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## Finding meaning in caring for a spouse with dementia

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### ABSTRACT

Dementia caregiving can be burdensome with many challenges, especially for spousal caregivers who are elderly and may have limited resources and chronic conditions of their own. However, it can also be an opportunity for growth and transcendence. Thematic qualitative analysis was conducted with 11 caregiver interviews to investigate how spousal caregivers of individuals with dementia found personal meaning in their caregiving experience. Caregivers commonly had altruistic values, and the discipline to live those values. They found meaning by believing in a choice of attitude and perceiving satisfaction in living according to their values in life. They had faith in a higher power, a strong sense of love for their spouses and they derived strength from past challenges. Positive attitudes among caregivers of individuals with dementia may be enhanced by sharing these stories and strategies. Study results also provide an expansion beyond commonly held views of caregiving for nurses.

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Dementia is characterized by non-reversible cognitive decline. Approximately 11% (5 million people) of older adults over 65 years old in the United States have dementia, and with the aging population the number is expected to triple by 2050 (Alzheimer's Association, 2013). Caregivers of individuals with dementia must endure continuous cycles of physical, psychological, financial and emotional challenges related to long-term dementia care. However, variations in reports of caregiver experiences exist from negative to positive. These variations can be somewhat explained by the ways in which caregivers derive meaning from their particular caregiving situations (Ayles, 2000; Kim, Shultz, & Carver, 2007). Finding meaning is considered a critical aspect of being able to grow as a result of stressful events (Davis & Morgan, 2008; Siegel, Schrimshaw, & Pretter, 2005), and the meaning an individual attributes to a circumstance plays a significant role in their affective responses to the situation (Frankl, 1959). Thus, the purpose of this study was to describe the experience of spousal caregivers of individuals with dementia who reported to having found meaning in their care. Understanding how these caregivers found meaning in their caregiving experiences may reveal insights or strategies that can be helpful to other caregivers who may be struggling to find meaning of their own.

### 1. Meaning in caregiving

Frankl (1959) suggested that true meaning in life is found through forgetting the self in favor of serving a cause or loving another person. Meaning can be discovered by (a) creating a work or deed; (b) experiencing beauty, goodness, truth or encountering another human being in their special uniqueness by loving them; or (c) choosing an attitude toward unavoidable suffering by being challenged to change oneself. Within the context of caregiving, meaning can be discovered in the very act of caregiving, in loving the spouse that one is caring for, or in being challenged to change or grow from the experience. Caregivers can find meaning based on the relationship with their spouse, the care they provide, or their inner strengths. Caregivers can choose to make their experience meaningful.

#### 1.1. Deriving meaning from caregiving

Existential meaning is at the core of one's purpose in life, and provides a lens into the question of how one makes sense of the self and one's existence in the world. Research indicates that older adults derive a sense of meaning by engaging in activities that are helpful to another, or are positive in nature (Trice, 1990). Caregivers may be able to derive meaning from the act of caregiving, in that they are caring for, helping and assisting another being who is totally dependent on them.

#### 1.2. Deriving meaning from the caregiving relationship

Meaning can also come from the caregiving relationship. Schulz et al. (2007) suggest that caregiver compassion, defined as a sense of

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shared suffering and a desire to alleviate the care recipient's suffering, is a critical component of caregiving. Relative alleviation of the suffering or shared suffering may be what makes caregiving meaningful to caregivers who feel compassion toward their care recipient. Sometimes meaning is found in the memories of the relationship. According to Caron and Bowers (2003), caregivers try to find recognizable behavior or expressions that are characteristic of the care recipient as they remember them. Similarly, in another study, caregivers reported being able to retain feelings of closeness to a spouse with dementia for as long as the spouse was alive (Hayes, Boylstein, & Zimmerman, 2009).

### 1.3. Finding meaning in suffering

Many caregivers refuse to relinquish care for extended periods and disregard the hardships of caregiving (Caron & Bowers, 2003). Interestingly, research has shown that higher caregiver burden coexists alongside a higher level of positives for the caregiver (Kim et al., 2007), and more growth (Siegel et al., 2005). Trauma and suffering have been recognized as opportunities for growth or personal development by many existential psychologists (Reker & Chamberlain, 2000; Tedeschi, Park, & Calhoun, 1998). Traumatic events challenge a person's fundamental assumptions or philosophy of life and thus inspire a search for meaning (Baumeister, 1991). Thus by choosing a meaningful attitude towards their unavoidable suffering, caregivers may be able to achieve more positives in their caregiving experience overall.

Post-traumatic growth has been studied in the aftermath of acute stress situations such as bereavement. However, there is relatively little research on growth in long-term stress situations such as caregiving, where the stress level changes continuously and there is no guarantee as to when it will end. Hence, finding meaning in the context of long-term or continuous suffering may be more difficult, than after an acute trauma.

## 2. Methods

This study was a descriptive qualitative study based on the premises of naturalistic inquiry (Boyatzis, 1998). Semi-structured interviews were used to explore how spousal dementia caregivers found personal meaning in their caregiving experiences. This interview method allowed for flexible questions to be used as a result of participant responses and open-ended questions to explore a relatively unexplored topic. This format helped keep the interview focused on the experience of finding meaning. The interview method stays faithful to the caregiver's own reality, and was appropriate for this study because meaning is a subjective concept of the individual in relation to their world (Mason, 2006).

### 2.1. Participants

Participants for this study were recruited from rural counties in a southeastern state in the United States where Alzheimer's disease prevalence had increased 31% over the past 10 years (Alzheimer's Association, 2013). Participants were self-selected individuals who responded to the study flyer or were referred by other participants. Caregiver eligibility was assessed by phone based on participant inclusion criteria: (a) being a caregiver living with a spouse with dementia (the spouse must have been diagnosed with dementia or must have been taking cognition enhancing drugs); (b) being the primary caregiver providing at least 3 hours of daily care; (c) having more than 1 year of caregiving experience; (d) being cognitively able to participate in interviews; and (e) being able to effectively communicate in English. By requiring participants to be primary caregivers with at least 1 year of experience and providing at least 3 hours of daily care we were able to recruit caregivers who had had

enough time to experience caregiving and reflect on finding meaning prior to data collection. Institutional review board approval from the researchers' affiliated university was obtained for participant protection. A total of 12 caregivers completed the interviews. One interview was excluded from analysis as it was determined that the caregiver was no longer the primary caregiver at the time of the interview. Eleven interviews were analyzed.

### 2.2. Procedures

Flyers were distributed at dementia caregiver support groups, geriatric clinics, adult day care centers, senior centers, churches, events in the community that dementia caregivers might access, and via e-mail or distribution to various listservs. Flyers were worded to target spousal caregivers who self-identified as having found personal meaning in their caregiving. Flyers directed caregivers who were interested in participating in the study to call the principal investigator (first author).

When caregivers contacted the investigator, the general study purpose, aims, and requirements were explained, and caregiver eligibility was determined. The investigator assessed the caregivers' cognitive ability to consent during this initial phone screening. If the caregiver orally agreed to participate in the study, the consent form was mailed or e-mailed to the caregiver. The investigator contacted the caregiver again a week later to confirm interest in study participation and schedule the interview.

Written consent was obtained before conducting the interview. All caregivers were cognitively able to understand the consent process. The interviewer explained the purpose of recording the interview and discussed the caregiver's right to discontinue the interview at any time for any reason. Interview data were collected by two digital audio recorders to ensure minimal data loss. To protect both the caregiver's and care recipient's privacy the interviews were conducted when the care recipient could be with another temporary caregiver or at adult day care. Interviews were conducted at a time and place of the caregiver's choosing to provide a safe environment to share personal stories. Member checks were done during the interview recordings to ensure credibility of collected data and clarify meaning. One caregiver sent additional thoughts to the researcher by e-mail after the interview. Upon completion of analyses, a summary of the results was sent to participants to ask for revisions or additions. All participants agreed to the statements. Participants were compensated \$15 for completing the interview, and one participant refused the compensation.

### 2.3. Data analysis

Digital audio tapes were transcribed verbatim. Transcripts were read multiple times and analyzed using the thematic qualitative content analysis method, a data-driven, inductive method described by Boyatzis (1998). Themes were identified based on the three research questions: (a) What meaning do caregivers find in caregiving? (b) How do they think they were able to find meaning? and (c) How has that meaning changed/affected the caregiving experience?

Data were analyzed during the data collection period to inform subsequent interviews. This method focuses and shapes subsequent interviews to help the researcher obtain data that best answers the research questions. First-level coding identified quotes and themes in each caregiver's story, with a minimum level of abstraction, and staying as close as possible to the caregiver's original words. Individual stories were reviewed and developed into individual caregiver matrices that included the caregiver's answers to each research question. In second-level coding, quotes and themes from the first-level coding were extracted according to the caregiver's answers to each research question. Findings were then compared

within the individual interview to determine how the answers to each research question were related to each other. At the third-level of coding, common themes across individual caregivers were reviewed cross-sectionally, to explore similarities and differences among participants (Bloomberg & Volpe, 2008).

Data analysis was conducted primarily by the corresponding author. Periodic meetings were held with co-investigators throughout the data analysis process to discuss findings and check consensus. A co-investigator, who is an experienced qualitative researcher independently analyzed several interviews to compare results and ensure that findings were consistent and true to the data (Bloomberg & Volpe, 2008). Data saturation was concluded based on criteria proposed by Guest, Bunce, and Johnson (2006). Guest et al. demonstrated in a thematic qualitative analysis of 60 interviews, 73% data saturation in the first 6 interviews, and 92% saturation by 12 interviews. The method they used was based on three assumptions: (a) a certain degree of interview structure, (b) inquiry of a coherent domain of knowledge, and (c) participant homogeneity. They demonstrated that saturation could be achieved with very few interviews in certain cases of thematic analysis involving a narrow window of content inquiry. The current study meets these three assumptions. A semi-structured interview guide was used, three specific content questions were inquired and a homogenous group of caregivers who met the inclusion criteria were interviewed. Therefore, based on this same method, the current study achieved data saturation.

### 3. Results

Of the 11 caregivers, 5 were male and 6 were female, ranging in ages from 63 to 81. Ten caregivers were Caucasian and one caregiver was African American. Their education levels ranged from high school graduation to post-doctoral studies. Length of caregiving ranged from 1 to 14 years. All of the caregivers considered themselves Christian or to be living Christian values. The following results were common across the participants regardless of caregiver gender, age, race, level of education, or length of caregiving.

#### 3.1. Meaning in caregiving

The first research question captured the personal meaning caregivers found in caring for a spouse with dementia. The source of meaning caregivers described stemmed from the spouse or caregiving itself. Caregivers who found meaning in keeping the spouse at home felt that being there for the spouse and having the spouse remain at home rather than an institution was meaningful. For these caregivers, meaning was derived from doing what they thought was important or meaningful to the spouse. In this sense, keeping the spouse with dementia at home seemed to be an act of determination, as reflected in this quote, "I wouldn't let her go to a nursing home if [at] all possible, if we can take care of her here. This is home [cries]."

Caregivers who described their marriage vows as a sacrament or as a promise that was meant to be kept found it meaningful that they were keeping that promise. Caregivers who focused on the changing relationships with their spouse expressed how much their relationship still meant to them:

And I apply that same kind of thing with this caretaking business. You know, what was it all about? Well, my marriage. This is, this was a sacrament to me, so and, and not just the good days, but in sickness and in health (2 years of caregiving)

We were so good to each other, and so there's no way I could do anything else but be good to her and take care of her. [...] Why should it change because that person is sick? (1 year of caregiving)

Husbands, distinctly, reported finding meaning in being able to return the love that they had received during their married lives. They told stories of how their spouses had been wonderful wives, mothers and women, who not only took care of them and their families, but also significantly impacted their lives. While they would not have asked for this situation (that is, the spouse's dementia) to befall them in their later years, they were still thankful to have an opportunity to give back to their spouse:

And it just seems that this is an opportunity. Most days I look at it that way. To uh, I shouldn't say pay her back, but I guess you know it's an opportunity, to return the love, and the care that I, I've been on the receiving end [of] from this wonderful woman. (4 years of caregiving)

When meaning stemmed from caregiving, it was related to personal growth they experienced in caring for somebody else, putting that person before themselves. They embraced the changes in their lives as a result of dementia caregiving, perceiving it to be meaningful; they felt good about what they were doing. Some also experienced changes in their philosophy of life or what they found meaningful in everyday life.

Well, I think we have a purpose in our heart we want to grow, you know. We want to learn. I don't, I don't want to be what I was ten years ago or 5 years ago or a year ago. (chuckle) You know, I want to grow in my faith and it takes the things around us, the trials and the tests to, you know, make that growth work and bear fruit, you know. (9 years of caregiving)

At least some of the meaning I find in caregiving is the opportunity to recognize my strengths and to identify those areas in which I am growing in this time of our lives. That seems a little 'me' focused and it certainly is not all about me but at the depth of my being that is what I am thankful for in this process. (14 years of caregiving)

#### 3.2. How caregivers found meaning in caregiving

The second research question (regarding how caregivers found meaning) was more challenging for the caregivers, because most were not consciously seeking meaning but rather found that it emerged as part of their journey. As one caregiver said: "It's just my existence. I haven't really looked for meaning." Strategies for how caregivers found meaning were accepting the situation, deciding to care, choosing a positive attitude, focusing on the blessings, and actively seeking resources.

#### 3.3. Accepting the situation

Accepting the situation meant accepting the disease, dealing with changes in their plans, and adjusting to their own (or their spouse's) limitations. It also meant accepting that there would be ongoing and unpredictable changes in many facets of their lives:

It's basically [that] you've got to admit that you're defenseless against the dementia. [...] Well, obviously she is not the cause [of the disease], so what it is, is my resistance to just accepting what's going on. You can't, there's, there's no way you win against the disease. So the sooner you surrender, the sooner you accept that, the easier it is to do the rest of it. [...] have no expectations, it'll be what it is. If you think, well, now, because there's these plateaus and you think, Oh man, I've got it. All I've got to do is lay out the clothes, get this, and everything will be cool. It's just no. It doesn't happen that way. (12 years of caregiving)

### 3.4. *Deciding to care*

As a part of accepting their realities, caregivers made a deliberate decision to care for the spouse, despite the expected hardship of dementia care. It was something they wanted to do, and by believing that their decision was a choice rather than an obligation, they were able to take the initial step of adopting a positive attitude towards that decision:

First it was a question of do I want to do it or not. I solved that one. So that gave me the meaning. Second one is okay, I'm going to be a good husband and not a caregiver. (12 years of caregiving)

### 3.5. *Choosing a positive attitude*

Having made the choice to care for their spouse, these caregivers realized they had a choice in how to view their situation and they could choose to reframe their view of the situation if they wanted. They also realized they did not have control over their spouse's dementia so they would need to focus on what they did have control over. In this way, they learned to be at peace:

Because bitterness does grow, and I could be very resentful, I could be very bitter. But I can't, I'm not going to be, you know. I have a choice, I have a choice. How is my attitude going to be, you know? What is my motive for the day? (9 years of caregiving)

### 3.6. *Focusing on the blessings*

By accepting their situation and choosing a positive attitude, these caregivers were able to see beyond their loss and focus on their blessings instead. These attitudes were expressed as being thankful, being optimistic, feeling blessed, focusing on the positive, taking joy in the moment and finding humor in things:

I learned that life does go on and you don't even think about it after a while because you, you find good things. I think anything that makes you stronger and gives you experience lets you know that this isn't the end of the world sort of thing, you know. And that you might as well enjoy each day while you can. You can appreciate the more simple things of life, you know, the less complicated things. It's like, Stop to smell the roses. (9 years of caregiving)

### 3.7. *Actively seeking resources*

Caregivers actively sought strength, resources, and support to continue care. Examples include participating in support groups or research studies; learning to accept and actively seek help or respite; reading on dementia to learn what to expect; and trying to maintain other interests such as gardening, religious meditation, or singing in a choir. These were deliberate activities caregivers remained engaged in to maintain balance in their lives. Learning to accept help was not easy for most caregivers, because they were not used to being dependent on others. Social support involved informal support from family and friends or more organized support, such as that provided by hospice or church organizations. The support or comfort caregivers got from their spouses, however rare or spontaneous, was especially important to them:

First of all, joining a support group is very, very helpful. I don't know what I would've done without mine. [...] I made friends with one couple and we used to meet at the mall at first, and we would walk, have lunch at the food court. You don't have to worry about if maybe he uses the wrong fork or takes his knife and, ah, puts jelly on chicken, or whatever. (2 years of caregiving)

Use your support, whatever support you can find, um, that's available to you. [...] Um, oh, be a part of every community. Be outgoing. If you're not outgoing, become outgoing. Um, maintain, maintain as many, maintain all positive relationships that you have as difficult as it may be at times. (8 years of caregiving)

### 3.8. *Common caregiver characteristics*

In addition to adopting these strategies, caregivers had several common characteristics: altruistic values, the discipline and determination to live their values, faith, love, and the ability to derive strength from past challenges.

#### 3.9. *Altruistic values*

Caregivers were altruistic, and this often stemmed from their religious faith or upbringing reflected in quotes such as: "Well, I was raised in a family that way...then my time in the military...So it's a way of life for me" (male: 10 years of caregiving). Because these values were embedded in their way of living, caring for a person with whom they have spent most of their lives was important to their existential meaning:

Putting somebody else ahead of myself. Yeah. To lay my all on the altar of sacrificing myself, you know. I mean, that's just what is required of us. And to say, "Not my will, but Thine be done." And every day, you know, "Lord, not my will, but Thine be done." (9 years of caregiving)

#### 3.10. *Discipline/Determination to live their values*

Having the discipline and determination to live according to their altruistic values was also a distinct common characteristic of these caregivers who found meaning. This was expressed by caregivers as the determination to do something about life's difficulties rather than worrying or simply doing nothing, meeting challenges rather than avoiding them, pushing on in the midst of difficulties, and taking 1 day at a time rather than being overwhelmed by worries of an uncertain future. This was expressed in comments such as, "I don't see myself just running away. I, I've not done that." or "Just dive in. Dive in. Just meet every challenge with as much gusto as you can."

#### 3.11. *Faith*

Determination to live their values may be explained by the caregivers' commonality of having a faith. Although most of the caregivers were not actively involved in religious organizations, caregivers reported that the values of their Christian faith tradition enabled them not only to see their decision to care as being meaningful but also to find the strength to carry out this decision. Through their faith, caregivers were able to trust that things were in the control of a higher power. So they were able to have hope, lean on the higher power for strength, and view caregiving as an opportunity to grow. Praying or prayer support from others was also important in their lives:

But, if you really live your faith, God never leaves you. He's with you and He's with you while you're caretaking or not caretaking. And you might even have an opportunity to see Christ in the person that you're caring for, whether that be a friend, a spouse, my mother [...] I'm not in charge of this, God is. And I'm just one of God's children trying to [live], whether I'm sitting in the prayer garden or tending to my husband or myself or whatever. That's the point I'm making. It's that some, that people have something to believe in. (2 years of caregiving)



### 3.12. Love

In relation to altruistic values or faith, caregivers commonly said love for their spouse was the reason they were able to find caregiving meaningful. Compassion and empathy for the spouse led caregivers to treat the spouse with dignity and to be sensitive to the spouse's feelings. This was true even when the spouse was no longer as aware of things as the dementia progressed and the caregiver could no longer be sure of what the spouse was feeling:

It's the compassion, the empathy, the just, you know, just such feeling, I can't describe it. And I want to make my husband as comfortable as possible and to make him, his life as easy as possible, you know, because I know that it's so frustrating for him not to be able to express what's on the inside of him, you know. [...] I just understand that he needs me. And I want to be there, I want to be here. Can I say any more? (9 years of caregiving)

### 3.13. Ability to derive strength from past challenges

Each caregiver seemed to derive strength from their experience, education, career, or upbringing. They actively searched for inner strength from their past lives with a confidence that they would be able to get through them. With this in mind, the difficulties of caring for a spouse with dementia could be faced as a new challenge rather than as a burden:

I try to remember all the things that happened to me and maybe there was a time when I dealt with some terrible tragedy. And people forget how strong they are, they really do, so I try to look back on all those other things that may have happened and how I handled it and did I learn anything from it and can I now apply it to this very tough job of being a caretaker? (14 years of caregiving)

### 3.14. Changes from finding meaning

In response to the third research question (regarding any changes in the caregiving experience due to finding meaning) caregivers expressed the notion that finding meaning helped them feel more peaceful:

I'm more relaxed. I don't worry. I guess I'll always be a worrier, but I don't worry as much about what's going to happen to us. I, I know that we're doing the best we can, and, and we still have good moments. (4 years of caregiving)

Many caregivers also expressed a sense of personal growth or broadening in their relationships with their spouses, in their life views or life focuses, or in the existential meanings of life. These caregivers demonstrated transcendence as defined by [Acton and Wright \(2000\)](#): a deeper understanding of the self and a deeper connection with others or a higher power, as a result of caregiving. Personal growth was related to putting another before the self:

It's a growing experience, you know. A changing experience. [It] makes you really care for somebody and [in] a lot of ways you might not if you were both on your own tracks, you know. You learn to try to understand what, what, where they're coming from. And that's very broadening, really. (3 years of caregiving)

## 4. Discussion

[Frankl's \(1959\)](#) theory of finding meaning in difficult situations is based on the idea that though one may not always be able to choose one's own circumstances, one can certainly choose the attitude that one takes to face those circumstances. The 11 caregivers interviewed in this study also made an initial choice to care for their loved one, and to take on an attitude that would make their experience meaningful.

Thus, they were able to experience acceptance, peace, changes in their focus of everyday living, personal growth and a richer view of life. Similarly, in other studies of caregivers of people with dementia, strategies such as living for today (rather than worrying about the future) and making the best of things were seen as a conscious decision to make life as meaningful as possible in the time given, rather than denial or minimizing the inevitable future ([Hellstrom, Nolan, Lundh, 2007](#)).

Although each caregiver's situation and circumstances made each of their experiences unique and different, their responses to the three research questions were similar. An important commonality of the caregivers in this study was that they were determined to live the values they believed in, and to apply those values in deciding how to treat the other or deciding how to best honor their marriages. For instance, caregivers explained how their ethics or moral values were the basis for the choices they made related to caring for their spouse. Valuing something involves an intentional act of upholding one's beliefs of something independent of the self, and it also reaffirms the individual's own sense of self-worth ([Jaworska, 1999](#)). As an individual's true meaning in life is determined primarily in relation to other people or the world surrounding the individual ([Frankl, 1959](#)), valuing someone or a cause is what gives meaning in life.

### 4.1. Implications for practice

In the current study, one of the caregivers expressed that the thought that caregiving could be meaningful or positive did not occur to them until hearing the researcher's short recruitment advertisement at a caregiver support group meeting. The caregiver commented that by rethinking the caregiving experience after hearing the advertisement, the positives in the experience suddenly emerged and caregiving felt meaningful. The caregiver called the researcher a month later to participate in the study. Other caregivers said that the interview itself helped them to reflect and realize just how much meaning they found in their caregiving experiences. This suggests that introducing positive stories and outlooks into the caregiver's world may be what is needed to trigger a positive perception. Future interventions using this approach may prove useful to caregivers struggling to find meaning.

[Frankl \(1959\)](#) suggests that a person can take responsibility for what he or she makes out of life by trying to rise above their challenging situations. The basis of Frankl's idea is the assumption that, even if the meaning itself is (yet) unknown, there definitely is a significant meaning to be found in an individual's story. Helping caregivers choose a more positive attitude and nurturing the belief that there is significant meaning in the caregiving journey can be a pivotal role of the nurse who interacts with caregivers of individuals with chronic conditions. Helping caregivers come to a realization of a special meaning in the caregiving experience is beneficial not only to the caregiver, but also to the care recipient as the caregiver's attitude toward caregiving can have a significant influence on the attitude toward the care recipient.

Further, these findings also provide a thoughtful insight in nurses' attitudes toward their own caregiving of clients, as nurses are 'caregivers' themselves. In a study by [Rhoads and McFarland \(2000\)](#), paid caregivers caring for seriously mentally ill individuals reported that caregiving gave their lives meaning, self-fulfillment or a sense of self-actualization. This study affirms the experiences of many nurses that even without a previous positive relationship (or indeed any relationship) with a care recipient, caregivers can still find meaning in the act of caregiving. As nurses, finding meaning in nursing care may be a critical component of the quality of provided care, satisfaction in the job, and to some extent, personal growth, as each client affects the nurses' lives and changes them. When the job gets challenging, it may be important for nurses to remember that there is an everyday choice to the attitudes they take and it is possible to find personal

meaning in their nursing care with each individual client. The strategies reported by the caregivers may also be helpful reminders and tips for nurses to help maintain a balance in life.

#### 4.2. Limitations and direction for future research

The study results suggest some common characteristics and attitudes among caregivers that enhanced their ability to make their care experiences more meaningful or positive. Although caregivers of this study were self-selected and mostly of a homogeneous racial group or geographic location, strategies such as accepting the situation, choosing a positive attitude, focusing on the blessings or actively seeking resources could be helpful to any caregiver. Altruistic values, having the discipline to live those values, faith and love may be important characteristics to any individual regardless of age, gender or race. Investigation of the differences between different cultural or racial groups could be a fascinating look into getting a better understanding of diverse perspectives on how people find meaning in challenging situations. As perception and meaning can change with time, longitudinal interviews across the course of caregiving are also recommended to provide a more complete picture of the process of change.

#### 5. Conclusions

Sharing positive stories of caregiving like the ones in this study with struggling caregivers may inspire hope or help them to reframe caregiving as a meaningful experience. Caregivers in this study reported that meaning in caregiving can provide satisfaction, thankfulness and personal growth to the caregiver. This seemed to translate to the quality of care provided as caregivers showed a high level of love and empathy towards the care recipient. To quote one of the caregivers: "Not (to) overlook the negative aspect, but (if) all you hear is caregiver stress and this and that, if that's all you hear that's what you'll expect. But there are humorous times. There are positive things, and an opportunity to give back. So people should know that." As suggested by this quote, the results of this study can be a basis for developing interventions for caregivers find. The strategies and attitudes of the caregivers in this study can help struggling caregivers feel that they have the power to shape their experience and adopt a more positive attitude towards caregiving and nurses can play a pivotal role in introducing and encourage them to those in need.

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