

“I Do It With Love”: Engagement in Caring for People With Dementia

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Abstract

For caregivers, the impacts of caring for their loved ones with dementia at home are complex. The purpose of this study was to gain understanding of the meaning and experience of engagement for caregivers of individuals with dementia living in the community. Participants are from a culturally diverse population of low-income caregivers and care recipients in the northeastern United States. We conducted in-depth semi-structured interviews with caregivers ($n = 17$) who were caring for parents, friends, or other relatives with dementia. We used interpretative phenomenological analysis and identified the superordinate themes of connectedness, meaningfulness, acceptance, and vigilance. We conclude that caregiver engagement is a multidimensional phenomenon, with some dimensions being contextual and specific to caregiving. It is a relational concept, referring to a committed, vigilant, and meaningful relationship of caregivers and care recipients as active collaborators. The different aspects of engagement can complement each other, or they can be in contradiction.

Keywords

caregivers / caretaking, dementia, health, lived experience, well-being

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Globally, dementia is a primary cause of disability and dependency among older adults, with high emotional and financial costs for families and nations (World Health Organization & Alzheimer’s Disease International, 2012). In the United States, an estimated 5.2 million people have Alzheimer’s disease, and one of seven people above age 70 have some type of dementia (Alzheimer’s Association, 2014). Approximately 60% to 70% of people with dementia live in the community, and more than 15 million family members and friends across the United States provide unpaid dementia care (Alzheimer’s Association, 2014).

For caregivers, the impacts of caring for a loved one with dementia at home are complex and contradictory. Negative consequences for caregivers, such as increased stress, depressive symptoms, and caregiver burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Chiao, Wu, & Hsiao, 2015), have been extensively studied. Despite the challenges, caregiving also has fulfilling aspects, such as enhanced meaningfulness of relationships, a sense of purpose and pride in the caregiving role (Cohen, Colantonio, & Vernich, 2002).

Engagement in Caring

Engagement of Health Care Providers and Caregivers

The state of “engagement” in one’s activities can be protective of well-being. In the tradition of job-related burnout studies, engagement is sometimes conceptualized as the opposite, or an “antithesis” of burnout (Maslach, Schaufeli, & Leiter, 2001), with the characteristics of energy, involvement, and efficacy. Others see engagement as its own construct, still in contrast to burnout, but with its specific dimensions of vigor, dedication, and absorption (Bakker, Schaufeli, Leiter, & Taris, 2008; Schaufeli, Bakker, & Salanova, 2006). Work engagement is considered to be

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associated with well-being, including higher morale, task performance, and other job-related outcomes (Bailey, Madden, Alfes, & Fletcher, 2015), with personal accomplishment, psychological well-being, and mental resources (Kanste, 2011); as well as with prediction of future work ability (Airila et al., 2014).

Engagement also has a significant history in the health care literature, where one direction of research has been the work engagement of health professionals, which shows positive associations with indicators of staff well-being (Kanste, 2011). Another direction of research has focused on patients' engagement in their own health care (Center for Advancing Health, 2010). Definitions of patient engagement vary and can refer to a combination of access to health care, adherence to guidelines, participation in decision making, communication with health professionals, and self-management (Bright, Kayes, Worrall, & McPherson, 2015). Often "engagement" is conflated with the concept of "patient activation," and some studies use the two terms synonymously (Greene, Hibbard, Sacks, Overton, & Parrotta, 2015; Gruman et al., 2010).

A recent conceptual review (Bright et al., 2015) of engagement in health care and rehabilitation concluded that the existing literature conceptualizes patient engagement as both a process (engaged with) and a state (engaged in). While the activation-related definitions place the emphasis on the individual, this definition as well as that by Naylor et al. (Naylor, Hirschman, O'Connor, Barg, & Pauly, 2013) constructs engagement as a relational concept involving multiple actors in the context of a holistic system.

While patient activation/engagement has been a rich area of research, there has been little application or adaptation of this concept to caregivers, nor research that explores this concept directly. Some examples are available, however, ranging from the development of an overarching framework which delineates the forms, levels, and influences on both patient and family engagement (Carman et al., 2013) to analysis of the caregiver engagement in decision making in a very specific clinical encounter (Boehmer et al., 2014).

One approach adapted in the assessment of caregiver engagement has been to see it as analogous to patient activation. For example, Pennarola et al. (2012) introduced and explored the concept of "parental activation" as a distinct construct—specifically in parents of children undergoing hematopoietic stem cell transplant (Pennarola et al., 2012). A similar approach, in which the measure for caregiver engagement was derived from the patient instrument, was utilized in the case of patient and caregiver engagement in heart failure care (Lee et al., 2015).

Engagement of Caregivers for People With Dementia

Focusing specifically on caregiver engagement in the case of dementia care, we identified several approaches. One has been to assess the extent to which caregivers are

involved in supporting the engagement of the patient in activities of treatment. For example, Toms et al. explored the meanings of the phenomenon "self-management" by interviewing both people with dementia and their informal caregivers. The findings indicate that the participants construct "self-management" as a relational process "between us," as well as within their family and social networks (Toms, Quinn, Anderson, & Clare, 2015). Hampson et al. describe a program designed to train caregivers to engage the person with dementia in daily occupations (Hampson & Smith, 2015).

Another approach is to focus on the engagement of caregivers themselves. Our mixed-methods project conceptualized engagement as a state, informed by the Utrecht construct (Schaufeli et al., 2006), and concluded that caregivers' engagement is key for caregiver well-being—it is directly associated with reduced burden and depressive symptoms for the caregiver, and also attenuates the effect of the patient's problematic behaviors on burden and depressive symptoms (Sceppa, Todorova, Jamal-Allial, Turner, & Bonner, 2015). Others have looked at caregivers' engagement in interventions, and concluded that "active engagement" of caregivers is associated with reduced depressive symptoms (Elliott, Burgio, & DeCoster, 2010; Schulz et al., 2003). "Therapeutic engagement" was assessed with a provider-rated measure that focuses on the relationship between caregivers and in-home providers. This study characterized engagement as caregivers' degree of openness, involvement, and connectedness mainly with the provider and with the intervention (Chee, Dennis, & Gitlin, 2005). Another group focused on adherence to the prescribed strategies of an intervention (Chee, Gitlin, Dennis, & Hauck, 2007), and concluded that active engagement of caregivers was associated with adherence.

Caregivers occupy a liminal position, and thus do not exactly fit in existing definitions and assessments of engagement. They are not the designated patients when in their caregiving role (though they may be patients concurrently, or may become patients as a result of the burden of caregiving). They are also not exactly employed health care providers, even though they can be working full-time on the task of caregiving. Few caregivers consider the activities with their loved ones as "work" or a "job" (Sceppa et al., 2015); yet, the physical, cognitive, and emotional demands of caring can be significant. Their position relative to the work of caring can be further complicated in programs in which caregivers, while still caring informally and at home, receive some compensation for carrying out these activities. In addition, cultural meanings and attitudes toward dementia differ considerably (Scotland, 2015). Therefore, understanding and describing the meaning of aging, caregiving, and caregiver engagement, as well as caregiving strategies in different cultures and communities, are important for acknowledging diverse experiences and designing effective caregiver support programs.

In summary, explorations of what engagement means and how it manifests specifically for caregivers are limited in the existing literature; engagement is often explored as analogous to patient activation/engagement. Thus, an in-depth exploration of what “engagement” in caregiving means for caregivers of individuals with dementia is warranted.

Purpose

We envisioned and designed the Vital Outcomes Inspired by Caregiver Engagement (VOICE) project through a collaboration between Northeastern University and a long-term services and supports (LTSS) organization in northeastern United States. This organization provides in-home care and support for family caregivers of older individuals with dementia and other chronic conditions, and serves a large number of individuals with limited financial resources and of ethnic minority status. These services are financed primarily through Medicaid waivers. The program offers financial support to informal caregivers who are caring full-time through a live-in arrangement, as well as the support of a registered nurse and a care manager (Sceppa et al., 2015).

The VOICE project seeks to provide a better understanding of the needs and interactions among care recipients, their informal caregivers, and staff (nurses and care managers), to provide recommendations to improve the well-being of people with dementia and their caregivers. The needs assessment used a participatory approach, involving staff and caregivers who shared their opinions and recommendations. The larger VOICE project uses mixed-methods research, which included in-depth interviews and structured surveys with staff and informal caregivers. Qualitative research is particularly appropriate for exploring the experiences of people with dementia and those who care for them, and for addressing the gaps that exist in our understanding of their needs (Carmody, Traynor, & Marchetti, 2015).

In this article, we focus on the experiences of the informal caregivers who are caring for someone with dementia. The objectives of this part of the qualitative component of the VOICE project were as follows:

- To understand caregivers’ experiences of caregiving—their perceptions of challenges, caregiver burden, and fulfillment in the context of cultural meanings and values of caregiving;
- To gain an in-depth understanding of caregivers’ meanings of “engagement”;
- To invite recommendations from caregivers for programs and policies.

In addition, the qualitative study aimed to inform

- the development of the surveys (for assessment of stressors, protective factors, and well-being outcomes);

- the design of a VOICE pilot training program intervention for staff.

Method

Recruitment and Sample

The Internal Review Board of Northeastern University approved all stages of the study. We visited several locations of the LTSS organization in the northeastern United States to meet with staff and inform them of the purpose of the study; to discuss their role in the study; and to gain important background information about the organization. From the full list of care recipients, we selected clients who have a documented diagnosis of dementia. Care managers called *all* those caregivers to inform them about the study and notify them that University researchers might contact them, without trying to recruit them to the study. Following the care managers’ calls, our team of researchers used purposive sampling to select caregivers to contact and called the selected ones to explain further the purposes and organization of the study. Caregivers were assured that everything they share with the team will be anonymous, that their participation is not associated with their care, and that they can decide not to participate or to stop the interview any time. They were also informed that the staff and management of the LTSS organization did not know which participants the researchers talked to over the phone and which they ultimately interviewed, nor did they have access to the interview recordings or transcripts.

We used purposive sampling to select a diverse group of caregivers from all those who were informed about the study to set up times for the interviews. While the approach of interpretative phenomenological analysis (IPA) which we used often favors more homogeneous samples, in our case we chose to have a sample with ethnic diversity, Spanish-speaking, and both male and female caregivers.

We conducted the in-depth interviews with 17 caregivers; 13 of which were women and four men, and six were in Spanish (see Table 1). Twelve interviews took place in person and four were conducted over the phone. Although the study focused on the experiences of caregivers, we were committed to including the voices of the care recipients when possible (Carmody et al., 2015). In many cases, however, the care recipient was unable to participate in the interview, often because of their later stage of dementia or their absence from the home due to adult day care. Care recipients were present for nine of the 17 caregiver interviews, and we conducted short conversations with seven of them, four of which were in Spanish (with their consent or that of their caregiver). In all but three cases, informal caregiver participants were caring for parents; in the other three cases, participants were caring for a friend, grandmother, or aunt. Due to regulatory requirements, spousal caregiving was not included in the policy of this organization; thus, this type of relationship was absent.

Table 1. Demographic Details of Study Participants.

Characteristics	N
Total caregivers	17
Age	
31–50	8
51–70	5
71–90	3
Missing	1
Gender	
Women	13
Men	4
Ethnicity	
White	9
Latino	6
Black	1
Asian	1
Education	
High school	5
Associate degree or some college	5
College degree	6
Missing	1
Caring for	
Mother	10
Father	4
Grandmother	1
Friend	1
Aunt	1
Language of interview	
English	11
Spanish	6

Interviewing and Analysis

We approached the interview and analysis according to IPA (Smith, Flowers, & Larkin, 2009), as the study aimed to understand the experiences and meanings of caring for the caregivers in the context of dementia. At the same time, IPA posits that the researchers are interpreting what is being said and its meanings. As the authors state, “The participants are trying to make sense of their world, and the researcher is trying to make sense of the participants trying to make sense of their world” (Smith & Osborn, 2003, p. 51). This methodological approach has been used in several studies of the experiences of caregiving for people with dementia (Quinn, Clare, Pearce, & van Dijkhuizen, 2008; Tuomola, Soon, Fisher, & Yap, 2016), as well as with other neurological illnesses (Hunt & Smith, 2004).

We developed a semi-structured interview guide to address the research questions, by including interview questions about the challenges that caregivers face and how they deal with them, what they like and find fulfilling about caregiving, and what resources they use as support in this role. Before starting the interviews, we obtained informed consent, including specific consent to audio record. The interviews with the

caregivers were open ended and flexible, and lasted between 30 and 90 minutes. We stored the audio-recordings on a secure server, transcribed them verbatim, translated them from Spanish to English when necessary—with the help of a professional company. We removed all identifying information during the transcription.

The analysis was supported by the qualitative data analysis software Atlas.ti (Muhr, 1997). We started the analysis through several overall readings of each transcript (by the first and second author). During the initial readings, we made notes about content of the transcripts that were close to the text, and then identified codes that were more descriptive and concrete. We continued with the interpretation of each interview and identified higher-order themes and sub-themes. The first and second author met regularly to discuss the codes as well as the higher-order themes that we were identifying. We did the same with each transcript, after which we focused on themes that were relevant and important across transcripts. In the following steps, we clustered these themes, which led to an identification of superordinate themes across cases and further abstraction and theorizing. The whole research team met periodically to discuss and verify the codes and themes of each transcript, as well as to finalize the structure of themes and sub-themes across interviews.

In the full analysis of the caregiver interviews, we paid attention to the overall experience of caregiving—we identified themes relevant to experiences of challenges and supports, burden, and fulfillment, in the context of cultural meanings and values of caregiving. For this specific article, however, we present a detailed and focused examination particularly of the ways in which the concept of “engagement” is manifested and the meanings that it takes on in the narratives of the caregivers. The published literature has a variety of definitions of engagement (Bailey et al., 2015; Macey & Schneider, 2008; Schaufeli & Salanova, 2011) which we were aware of, and they served to guide our interpretation of “engagement,” particularly those that see it as a co-constructed process and state that enables health professionals, caregivers, and clients to be active, committed, and invested collaborators in health care and invested in meaningful relationships with each other (Bright et al., 2015). However, we approached the analysis of the interviews predominantly inductively with a broad understanding of what engagement might mean, to be open to unexpected meanings and understandings. This inductive approach allowed us (to some extent) to set aside existing theoretical constructs and definitions of engagement and leave the meaning open to the voices of the participants, while still setting boundaries for what constitutes “engagement.”

Dimensions of Engagement

The major (interconnected) themes and subthemes we identified are listed in Table 2:

Table 2. Overarching Themes and Subthemes Identified Through the Interpretative Phenomenological Analysis.**Overarching Themes and Subthemes**

Connectedness: Being with each other

Attunement

Transformation of self and relationship

Meaningfulness: Finding and creating meaning

Love and happiness

A gift, a privilege, a responsibility

Acceptance

Vigilance

Providing daily care and safety

Interacting with health providers and the health care system

Caring for the caregiver

Connectedness: Being With Each Other

And mom and I'll have conversations, which I'm very, very grateful for. We'll sit and we'll talk back and forth. (Woman, age unknown, mother)¹

Connecting with the loved one for whom the caregiver is providing care is a key experience of engagement. Caregivers often saw the opportunity to forge or sustain this connection as the essence of what gave meaning to caregiving. The relationships were complicated, anger and arguments happened, and both sides could initiate them, but connecting gave meaning to caregiving even if it fluctuated. The relationships were also not always equal or reciprocal, and varied with time, with the severity of dementia, and with other events in their lives.

There were examples in which the care recipient was the one looking for togetherness, while the caregiver was trying to avoid it, wanting to be alone for a while, to do activities with others, or just to disengage. This could happen at night, for example, when the caregiver was trying to carve out some time to be with other members of the family and take a break from caregiving:

And she comes and sits here, to watch some TV. She doesn't like watching TV by herself, which is weird. We want to watch TV by ourselves so we can get away. She says it's more fun watching with people who she can talk with. (Man, 31–50, mother)

Most of the stories were about the caregivers themselves finding satisfaction in connecting with their loved one, no matter what the level of cognitive decline. They found the connection meaningful and fulfilling, and it took on different forms depending on how the recipient was able to communicate. When there was time and the caregiver was not tired, sitting around and sharing stories, stories about the past, including stories which they did not know about each other, was a special treat.

Yeah, we talk about a lot of things [when we are together]. We talk about her—she had brothers and sisters, she's the only one left in her family, and so we'll talk about that and where we used to go in the summertime, my grandmother. Her father was an architect and we had a shore cottage and a place on the lake in . . . , which we all adored and we grew up going there in the summers, and so it meant a lot to all of us. And so we'll just talk about . . . oh my gosh, remember the shore cottage and this and that. So she remembers all that. (Woman, 71–90, mother)

A different type of closeness could develop at these times, as the two people now had fewer external activities and spent much more time together.² Even when they did go out of the house or meet with others, if the loved one was able to, they did so together. Friendships developed—as one participant said about his mother, “She's my pal.” Listening was meaningful in itself, but it also led to understanding. Many of the caregivers talked about how they had grown to understand their loved ones, as well as to understand the disease and separate the person from the disease.

Attunement

So we just have to, you have to change how you'd say things or how you do things . . . (Woman, 31–50, mother)

We refer to “attunement” as a specific nuance of engaging through connection with each other. We identified this dimension of engagement when the caregiver spoke of just being together and understanding each other, often without words. It is a sense of resonating with the other and interpreting their needs and what they would like to express, even in cases of more advanced cognitive decline when direct expression was compromised. In these cases, caregivers and care recipients communicated in ways that were unique to the dyad, that they could understand. The caregiver met their loved one where they currently were with their forms of communication and their needs. To do this, they needed to be closely engaged, attuned to the feelings, behaviors, and unspoken requests of the care recipients:

Sometimes from the daycare, he brings a [puzzle], like a word search. On Thursday he said, “mija, do that for me, it's homework” and I say “no, no, let's do it together.” And I searched for the word. It's not easy for him because he's never done it, but he looks and searches on the paper. [. . .] We call it his school. He'll say “I'm going to school now.” And I'll remind him that it's on Tuesdays and Thursdays. We call it school because it's very difficult for him to pronounce the word “daycare.” (Woman, 31–50, father)

Relationships changed in different ways during the years of advancing dementia and caring for the loved one with dementia. Participants shared many examples of how they felt the connection got lost, or how, though transformed, they found alternative ways of communicating and listening to their loved one. Caregivers adjusted to the new ways of

interacting and understanding each other, needed in light of the changing cognitive or physical status of the care recipient. Some caregivers argued that this attention to the new ways of communicating was important to sustain their loved one's health and limit further decline in well-being—and was one reason they insisted on caring themselves, and thus ended up not taking any breaks from caring.

Caregivers also learned to read the recipient's state and to know what would help them calm down if agitated, what they like and dislike, or how to coax them into a certain behavior they did not want to do (such as eating and showering). For example, some caregivers went to bed early and got up very early in the morning, to be in tune with the sleep rhythms of their loved one. In general, they sensed and adjusted their schedule to what the care recipient needed.

Transformation of self and relationship. While some experienced caregiving as natural continuation of their previous lives and relationship, even if there was a change in living arrangements, for others it was a transformative experience in the direction of increased connection. Several caregivers felt that the new situation of caring for their loved one had helped them get to know that person better and learn about their stories in a way that their day-to-day lives previously had not. Others perceived caregiving as having had a strongly transformative impact on the nature of the relationship, and having dramatically redefined both the caregiver and care recipient identities.

One caregiver shared his interpretation of how the love embodied in the caregiving transformed his mother (who he had previously seen as a cold and depressed woman), as well as their relationship from estranged mother and son, to sharing mutual love and respect. After having decided to care for her, he had to change his perspective about their past, which was strained. They talked about the past, she shared stories which he had not heard before (“She revealed things that she'd never revealed before to anybody”), and thus he made sense of his mother's past:

I just treated everything that she did with unconditional love. And I actually watched as she went through a transformation, where she was acting infantile, childish, as an adolescent young person. And then I watched her behaviors and it was sort of an amazing thing to see. . . . I found my relationship change to that of not having a mother to having a loving relationship with my mother. (Man, 51–70, mother)

While this participant had come to a reframing and ultimately transformation in the relationship and thus in the meaning of caregiving on his own, he also believed and recommended that such shifts can be taught to other caregivers through counseling.

In summary, engagement through presence and attunement helps caregivers to ensure that they are taking the best possible care and to understand what the loved one needs. It

leads to synchronicity and coordination between the caregiver and care recipient, and when relevant, also between other friends or members of the family.

Meaningfulness: Finding and Creating Meaning

So it's scary too. But it was very satisfying. I'm very glad that I did it. I'll be able to sleep good at night. I taught my kids something out of the whole process. (Woman, 51–70, mother)

Being engaged in caregiving also meant being able to find meaning and purpose in it—to make sense of one's own life and identity, as well as to have fulfilling and less stressful connections and interactions with the care recipient. Caregivers talked easily and energetically about the positive and fulfilling aspects of caregiving, some even denied that they found anything stressful or difficult in this role (Scotland, 2015). Often, the meaning found in caregiving was the engagement and connection itself, as mentioned in the first theme.

Love and happiness. When reflecting on the meaningful aspects of caregiving, many participants stated quickly and briefly that what made it meaningful for them was simply love. When we asked the question about what makes caregiving meaningful, some, particularly Latino participants, reacted as if this does not need an explanation, as the answer is self-evident. Some answered very briefly:

I do it with love, it doesn't give me any trouble and my mom is my mom and she'd give her life for me and during her life span she worried about me and now I have to care for her and I do it with love. (Woman, 51–70, mother)

It's special. I only got one Mom. (Woman, age unknown, mother)

Others also stated that they are caring for the person because they love him or her, and then told more detailed stories about how love manifests itself and what they do together. They talked about the importance of appreciating each moment they could share together, including mundane activities. They experienced these moments as gratifying and they valued them, but they were also bittersweet, as caring could be fulfilling as well as frightening. Caregivers also talked about shared memories and about what makes their loved one happy. The act of caring also often made the caregiver happy, through knowing that the person was safe and cared for, or through cherishing the fact that they could interact with each other:

I saw signs probably about ten years ago, little things. But I didn't really [pay attention]—you know, she was still—and when I came up [to live with her] she was still being in the yard and everything. Once in a while she'll help me, we'll sit on the deck a lot. Yesterday we were on the deck for about three hours.

And she likes the leaves so I put the leaves on a bench, on the chair and then the bucket. And she would take the leaves and rip the leaves and put them in the bucket. Always in the garden—we had the most beautiful garden. Mom had the best garden. Right, Mom? (Woman, age unknown, mother)

She was happy. Yeah she was happy. In her own little world, she was happy. I think with Alzheimer's you lose your mother twice. You lose your mother to the disease and then you finally lose them to death. So it's a process that you go through. I would've loved it if she was able to sit and chat with me and know my name and all that but she didn't. She didn't. She knew I loved her and she was very happy here. My boys would come in. It was familiar. (Woman, 51–70, mother)

Similarly, through brief answers caregivers explained that the purpose of caregiving was simply that the loved one was in the home, and they were together. The fact that they could stay together without having to send the care recipient to a facility, in itself made everything worthwhile. When they stated this, participants did not elaborate, as what they were saying was so clear:

I just like the idea that I can keep her home. That's my biggest thing—that I can share this time with her, because she won't always be here, and I'm blessed that way. (Woman, 71–90, mother)

These statements also carry with them the implied alternative of not “keeping them at home.” People who did not have in their worldview the idea of sending their loved one to a facility³ usually did not attribute the meaning of caregiving as “keeping them at home,” as the fact that they would be taken care of at home was a given.

A gift, a privilege, a responsibility. Caregivers' philosophies of what caregiving means and why it is important varied. For some people, it was a question of morality and that it was the right thing to do; for others, it was the value and appreciation of every moment, as these moments were limited. Caregivers perceived the fact that they could be close to their loved one at this stage of their lives, as a privilege, as a responsibility, as a reward, as a gift, or as a duty:

But she was a great mom. I had to do it. I had to do it. [. . .] I know that I did right by her. And that's what counts. (Woman, 51–70, mother)

And I was lucky in that I saw that, and I considered it my duty and my privilege to honor my mother with unconditional love rather than trying to hold together the old life that I had before. [. . .] I think it was an enormous gift to me. I think if people took this on as something that was the expression of your life, this is it; this happened. You know what I mean? [. . .] But the fact of the matter is, I think that we're all souls and when you have the responsibility for another soul and you can do your best with that, you can rise up and do your best and put your other desires

to some extent behind you, there's a corresponding, almost like there's a built-in reward. There's a built-in benefit that I can only say that I feel that I was privileged to experience. (Man, 51–70, mother)

For others, gratitude to their loved ones (usually parents) and the opportunity to give back for the many years of caring they had received were the main motivations and rewards for caregiving. Some felt that they were repaying for the love and care they received from them. This intergenerational gratitude and appreciation can be associated with cultural values, including the value of familism, particularly relevant in Latino culture (Scotland, 2015).

Well, she pretty much saved our lives, she brought the kids to this country, through that whole civil war. She was strong woman back then. They had to survive, running and escaping with the kids. I think we owe her something. And either that or she's going to end up in a nursing home. We can't really picture that. If she's in this condition in a nursing home, she'd be gone. And that's what her fear is—every time somebody different comes she's like, “Oh,” she's afraid somebody's going to take her away. She doesn't really like that at all. (Man, 31–50, mother)

In summary, creating meaning and purpose in caregiving is a way of engaging with the existential dimensions of caring for an elderly loved one, as well as a basis for further meaningful engagement with the care recipient (and others). Narratives in which caregivers attribute meaningful purpose to caregiving often had a calmer tone, including the way that the caregiver talks about engaging more fully with the recipient during their interactions and appreciating each moment.

Acceptance

You just gotta roll with the punches. (Man, 71–90, friend)

Caregivers expressed acceptance of caregiving and the situation in general through different phrases. Independent of the specific content of the story, these phrases indirectly communicated that they were taking things in stride. Phrases such as “It's just the way it goes”; “You just do it”; “You have to accept it with peace”; “You do what you have to do”; “I'm alright with it”; “It's a part of life”; “It just is and I do it and I don't regret it”; “I do it because that's what needs to be done”—both expressed and constructed the attitude of acceptance. When they reflected on the importance of having their loved one close and at home, being able to make sure they are healthy, taking their medications, dealing with the difficulties provoked by their behavioral and cognitive problems—caregivers talked in a way that acknowledges the difficulties, but accepts the changes brought on by the situation:

[What is important is] that she's here. Yeah, she's here with us. So I'm doing my job to take care of her now. Because that's

what needs to be done. I just do because it's what should be done. So that's me, though. That's how I've always been. It's just like with anything. Like I said, at least I know and I feel better that I know that she's taking her medications, she's doing what she needs to be doing, and at this stage of where she's at and what happened with her, I'm thankful for every day that she's here. (Woman, 31–50, mother)

It doesn't—it's just a part of life. I don't get angry about it, I just do it. That's how it's supposed to be, I think that's the way it should be. So I don't—but it is tiring. (Woman, 31–50, mother)

Another dimension of acceptance had to do with how participants experienced the caregiver role. The person who had taken on the caring had sometimes done so as there was no one else around, or no one else was willing. In other cases, there were other relatives, sometimes multiple siblings—but the person caring often felt that they were the ones who were meant to do it. They explained why it was them in particular—they explained it with their personality and attitude (e.g., ability to be patient); their profession (several of the caregivers also had helping professions); previous caring experience (of their own children or other relatives); or the sibling order (being the oldest):

I've just always been the caregiver, being the oldest, so I've always been the one that takes care of everybody and everything. So I don't, I mean, for me, having my mom here with me is better than any place she could be. [. . .] I think it's been instilled in me to always be the caregiver, since I was a little girl. So I can't not be taking care of everything at all times. I can't not know what's going on at all times, because I feel like I always need to make sure everything's okay, all the time. My husband wonders how I haven't had a heart attack yet. (Woman, 31–50, mother)

When the participants accepted their role as caregivers, they dealt with the specifics of dementia. Through the years, they learned an acceptance of the disease and of the progression of dementia:

Then came the dementia. At first it was good because we said why should we put mom in a home, it's better that I take care of her here in the house. So we've been taking care of her. And all is well. Sometimes there are difficult days but we bear it. (Woman, 31–50, mother)

They also made many adjustments in their daily lives, which needed to be changed periodically as the disease progressed. They adjusted what they themselves did, or the ways their family lived their daily lives, to be synchronized with the care recipient. One caregiver gives an example of a small change in the way she cooks the food, and reflects (and accepts) changes in general:

I do bland my food now, I don't put spice in it, because she can't eat that. But it's not, it's not an inconvenience. We just put spices

on it after, you know what I mean. So it's not a big deal. So you just need to cater and change things a little bit and the littlest thing sets her off in a different direction. So we just have to—you have to change how you'd say things or how you do things. (Woman, 31–50, mother)

It's just you've got to take each day at a time. There's no pattern. There's no two days exactly alike. There might be, but I don't know what it's gonna be when he gets home today. He may be very nice. He may be all nice all night. No arguments, nothing. You never know. But you have to be ready. (Man, 71–90, friend)

In summary, acceptance, of both the disease and that they are the ones who are chosen to be the caregivers (because of their personality, profession, previous caring experience, attitude), is experienced as a dimension of engagement. Acceptance supports engagement—specifically the ability to meet the recipient where they are—rather than arguing with the situation and fighting the consequences of the disease. According to the participants, acceptance promotes calmness for both themselves and the care recipient, and thus is a way to make sense of the situation.

Vigilance

Providing daily care and safety. Engagement in the tasks and routines of caring, in addition to engagement with the care recipient, is another theme that we identified. In making the decision to care for their loved ones at home, participants had committed to dedicating a significant part of their time and daily schedule to the needs of the care recipient. This included ensuring a predictable daily routine in which they completed all the everyday tasks, monitored treatments and medications, examined new symptoms, and ensured safety. The routine provided predictability for both the caregiver and the recipient and unexpected situations were less stressful within the structure of the routine; some caregivers underlined that they tried not to deviate from this routine. At the same time, caregivers often pointed out, one never knew what would happen—what behavioral, emotional, or physical challenges would arise at any given moment—and thus they tried to “roll with the punches.” One participant alluded to the ongoing unpredictability of caring for people with dementia: “Just listening and watching him, waiting for what comes . . . cause you never know” (man, 71–90, friend). Whether sustaining the routine or mitigating surprises and emergencies, it was clear that caregivers were highly dedicated to their role and to the details of care. They were determined to keep their loved ones at home, and thus were dedicated to making that experience as happy and safe as possible:

On a typical day, I get up, she gets up. I make sure she washes her face and brushes her teeth. I go with her to the bathroom, make sure she bathes and after that then I make her breakfast. After I make her breakfast, I give her her medicine and we sit

together to talk or watch television. And like that we pass the day. If she gets anxious, I go out with her to visit someone. Afterward we come back here, when I get back I cook, and that's it, we come back, we eat, after we eat, we sit to watch television. (Woman, 31–50, mother)

In other cases, however, it was more appropriate to assert their position and insist that the care recipient do a particular activity that they were avoiding (e.g., taking medications) or not continue to do a particular activity that might be unsafe (e.g., cooking). This also required patience and persistence on repeating what they felt needed to be done, especially if the care recipient was forgetting or resisting.

And then I had to bring her home to take care of her when she just doesn't take care of herself. She won't—well, she'll feed herself if it's junk food, she'll sneak stuff. But she doesn't make food, so I have to make her meals and food. I make her take her medication. She won't do that unless I give it to her to take in front of me. She doesn't remember certain things she does or says. She's at that stage now—we'll see her do something that she shouldn't have done and question her on it, and she'll be like—I didn't do that, when it just happened like three minutes ago. (Woman, 31–50, mother)

Clearly, the safety of the care recipient was a primary concern for the caregivers, and they were constantly vigilant about their status and behaviors. While most did put a lot of value in also ensuring the happiness and psychological well-being of their loved ones as described above, others really highlighted the importance of physical safety. This vigilance was a form of intense engagement in the care, which thought very important, also took quite a toll on the caregiver:

But I think the hardest thing is the time restraints and responsibility for taking care of any elderly person or disabled person, it's that constantly weighing in the back of your head, did I do this, did I forget that, did she take her pills, I think that's what's wearing on caregivers. (Woman, 71–90, mother)

They experienced the vigilance as also entwined with ongoing fear because of the potentially dangerous outcomes of some situations, or fear that they would not be able to manage with the responsibilities and the expectations:

But there were many times that I was afraid when I couldn't lift her up. One time she just let go and sat down on the floor. I couldn't get her up by myself. Luckily my son was here. So it's scary too. (Woman, 51–70, mother)

Interacting with health providers and the health care system. As part of managing the health needs of the care recipient, caregivers often interacted with health care providers and the system in general. They felt that they needed to be adequately informed and spent much time collecting information about dementia as a disease, and about caring for people with dementia:

His doctor said, "I think he's coming down with dementia." And I'm like, "What? What is that?" So I did a lot of research on my own, read tons of books. I took four classes on Alzheimer's and dementia. (Woman, 31–50, father)

Some caregivers were actively researching relevant topics through the Internet, as well as carefully reading the materials that LTSS staff provided to them when visiting. They also dealt with health-related events that were not directly related to dementia, but could be brought on by the increasing cognitive problems or physical vulnerability, such as falls and accidents—in such cases, the caregivers had to be prepared and organized about what needed to be done immediately. Caregivers were well informed about the medications that their loved ones were taking and monitored them closely, inventing different strategies to ensure that they took them.

In addition, engaging in their health care meant that caregivers were aware of multiple aspects of the care recipient's behaviors and attitudes, which could contradict what was shared in the meetings with their health care providers.

When the physical therapist comes she's like, "Yep, I'm fine. I have no problem at all. Yeah, I'm good." And the reason she says that is this fear that she's going to take her to the nursing home. So she gets herself up and she's energized and she can do it. Just it's really difficult: as soon as they leave, [she says] "Oh, I just want to die. I'm tired. I don't want to do this." It's really hard. I think sometimes I get frustrated even just bringing her to the doctor. She's says, "I'm fine. It's just old age." And as soon as we're out of the building, "Oh, I'm so tired, this joint pain." I say, "We were just in the doctor. Why didn't you say all that stuff?" She wouldn't say it to the doctor; I don't know why. (Man, 31–50, mother)

However, caregivers also faced difficulties in the health care system. Some shared that they faced the disinterest or depersonalization from the staff in the hospitals or in senior care facilities that they were visiting, and found themselves having to be strongly assertive to make sure that the needs of their loved ones were met. Others felt intimidated or just disoriented in the paperwork and in the communication with health care providers. Some caregivers expressed their need for help in this area, and hoped that LTSS staff could act as mediators or advocates in helping them navigate the health care system. This was true for both English-speaking and Spanish-speaking participants, as well as for people with low or high education—as it had to do with the difficulty orienting themselves to a complicated system, understanding their rights, and finding the time to be able to research these.

Caring for the caregiver. Few of the caregivers we interviewed talked about being vigilant about their own health. In fact, they did not take advantage of opportunities to rest and take a break from caregiving, not wanting to leave their loved ones alone or with someone else. Most caregivers had not taken breaks or vacations in years, and even those who did

have alternate caregivers whom they trusted were still reluctant to leave their loved ones with someone else, knowing that they would worry about what is happening while they are away. Some were concerned that the alternate caregiver would not have the experience or knowledge of the particulars of the care recipient to provide adequate care. While this dimension of engagement underlined the close bond between caregiver and care recipient, it could also be contributing to caregivers' fatigue and stress:

After [the organization] got involved with me and helped me and they said, "You have to go up to bed. You have to sleep. You have the monitor. You can hear her. You can come back down." And they were right. And when it's your mom it's different. It's different. You always wonder is it the disease? Is it because I'm not taking care of her right? Am I not feeding her often enough. (Woman, 51–70, mother)

While some were visiting the gym while their parent was at the senior day care center, most were not paying particular attention to exercise, nutrition, or stress reduction for themselves.

In summary, caregivers were engaged in caring through their dedication to providing the best care and sustaining a predictable daily routine. The safety of the care recipient was a primary concern, so they were constantly vigilant about the status and behaviors of the care recipient. Caregivers made efforts to be adequately informed about dementia and about caring for people with dementia. They felt that they needed more support in interacting with the health system in general. In their dedication to the daily routine, safety, and adherence to the treatment prescriptions for their loved ones, caregivers often overlooked their own needs and well-being.

Discussion

Caregivers' engagement in their role of caring for people with dementia is important as it has implications for well-being of the care recipient and that of the caregivers themselves. Previous research has illustrated that engagement can be a key resource for sustaining caregiver and care recipient well-being (Kanste, 2011; Sceppa et al., 2015). The concept of "engagement" has been the subject of multiple theoretical discussions and empirical investigations, with ambiguity in its definition (Bailey et al., 2015; Bright et al., 2015; Schaufeli & Salanova, 2011). These discussions have addressed mainly two areas—that of employee and work engagement, and that of patient engagement—and have rarely included engagement of informal caregivers. As caregivers have a specific role, which can be analogous to work, yet not quite; analogous to being a patient, yet not quite—that involves sustaining a close emotional relationship with the care recipient, the understanding of the meanings and dimensions of their engagement is important. To gain further understanding of caregivers of people with dementia experience engagement,

we conducted an in-depth qualitative study in which caregivers shared their reflections and described their daily lives.

Our study shows that engagement in caregiving has multiple, interconnected, and nuanced dimensions and meanings.

Connectedness

One clear dimension of caregiver engagement is the interpersonal one, as the engagement with the care recipient and in the relationship is a base for everything else that happens in the caring. Thus, engagement is primarily a relational process, during which the relationship quickly changes, and the caregiver and recipient continuously co-construct and reconstruct it. Reflections on the experience of being with their loved ones and on the history of that relationship, as well as what it means now, were key themes in the interviews. The connectedness between the caregiver and recipient was central to the caregivers' experience, as they sensed the changing needs and state of their loved ones and adjusted to those. They learned to understand the new developments and were attuned to the care recipient's nuanced and subtle shifts in their condition.

The most prevalent conceptualization of work engagement (reported to be used in 85% of relevant articles (Schaufeli & Salanova, 2011) defines it as a "positive, fulfilling, affective motivational state" (Bakker et al., 2008). This definition of engagement is more relevant to the specific construct of "work engagement," which is regarding one's relationship to one's work. However, the broader concept of "employee engagement" has additional dimensions such as relational ones, including toward the employee's organization (Schaufeli & Salanova, 2011). For example, coming from human resource development theory, Soane et al. (2012) proposed a model and measure of employee engagement, which has three facets of "intellectual, social and affective engagement." It is based on Kahn's (1990) theory of engagement, which also stresses the social component through connectedness with others, yet until recently "social engagement [had] not been conceptualized or operationalized as a facet of engagement" (Soane et al., 2012, p. 532).

Similarly, in the area of patient engagement/activation, most definitions focus on the individual patients and their behavior (Center for Advancing Health, 2010), while a few bring in a relational perspective (Bakker et al., 2008; Toms et al., 2015). In a qualitative study of how caregivers managed home care problems, Davis et al. (2014) identified several types of caregiver management styles (in the case of Alzheimer's and Parkinson's disease), a key difference between them being the way they conceptualized the relationship with the care recipient. The "adapters" talked about their activities as a partnership often using "we," analogous to the "We do it between us" theme identified by Toms et al. (2015). The "strugglers," however, saw themselves as being "alone" in the activities of caring (Davis et al., 2014).

Meaningfulness

Another dimension of engagement we identified was that of meaningfulness (of the activity of caregiving and of the relationship with the care recipient). Participants shared their experiences, which we interpret as examples of meaning creation and constructing a purpose in their caring. Caregiving was often made meaningful and fulfilling through the shared love. They felt that they were contributing to the health and happiness of their loved ones, and thus were useful and were giving back for years of love and care previously given by their parents to them. While some created meaning through framing caregiving as a duty and responsibility, others did so through seeing it as a gift and privilege; in any case, the creation of meaning resonated with engagement with the loved one and in the caregiving.

Meaningfulness has at times been introduced in the discussions of (work) engagement, though due to the prevalence of other approaches, it is a less evident theme in the literature. Meaningfulness was identified as a key aspect of engagement in the article that set the stage for the concept (Kahn, 1990). Interestingly, that article was based on two grounded theory qualitative studies, where meaningfulness was identified inductively and theorized within the engagement construct—as encompassing meaningfulness, psychological safety, and availability. This approach to understanding engagement was incorporated into a study with (formal) home health care givers (Nielsen & Jørgensen, 2016), one of the few existing studies that addresses caregiver engagement, approaches it qualitatively and inductively, and identifies several ways in which meaning creation is experienced in relationship to engagement. In addition, this article underscores the importance of relationships with others as integrated with the creation of meaning (Nielsen & Jørgensen, 2016), which we also found as discussed above, as caregivers consistently constructed meaning through connecting it with the past and present relationships with their loved ones.

Acceptance

Acceptance is closely related to the meaningfulness of caregiving, in particular to the meaningfulness and attunement in the relationship. Acceptance of the disease of their loved ones resonates with openness to constructing alternative meanings of and purpose for caring. It can open up space for more meaningful engagement with the care recipient, which is in tune with their current condition. This could happen as a result of the caregiver dedicating less energy to fighting the situation—thus enabling to focus on the value of each day spent together and to meet the care recipient where they are. It captures a “peaceful” state that supports engagement.

Acceptance as a construct needs further elaboration in terms of its role as a dimension of engagement. This concept has not appeared in the engagement literature, possibly as it represents a dimension that is more specific to the engagement

of caregivers, particularly caring for people with different diseases and disabilities.

Vigilance

Caregivers were engaged in care through their dedication to providing the best care and through sustaining a predictable daily routine. The safety of the care recipient was a primary concern, so they were constantly vigilant about the status and behaviors of the care recipient. Caregivers made efforts to be informed about dementia and about caring for people with dementia. They felt that they needed more support in interacting with the health system in general. In their dedication to the details, safety, and adherence to the treatment prescriptions for their loved ones, caregivers often overlooked their own needs and well-being.

The caregiver is attentive to many details, ensures that the treatment proceeds well, and makes sure their loved one is safe throughout the day. In this sense, this theme echoes several constructs in the literature, such as both dedication and vigor from the Utrecht model of work engagement (Schaufeli et al., 2006). Part of the vigilance theme relates to the “activation” construct in the patient engagement literature, which refers to the patient’s “knowledge, skills and confidence for managing his/her own health and healthcare” (Center for Advancing Health, 2010). In addition, vigilance encompasses ensuring safety, which connects to the “safety” psychological condition proposed by Kahn (1990), where it referred to the employee’s own sense of psychological safety, as a condition to be engaged in one’s role. In caregiving, the “safety” subtheme is a relational one, focused on the other, often to the detriment to one’s own well-being and possibly even one’s own safety.

In summary, the experience of caregiver engagement is multidimensional and nuanced. It can encompass several aspects, including connectedness, meaningfulness, acceptance, and vigilance. These aspects of the experience can complement each other, or they can be in contradiction. Complementary connections between dimensions were evident in the ways connectedness and meaningfulness were interdependent, as well as the ways in which acceptance reinforced connectedness.

However, we also found that high caregiver activity in ensuring the medical care of the recipient could be associated with disengagement from the relationship and the meaningfulness of caregiving. When the caregivers were intensively engaged in ensuring the health and safety of their loved ones, including in the formal health care system, they could disconnect emotionally and even physically from them. It is possible that this active engagement with medical care provided a sense of control when the disease had progressed to a place in which the care recipient and the family lost the sense that they were understanding, adjusting, and coping.

Another way in which the different dimensions of engagement can be in contradiction is the observation that high

engagement in caregiving (the relationship, the daily care, or medical care) is often associated with minimal engagement in sustaining caregivers' own health. A barrier to taking time for their own health was caregiver's strong connection to the care recipient, accompanied by excessive worry or guilt (Horrell, Stephens, & Breheny, 2015). While it is clearly important for caregivers to find ways to be engaged in sustaining their own health, a focus group study has illustrated that caregivers can find this expectation to be frustrating, unrealistic, and one more added responsibility (Lilly, Robinson, Holtzman, & Bottorff, 2012). Thus, it is important to understand not just the individual but also the gendered, organizational, and political dynamics that could be directing unrealistic expectations for caregiver engagement (Bailey et al., 2015; Lilly et al., 2012).

The qualitative interpretative phenomenological approach our study took toward understanding caregiver engagement elucidates a multidimensional phenomenon with some of its dimensions being specific to caregiving. In much of the literature, there has been an understandable effort to delineate the construct of "engagement" as distinct from the "conditions for" or "antecedents of" engagement. Yet phenomenologically, many of these, such as connectedness and meaningfulness, are integrated into the experience.

Limitations

While our project included men and women with diverse ethnic backgrounds, a more focused analysis of the cultural nuances is warranted, as well as further research on the meanings and experiences of diverse caregivers, in terms of gender, ethnicity, and socioeconomic status. A specific aspect of our project was that the participants were caregivers who receive a stipend from the organization for providing the care and they are caring full-time, while not working or only working part-time. The experiences of engagement for caregivers who need to work at other jobs full-time could be different, though we are confident that there is important overlap.

Implications

From the in-depth qualitative analysis conducted in this article, we can identify some implications for caregiver engagement and well-being. Understanding caregiver engagement as a multidimensional construct, some aspects of which are specific to caregivers compared with employee or patient engagement, can help support caregiver well-being. In developing programs to support caregivers, an awareness of these dimensions of caregiver engagement can help sustain and energize engagement, which could minimize the negative impact of stressors on their well-being. At the same time, we need to be cognizant of the potential problematic aspects of excessively high engagement (Halbesleben, 2011), which can proceed toward burnout. It also means being careful not to have unrealistic expectations of caregivers in terms of

both how extensively they can engage with the recipients and in caring for their own well-being; in other words, it is important to make sure that caregivers have structural support.

Interventions, which draw caregivers' awareness to the importance of rest, adequate sleep, exercise, and nutrition (to increase vigor), as well as integration in a social network, would be significantly beneficial for caregivers' well-being. Interactions with caregivers geared toward reframing, meaning making, storytelling, and constructing meaningful narratives about caregiving (such as through peer support groups, facilitated groups, or coaching and counseling) could support caregivers in finding purpose, which can help them cope with the more stressful aspects of caregiving. Reflective conversations with caregivers and staff could support them in exploring alternative meanings of caregiving, finding purpose, acceptance, and creative ways of connecting with their loved ones.

During the interviews, we also asked caregivers for specific recommendations for improving their quality of life and the LTSS program in which they are enrolled. Some of their recommendations directly or indirectly are related to engagement. For example, they stated that they need training in dementia knowledge, skills, and competencies (which can lead to greater confidence and engagement in care and with the care recipient); that the staff can support caregivers best when aware of the cultural meaning of caregiving; that they would appreciate greater staff engagement with them, the caregivers, in addition to the care recipients, and others. These recommendations are described in detail in the VOICE report (Sceppa et al., 2015), and are also reflected in the VOICE training program which was informed by this needs assessment study (Karlin, Young, & Dash, 2016).

Conclusion

Our study concludes that caregiver engagement can be seen as a multidimensional phenomenon, with some of the dimensions being contextual and specific to caregiving. We see it as a relational concept, referring to a committed, vigilant, and meaningful relationship of (formal and informal) caregivers and care recipients as active collaborators in the care recipient's health care and the caregivers' own well-being. Broader dimensions such as cultural expectations and structural requirements for the caregivers, from social and health care institutions also need to be taken into account to ensure the well-being of caregivers and their families.

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Notes

1. To preserve anonymity, we identify only the gender and age group of the caregiver, as well as for whom they are caring.
2. All caregivers and care recipients live together, as required by the long-term services and supports (LTSS) organization.
3. In some interviews, it was clear that the family was not even considering sending the recipient to a facility—our assumption is that this could have to do with cultural traditions of how aging parents are cared for; however, additional analyses would be needed to confirm this.

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