded to the holistic approach to care, but on the other hand, researchers identified good health as an antecedent for caregiving; this finding is not congruent with our study. One of our participants had to move in with her parents because of her own ill health, and during the time that she was coping with her own illness, her mother required her assistance. Similar to the participants in our study, the requisite caregiver knowledge and skills expressed by Schumacher Stewart, Archbold, Dodd, and Dibble (2000) included monitoring, interpreting, making decisions, taking action, adjusting to changing needs, comforting with hands-on care (direct care), accessing resources, working with the ill person, and negotiating the health care system.

Based on the six participants in this study, the following definition of caregiving was formulated:

Caregiving is the process of helping another person who is unable to do for themselves in a "holistic" (physically, mentally, emotionally, and socially) manner. Caregiving is facilitated by certain character traits, emotions, skills, knowledge, time, and an emotional connection with the care recipient.

### **Conclusion**

Identifying a universal definition may help research teams and other health professionals to create a standardized language, enhance applicability and serve to guide and inform future research in an effort to improve the process and outcomes of

caregiving. Ultimately, a theory of caregiving based on cultural values and beliefs may be developed. Clearly, there is a need for future research in these areas. It is hoped that this hybrid concept analysis may be the beginning for future studies on the process of caregiving.

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