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Characterizing Dementia Caregiver Style in Managing Care Challenges: Cognitive and Behavioral Components

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Abstract

Background: Caring for a person living with dementia can take a physical and emotional toll, but understudied is the process by which family caregivers actually provide care. Caregiver management styles may vary and affect care decision-making, experiences, receptivity to and participation in interventions and outcomes for the caregiver and person living with dementia.

Methods: Participants included 100 primary family caregivers for persons with dementia who were on average 64 years old and had been providing care for 55 months, 74% female, and 18% non-White. Participants were interviewed in Michigan and Ohio regarding their cognitive and behavioral management of a recent care challenge and values guiding their decision-making. The rigorous and accelerated data reduction technique was used to analyze qualitative data leading to the identification of caregiving styles. Styles were compared across sample characteristics using Chi-square and ANOVA tests.

Findings: Five distinct styles emerged: “Externalizers” (superficial understanding, self-focused, frequent expressions of anger or frustration), “Individualists” (provide care by going it alone, emotionally removed, lack management strategies), “Learners” (recognize need to change their approach but are stuck, emotionally turbulent), “Nurturers” (positive affect and empathy toward care, reflect natural mastery), and “Adapters” (arsenal of acquired management strategies, adapt to challenges). Style groups differed significantly in terms of age and use of formal care supports.

Discussion: We identified five distinct styles by which caregivers addressed care challenges using a robust qualitative methodology. Styles may be important to identify in order to better tailor interventions to needs and abilities.

Keywords

dementia; caregiving styles; care management

As dementia progresses, functional assistance, compensation for memory impairments, and management of behavioral and psychological symptoms become crucial to the survival and well-being of persons with dementia (Black et al., 2013). The majority of community dwelling persons with dementia (as many as 92%) receive such care from a family caregiver (de Vugt et al., 2004; Kasper, Freedman, Spillman, & Wolff, 2015). Caregivers may assume this role due to a wish to keep the person with dementia at home, their proximity to the individual, a perceived obligation to the individual, and/or a societal expectation that families will be responsible for their long-term care (Alzheimer's Association, 2019; Gitlin, 2019).

Yet, in contrast with formal caregivers, half of family caregivers have never provided medical/nursing tasks before and most do not have time to prepare themselves for their care role (Alzheimer's Association, 2020; McClendon & Smyth, 2013). This may lead to a variety of adopted care management strategies, some of which may be harmful (McClendon & Smyth, 2013). Despite a large literature on the stress process of family care (e.g. burden, overload) (Cuijpers, 2005; Mausbach, Chattillion, Roepke, Patterson, & Grant, 2013; Pinquart & Sörensen, 2006), considerably less attention has focused on how caregivers actually manage and provide care and how this may impact their own well-being and care outcomes. The aim of the current study is to explore and typify dementia caregivers' management styles.

Care management.

Understanding care management draws upon psychological concepts including coping, adaptation, adjustment (le Navenec & Vonhof, 1996). For example, coping characterized by avoidance, confrontation, or disengagement has been associated with increased depression and anxiety in caregivers (Neundorfer, 1991) and increased frequency and severity of behavioral and psychological symptoms in persons with dementia (García-Alberca et al., 2013; McClendon & Smyth, 2015). Caregiver neuroticism has been associated with stress, worse health, and more depressive symptoms among caregivers and faster cognitive decline in persons with dementia (Hooker, Monahan, Bowman, Frazier, & Shifren, 1998; Melo, Maroco, & de Mendonça, 2011; Terracciano & Sutin, 2019). In contrast, caregiver agreeableness and extraversion protect against developing burden and depressive symptoms (Melo et al., 2011; Orgeta & Leung, 2015), and are related to decreased mortality risk for persons with dementia (Norton et al., 2013). Yet it is important to understand how caregivers manage particular dementia care tasks, not just how they cope with general life stressors.

Caregiving styles.

Existing qualitative studies on caregiving management styles are few and limited by their disparate frameworks and small sample sizes. Caregivers have been classified as "open" versus "closed" depending on their behavioral and affective responses (n=39) or

“pre-decision” or “post-decision” in regard to their care-related behavioral decision making (n=28) (le Navenec & Vonhof, 1996; Wackerbarth, 2002). Looking at both dementia and Parkinson’s caregivers (n=27), Davis et al. (2014) identified three styles: “adapters” (bring existing skills to care), “strugglers” (do little to resolve care problems), and “case managers” (use formal care supports). Using a framework of caregivers’ acceptance of the care situation, de Vugt and colleagues (2004) identified three styles based on utilized management strategies (n=99) including the “nurturing” (parent-child approach to care tasks), “supporting” (follow the lead of the person with dementia in care activities), and “non-adapters” (anger and lack of acceptance toward the care situation). These studies primarily focused on actions, interactions, or activities, but did not explicitly consider a pattern of beliefs, acceptance or understanding of dementia and the care role. This is important as cognitive behavioral theories suggest that attitudes and beliefs influence and correlate with one’s enacted behaviors (Ajzen & Fishbein, 1980; Beck, 1976; Fishbein, 2008). An understanding of both the cognitive and behavioral facets of styles thus offers a more comprehensive understanding of caregiver’s management styles and how their perceptions drive their actions or behaviors.

One of the more nuanced studies by Corcoran (2001; n=97) focuses on caregivers’ preferred ways of interacting with persons with dementia in their daily life. Four caregiving styles were identified: “facilitating” (creating one-on-one activities), “balancing” (simple activities not requiring supervision), “advocating” (activities allowing the caregiver to monitor the person with dementia’s function) and “directing” (giving verbal and written direction). In contrast with prior research such as Corcoran’s which focused on typical daily routines, we aimed to extend this work by focusing on caregivers’ responses to a care challenge they recently encountered. As stress and coping theories suggest that stress occurs when a stressor is perceived as beyond one’s coping abilities, exploring a caregiver specified care challenge enabled us to consider care management in times when coping was necessary more than ordinary routines which may not elicit a stress response (Lazarus & Folkman, 1984; Pearlin, Mullan, Sempke, & Skaff, 1990).

The current study.

In the current study, we draw on both Reasoned Action Theory, which suggests that attitudes and behavior are related and interdependent, and cognitive behavioral theories more broadly (Ajzen & Fishbein, 1980; Beck, 1976; Fishbein, 2008). We consider caregiving style as a pattern of *cognitive* understanding of dementia and associated emotional response, which connects to and impacts the *behavioral* management strategies adopted in the provision of dementia care. Our aim was to understand how caregivers react when care surpasses their routine and taxes their usual coping capabilities. We hypothesize that in the face of care challenges, certain perceptions and behavioral care management strategies will align together to form distinct styles of caregiving. We extend prior work by using a rigorous qualitative methodology in a large sample allowing operationalization of caregiving styles that have clinical utility for intervention design. An additional shortcoming of previous work on style is a lack of mixed methodologies which can help to generalize exploratory findings; thus in the current study we compare identified styles across sample characteristics. We hypothesize that sample characteristics will vary across caregiving styles. Ultimately, an

understanding of caregiving style can be used to individualize supports to meet caregivers' specific profiles and needs that emerge in the face of stressors.

Method

As part of a broader mixed-methods study on dementia care management and biopsychosocial outcomes of care, this study uses a qualitative interview and analysis approach to explore the cognitive-behavioral care management approaches dementia caregivers bring to care challenges they face.

Participants.

Participants included 100 adult family or friend caregivers (IDs: 100 to 199) who held the primary responsibility of care for a person with a diagnosis of Alzheimer's disease or a related dementia (excluding mild cognitive impairment). Caregivers could not be providing care for a person living in a nursing home or assisted living facility or with a life expectancy of less than 6 months. Caregivers were a convenience sample recruited through the Michigan Alzheimer's Disease Center's participant database, support groups, and other programming, and other University of Michigan recruitment platforms (e.g. UM Health Research Database). Caregivers were interviewed in their homes or public place of their choosing (e.g. coffee shop) within 60 miles of Ann Arbor, MI. The study was approved by and followed University of Michigan Institutional Review Board policies. All participants gave their signed informed consent and received a small stipend for their participation.

Interview.

Qualitative interviews were conducted from January to December in 2018 as part of a baseline (cross-sectional design), in-person semi-structured interview. The full 90-minute interview included quantitative measures on demographics, care context, dementia severity (e.g. cognitive decline, activities of daily living), caregiver management and coping, and outcomes (e.g. depression, burden). The open-ended qualitative portion was given at the beginning following the demographic items and prior to other quantitative measures to avoid priming. Participants were asked to describe a caregiving-related challenge they had encountered recently, why it was challenging for them, how they handled or responded to the challenge, and about attitudes and beliefs they held that played into their care decisions. (*Note.* Caregivers commonly discussed more than one challenge, $n= 193$; see Supplementary Table 1. However, our analysis focus was on perceptions of and responses to challenges as opposed to the challenges themselves as described below). On average, qualitative interviews lasted 10 minutes (range 5–25 minutes) as part of a 90-minute baseline interview. While interviews varied in length, the focus of the qualitative method is to capture the depth and quality of a participant's experience. During analysis, four interview transcripts were identified as not offering enough detail for thorough coding and thus the analytic sample is 96 caregivers. The PI and trained research assistant conducted all interviews and took immediate notes concerning emerging themes. All interviews were recorded and transcribed for analysis. Any interview responses that indicated potential risk to the caregiver or person with dementia were discussed with a board-certified geriatric psychiatrist (HCK) to determine whether follow-up was needed.

Qualitative analytic approach.

A team-based approach to qualitative analysis was undertaken utilizing Watkins' (2017) "rigorous and accelerated data reduction" (RADaR) spreadsheet technique and based on the grounded theory analytic approach (Charmaz, 2006; Strauss & Corbin, 1990). Following a thorough reading of the transcripts and becoming "one" with the data, the process starts with an "all-inclusive data table" which incorporates interview transcripts into a spreadsheet. Iterative reduction phases are undertaken until the team comes to a consensus and produces a more specific presentation of the data to allow for defining and classifying caregiving styles.

In the current study's initial reduction phase, the team reviewed the all-inclusive data table for text relevant to *cognitive* attitudes regarding care and *behavioral* care management strategies and began the process of open coding to identify sections of text with overlapping concepts and categories. In the second phase, focused coding was used to solidify commonalities found across the open codes. Codes and definitions were iteratively refined and ultimately focused codes were applied to each participant with consensus reached by the team. Styles began emerging across this process as certain codes tended to group together, and thus individuals could be grouped together in relation to similar focused codes. This was also true in cases where participants described multiple care challenges in their responses. In the final step, conventional content analysis was employed to see which codes were most frequent across the different identified styles (Hsieh & Shannon, 2005). Full transcripts were further re-read to confirm that each participant was classified to the correct style according to their full interview in addition to their focused codes. (Further detail on the RADaR analysis and associated exemplar photos in Supplementary Table 2.)

Quantitative Style Comparisons.

Sample characteristics were run for the total sample and presented by caregiving style classification. Chi-square and Anova F-tests were run to explore group differences on sample characteristics.

Findings

Sample characteristics.

Participants were on average 64 years old, had been providing care for 55 months, 74% were female, 18% were non-White, and 33% were employed. Over half of caregivers were spouses of the person with dementia (59%), with 31% adult children and 10% other friends or family members (Table 1 presents overall and style-specific demographics).

Caregiving Styles.

Five caregiving styles were identified: Externalizers, Individualists, Learners, Adapters, and Nurturers. Each style is described in detail below and facets of each style according to key themes are displayed in Figure 1.

The Externalizer (N=14), "If you think you're punishing me, you're only punishing yourself" (ID 172).—Externalizers view dementia symptoms and behaviors

as volitional or tend not to consider the condition in their behavioral management approach. They often try to pull the person with dementia back into their own lived experience (e.g. “remember your mother died 20 years ago”) or otherwise view the person with dementia as the source of frustration. As reflected by the following participant, Externalizers may not even acknowledge that the person with dementia’s engagement with reality has shifted, treating them as if they are still in the caregiver’s reality.

Everybody’s told me ‘don’t argue’... I just don’t like just letting it go... I’ll admit 100% I do have a problem... sometimes I will say ‘well, you know that’s not true’ and so – BAM... we get home and I don’t know if she tries to lie about it or what... she’ll act like that never even happened. (ID 107)

Externalizers do not understand that normative forms of interaction prior to dementia diagnosis may no longer be effective means of communication. Due to this, the caregiver’s approach is often rigid, and they do not consider or may not be aware of other management strategies. Their name is coined “Externalizers” given that they tended to externalize feelings of frustration and anger and they use reason and confrontation as their primary behavioral strategies to engage with the person with dementia. The Externalizer’s coping ability, self-focus, and resulting helplessness is displayed in the following quote,

I have to say what I consider very cruel and very difficult things for me to say to her. I said ‘fine, you don’t want to go to the doctor, when you don’t feel good – if you’re really sick and you’re dying, don’t call me, just die... Because I can’t do this emotionally and mentally anymore. (ID 151)

The Individualist (N=15), “You just live through it, you just do it” (164).

—Individualists hold a better understanding of the symptoms of dementia relative to Externalizers, however are less reflective and more detached, with no emotional element or processing to their care. “I just usually take care of it – and I mention, you know, that somebody left the yogurt out, no accusation...” (ID 123). However, their lack of reflection on care strategies results in a rigid care management style that appears to work for the Individualists exemplified by the following conversation,

Go there and do it. Remember when I told you, that is part of my responsibility? That’s what you have to do.

Interviewer: Have you figured out any strategies that have made it easier for you over time? Have you changed your approach?

No, just go there and do it. (ID 190)

As their Individualist name suggests, they also tend to take all responsibility on themselves as a “lone wolf” and do not chastise the person with dementia but do it themselves. For example, as one participant said,

I have to take care of her, then I have to take care of myself, then I have to take care of the house. I’m capable of doing all of that but I don’t have time to do it... If I tell her to get a cup of coffee and she doesn’t do it, we don’t make a speech out of it, we just go and do it. We’re not looking for any arguments because there’s just no way to argue. (ID 160)

This quote also highlights how growing knowledge of dementia leads to reduced frustration. Individualists focused on meeting basic care needs rather than emotionally responding to care challenges. Other than preventive actions carried out to avoid a future negative action by the person with dementia, no management strategies were commonly used by this group—in their own words, they “just do it.” For example, one participant shared, “I’d be like ‘let’s just get this over with!’ ...overstimulation is just part of the dementia and I don’t feel I owe anybody any explanation. Just go on and get what I have to get done” (ID 145).

The Learner (N=35), “So as you go along, you stumble on a few things – but stumble it is” (ID 124).—The Learners are beginning to understand that behavioral and functional changes due to dementia are non-volitional, leading to less anger and frustration with the person with dementia than Externalizers and the development of some basic care strategies like reason and trial-and-error. Yet, they experience a range of other emotions from empathy to guilt, or repress their feelings altogether. As the largest style, the Learners fall along a spectrum of those who are more self-focused and less reflective, to those who are more person with dementia-focused and emotionally invested. However, what aligns these caregivers as Learners is their recognition that their approach is ineffective and must evolve (in contrast with Externalizers & Individualists), yet a lack of agency to identify adaptive strategies (in contrast with Adapters and Nurturers).

Self-focused, emerging-reflection on care approach.: Learners are growing in understanding of the non-volitional nature of dementia symptoms as reflected in the following quote, “I’ll just have to tell her ‘there’s something wrong, look at your feet’ ... [I’ll] take a deep breath, [laughs] and just, ‘okay, she’s not doing this on purpose’” (ID 133). While this caregiver understands the act was non-volitional and his approach ineffective, he has not yet tried to find a more adaptive solution. Others attempt new approaches, yet do so in ways that are stress reducing for themselves:.

I try to keep my calm and tell [the care recipient] in different ways, and sometimes I would write it and give it to him so when he asks again I said “read it” ... I can’t be upset with him because he doesn’t know what he’s doing so I keep on thinking about *the ways that don’t stress me so much*. (ID 136)

While these caregivers begin to adapt, their care strategies do not always work, and thus they described adjusting their emotional perspective to cope and reduce their own stress.

Person with dementia-focused, emotionally invested.: As understanding of dementia grows, the rest of the Learners begin to focus more on the person with dementia, recognize the limitations of their rigid care strategies, and have an increasing openness to adaptability. They experience deeper emotional involvement with the care process and focus on the person with dementia more than those on the non-reflective end of the spectrum. For example,

when you explain the same thing so many times... It feels selfish, but it feels like the amount of time that I spend doing that, I sort of resent... I feel a lot of guilt... I do think it’s important for him to engage as much as he can so I would rather help him, even though it’s harder.... (ID 106)

For some, as their strategies begin to fail and they don't accrue efficacy, their emotional investment can result in helplessness. One participant displayed a willingness to adapt but demonstrated helplessness as her strategy failed,

I can't stop him. My technique is awful, I don't know what to do, I yell... 'stop it!' or I try to wave my arm in front of him. I don't know how to divert him...I know everything I'm doing is wrong and I've tried logic, like that he's scaring [the cat]...I kept saying 'Please, sit back down' and then I was like out of it, just losing it, I was like 'I don't know what to do! Do you want to sing?' (ID 152)

Although Learners tended to show awareness that they were experiencing difficulties in care management, they had not yet adopted adaptive behavioral care management strategies.

The Nurturer (N=15) “I value... making the most of what is present rather than what is lost” (ID 170).—Nurturers understand dementia and look at the condition and care process with optimism, mastery, and empathy. They also seem to be more naturally adaptable as part of their orientation to care and way of interacting with the world. One caregiver describes her approach this way,

I call them faces... Is it more I need to be more of a caregiver/outsider, dealing with it on more of a medical-type 'this is what we're doing', or the daughter face where 'hey mom, let me help you get up, hey great swinging your legs over and getting out'... I've learned that I have to just step back and ask a few open-ended questions to see what her responses are and then I'll know what face needs to shine at that moment. (ID 153)

This caregiver's metaphor of “faces” highlights her caregiving style: it's not a mask to put on or a care strategy to choose, it's a part of herself and her orientation to care.

Nurturers provide more of an optimistic, “person with dementia-focused” orientation than a “strategy-focused” orientation. Here a caregiver describes her focus on maintaining a meaningful life for the person with dementia:

I value her as a person, I value her life...I try to make her life still be useful to her and fulfilling, I've got her painting pictures that she'd never really done before... [I try and think] what can I do for her to keep her life still of interest to her and try to keep her going, keep her mind stimulated. (ID 109)

While they use few strategies, their strategies of comfort and teamwork emphasize an empathic partnership. One caregiver described the simple task of teeth brushing as a fun game they play together,

We got a little game, every night at bed time I say 'time to brush our teeth' and she drags on a little bit... and we brush together, not at same time she does it and I help her, then I brush my own teeth, and that's acceptable to her, because I'm doing it, too. (ID 196)

Rather than trying to reason a person with dementia out of irrationality, these caregivers interact directly with the disordered thinking of the person with dementia. For example, a wife discusses her interactions with her husband's hallucinations:

[He] will wake up and there will be a man in a black coat, ‘they’re taking the house away from us’...so then what I’ve done is... I open the door and I yell and scream at these men... They go away and then we go back to bed and everything is fine. (ID 159)

These dyadic care strategies engage with the person with dementia’s different reality in an efficacious, person with dementia-focused way.

The Adapter (N=17) “Always expect the unexpected” (ID 142).—Adapters describe how their accrued mastery and understanding of dementia led to behavioral change which ameliorates psychological distress (unlike Learners, Adapters care approaches were efficacious and non-emotional)- exemplifying the cognitive-behavioral duality of caregiving style. When a challenge arises, in contrast with Learners, they demonstrate their ability to control their response and adapt. “‘Oh my god, you took the wrong pills!’ And then, ‘okay, I’ll figure something out’” (ID 142). However, the hallmark characteristic of the Adapters is their wide variety of effective utilized management strategies. Adapters talk about their successful, often creative care management strategies and their paths to reach this point rather than the impact the stressor has on them or the person with dementia.

We hide her bobby pins, hide her hairbrushes, combs... Or pretending that we did her hair, just like blowing some like hot air on her hair, she falls for that one almost all the time. (ID 101)

These caregivers are engaging with the different lived experience of the person with dementia in a variety of productive ways, often by entering or shaping their lived experience (adaptive) but sometimes by pulling them back into their own reality (more rigid). One strategy that works well for Adapters is projecting the focus of a care challenge on themselves or someone else rather than on the person with dementia to reduce stress,

I see he’s a little unsteady and he would get upset if I would grab him, I’d say ‘My vertigo is bothering me, can I hang on to you?’ and I’m actually supporting him. (ID 173)

Caregivers describe these strategies as acquired by learning through the caregiving experience.

I got her over to the windows so she could touch the pane and I said ‘feel the heat there’ and then of course the next day, she [opened the blinds] and I said to myself ‘how stupid can you be! She doesn’t understand. If she did understand, she’d forget in about 3 seconds so... just pull the things down and don’t say anything’. So it took me a little while to get my brain together. (ID 192)

Ultimately, Adapters have built up an arsenal of effective strategies, leading to efficacy in future caregiving challenges or, as one participant said, we just deem it our ‘new normal’” (ID 108).

Comparing sample characteristics across styles.

The styles differed significantly by age and use of formal care services. Externalizers were the oldest style category on average (M=72.5 years), whereas Nurturers were the youngest

on average ($M=58.07$). Nurturers were least likely to use formal sources of care support (20%), whereas Adapters were most likely to be using formal supports (70.6%). For full comparison of sample characteristics by caregiving style see Table 1.

Discussion

This study suggests that cognitive processes and behavioral management practices mutually interact to define five distinct dementia caregiving management styles that form a new typology with which to understand enacted care. In line with Reasoned Action Theory (Ajzen & Fishbein, 1980), these styles reflect the interdependency of beliefs and behavior caregivers embrace as they address a care challenge. Caregivers with a more superficial understanding of dementia (Externalizers, Individualists) tended to show more anger and preventive actions to reduce negative outcomes without changing their approach, whereas caregivers with greater understanding and adaptable views (Adapters, Nurturers) drew upon a larger arsenal of management strategies (e.g. diversion, comfort, teamwork) proving effective in resolving care challenges. On the other hand, the Learners, fell somewhere in the middle on a spectrum from more self-focused and less-reflective and to deeper emotional involvement and focus on the care recipient. Learners showed increasing understanding but without developed efficacious approaches to care management.

Alignment with prior studies on caregiving styles.

While our styles align with prior studies, we also identified key new themes. Similar to Davis et al. (2014), de Vugt et al. (2004), and Corcoran (2011), there seems to be a style characterized by anger, irritation, and lack of adaptive management strategies. Our analysis shows that this may be driven in part by a lack of true understanding of the symptoms of dementia and a rigid approach to care. Corcoran (2011)'s "facilitating" style and de Vugt et al. (2004)'s "supporting" style align with our Adapters and Nurturers in that they take a more care recipient-focused and teamwork management approach to care. In our study, we saw how the adaptability and efficacy of the Adapters was accrued over time by learning from past mistakes. We note that our study probed care management in response to care challenges, whereas most prior literature explored routine care. Some care tasks may be viewed as stressful by one caregiver but not by another, and allowing caregivers to describe their own care challenge enabled us to explore care management in a context where coping capabilities were challenged. Thus our findings complement prior work, suggest that care styles may extend to a caregiver's management of both routine and challenging care tasks, and may reflect growth and change over time in the caregiving journey. Yet as only one care challenge was examined in our study, future work should consider a variety of care challenges alongside routine care and caregivers' change in care approach over time.

In line with Aneshensel and colleagues (1995) seminal work on the caregiving "career", these styles might be seen to reflect destinations along the caregiving journey. Stemming from the Trans-Theoretical Model (TTM) of change (Prochaska, Velicer, DiClemente, & Fava, 1988), Gitlin and Rose's construct of caregiver readiness (Gitlin & Rose, 2014), understanding of dementia and readiness for behavioral change, seems to be one component of style that reflects stages of this caregiving journey. For example, Externalizers seem to

be at the “pre-contemplation” stage where they lack knowledge of dementia and don’t deem behavioral change necessary, whereas Adapters and Nurturers are at the “action” stage with full understanding and evidence of active behavioral management strategies. Learners were at the contemplation or preparation stage suggesting growing understanding and awareness of need to change, yet lack of accrued adaptability which corresponds with them caregiving for the least amount of time and for persons with higher cognitive capacity.

Extending prior work, a unique facet to our study is a specific examination of how caregivers engaged with the lived experience of the person with dementia. For example, some caregivers attempted to pull the person with dementia back into the caregiver’s lived experience to what was normative to them (e.g. arguing in attempt to dissuade the person with dementia from a delusion-; e.g., the Externalizer). With greater understanding and acceptance, however, caregivers would modify their surrounding environment to change the lived experience for the person with dementia (e.g. preventing walking about by hiding shoes) or directly enter the person with dementia’s lived experience (e.g. when the care recipient has delusions, the caregiver asks questions and involves them in what they are experiencing to better be able to respond; e.g., the Adapter and Nurturer). From a behavioral perspective alone, Externalizers and Individualists might appear similar in that they demonstrated a lack of adaptive care strategies, while Adapters and Nurturers appear similar in their use of multiple adaptive care approaches. However, considering the interplay of cognitive and behavioral approaches, as well as engagement with the person with dementia, these styles appear distinct and nuanced in their approach to care management.

Distinctions in caregiver characteristics by style.

Caregiver characteristics tended to align by style profile. Prior research has found that male caregivers take a more “task-oriented” care management approach whereas women may be more “nurturing” (Carpenter & Miller, 2002; Corcoran, 1992). This was reflected in our style classifications with the highest proportion of women in the Nurturers style (80%), emphasizing comfort and person with dementia well-being. Men were represented most in the Individualist (33.3%) and Adapter styles (35.3%), thus spending more focus in their interviews on their care strategies and tasks, as opposed to their emotional responses to care. Similar to Hong, Luo, and Yap (2013) who found that caregivers with lower levels of educational attainment used more criticism as a management strategy, Externalizers had the lowest educational attainment. Hong also found that caregivers who provided care for more than a year used a more encouraging and nurturing management style. Likewise, our Adapter group had been caring the longest and for individuals with the greatest dementia severity and functional impairment suggesting that stage of dementia may impact care management.

However, Nurturers who used comfort as a primary management strategy had cared for a shorter period (2 years less than Adapters, on average). This may be a cohort effect as Nurturers were also younger and more likely to be non-spousal, aligning with prior research suggesting adult children report lower quality of life in their care-recipient, potentially leading to use of comfort as a management strategy (Conde-Sala, Garre-Olmo, Turró-Garriga, Vilalta-Franch, & López-Pousa, 2010). Additionally, as 20% of Nurturers

were non-spousal/child caregivers it may suggest it is easier to be nurturing when more relationally removed from the person with dementia, whereas Externalizers who express frustration and anger had the highest proportion of spouses, the most relationally intimate care relationship. These findings may also imply a temporal nature of caregiving style. As Adaptors had cared for a long time and learned along the way, it may be that Learners could become Adaptors through learning new behavioral management techniques. On the other hand, the rigidity of an Externalizer may be more trait like and less amenable to intervention. Future studies should explore the mutability of caregiving styles.

Of note, 23% more Nurturers identified as religious than Externalizers, suggesting that consistent with prior research, a faith-base may be associated with a person with dementia-focused perspective and more positive engagement strategies (Stuckey, 2003). Only 20% of Nurturers utilized formal care supports relative to 70% of Adaptors, reinforcing the instrumental approach of Adaptors. Acquired efficacy and adaptability with condition progression may also lead to increased service seeking, in addition to caring for an older and more frail group of persons with dementia. However, only two caregiver characteristics, age and use of formal supports, differed significantly across styles. Thus while patterns of differentiation exist, it may be that style is distinct from caregiver characteristics or that our sample size precluded significance and findings should be extended in a more diverse sample.

Application to caregiver interventions.

The distinctions found between the styles provide insights as to how interventions might be tailored to achieve the greatest adherence and effect. Learners or Externalizers who initially lack adaptability and/or management strategies could grow through individualized intervention to become an Adapter engaging with dementia in a variety of effective ways. Because of their rigidity, Externalizers may first need to step inside the shoes of the person with dementia and view care challenges from his/her perspective, and not just their own frustration, before they become amenable to learning and practicing new behavioral approaches to care. Gitlin and colleagues (2016) work on caregiver readiness suggests better behavioral intervention outcomes among caregivers open and adaptable to changing their behavioral approach. Thus in contrast with Externalizers, Learners might be key targets for behavioral interventions as they recognize a need to change their approach but are “hitting a wall” with their trial-and-error management not producing desired results. Nurturer’s primary care strategy of comfort may not be effective for all care challenges, and over time they may need to adapt like Adaptors. Though Nurturers were managing well with positive affect and efficacy, 60% were employed, and only 20% were using formal care supports. Thus they may benefit from respite care or other services to help them maintain care and self-care over time as dementia progresses. Likewise, a support group might not be appropriate for an Individualist who is emotionally removed and has not yet hit a wall in care management. Prior research suggests support groups may not be effective if caregivers view their situation as unique and are not open or amenable to suggestions provided. Yet Individualists might benefit from respite care to take some time away (Golden & Lund, 2009). Future work should further consider how tailoring interventions to style may reduce maladaptive care approaches and help care dyads maintain function and independence.

Caveats.

Our sample was not nationally representative; thus our findings should be validated in a larger, more diverse sample of caregivers. Further all caregivers agreed to participate in the study, and it may be that those who didn't choose to participate reflect different caregiving styles. While our caregivers were caring for persons with dementia across the range of dementia severity, the interview was collected at one point in time regarding one primary caregiver-identified challenge and findings are exploratory. While only asked about one care challenge, caregivers were able to identify a situation that was particularly challenging for them and often described multiple challenges. We probed to understand the complexities of the caregivers' responses and build on previous literature of management of routine care, yet future work should extend our model by garnering care management in multiple contexts. We cannot determine whether style is shaped by years caregiving, if caregivers changed styles over time, and whether caregivers would have responded differently to other care challenges. Future investigations should explore these styles over time and context contingent on intrinsic and external factors of caregiving and control for the role of personality characteristics, education, and finances in care decision making. This typology is not meant to classify certain styles as inherently "bad" or "good," as all caregivers face unique challenges and have room for growth. Yet, prior literature suggests that coping strategies of avoidance, disengagement, or anger used by caregivers are associated with increased depression and anxiety in caregivers and negative symptom profiles for persons with dementia (García-Alberca et al., 2013; McClendon & Smyth, 2015; Neundorfer, 1991).

Conclusion.

We sought to qualitatively explore caregivers' responses to a care challenges and found that caregiver's shared commonalities in their cognitive stance toward care and behavioral management strategies utilized could be classified into five distinct styles. The aim is for these typologies to help us better identify caregivers who may be at risk for burden or provision of non-optimal care, and develop caregiver supports and interventions that address caregivers' unique pre-existing and accrued understanding, emotional experience, and ways of managing care. Next steps include further validation of these styles, scale development to efficiently assess style, and determining how style may be associated with key health outcomes, such as whether there are physiological differences in stress levels.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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	The Externalizer	The Individualist	The Learner		The Nurturer	The Adaptor
Cognitive Orientation toward Care	Understanding of dementia	Lack of understanding Superficial acknowledgement of dementia	Superficial acknowledgement of dementia	Understand dementia		
	Adaptability	Rigid	Direct	Rigid lite ---- Still learning ---- need to change	Naturally adaptable, mastery	Accrued adaptability / efficacy
	Emotional Expression	Frustration, anger, helplessness	Emotionally removed	Emotional tempering, repressed	Positive emotions (e.g., empathy) Negative emotions (e.g., helplessness)	Empathetic, positive affect Emotional regulation / homeostasis
	Orientation to self or other	Self-focused		Self-focused lite ---- care recipient-focused lite	Care recipient-focused	
Behavioral Care Management	Caregiver engagement with CR Lived Experience	Negative engagements			Positive engagements	Variety of engagements
	Prevalent management strategies	Reason, anger	Preventive actions, "just do it"		Reason, trial-and-error Comfort	Diversion, disperse responsibility, environmental modifications, preventive actions Teamwork approach

Figure 1. Cognitive and Behavioral Characteristics of 5 Caregiving Styles
Note. Rows are themes derived from qualitative analysis of caregiver interviews with key codes associated with the theme represented in each column by caregiving style

Table 1.

Sample Characteristics by Caregiving Style

Sample Characteristics	Full Sample (N=100)					Individualists (N=15)			Learners (N=35)			Nurturers (N=15)			Adapters (N=17)		
	M(SD), Range/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%	M(SD)/%
Age	63.7(16.2), 20–90	72.5(9.7)	60.8(15.6)	67.4(12.4)	58.1(19.8)	61.3(16.8)	2.4(4), p<.05										
Female	74%	69.2%	66.7%	80.6%	80.0%	64.7%	2.4(4), p=.7										
Non White	18%	0.0%	26.7%	11.4%	26.7%	31.3%	7.3(4), p=.1										
Married	74%	76.9%	80.0%	80.6%	60.0%	70.6%	2.8(4), p=.6										
College degree	72%	53.8%	93.3%	75.0%	66.7%	64.7%	6.3(4), p=.2										
Some financial difficulty	20%	15.4%	33.3%	19.4%	6.7%	23.5%	3.7(4), p=.5										
Employed	33%	15.4%	26.7%	27.8%	60.0%	29.4%	7.7(4), p=.1										
Religious	73%	53.8%	73.3%	75.0%	86.7%	70.6%	4.0(4), p=.4										
Relation to Care Recipient																	
Spouse	59%	69.2%	60.0%	63.9%	60.0%	47.1%	6.7(8), p=.6										
Child	31%	30.8%	33.3%	25.0%	20.0%	47.1%											
Other	10%	0.0%	6.7%	11.1%	20.0%	5.9%											
Care Recipient Dementia Diagnosis																	
Alzheimer's	52%	53.8%	40.0%	50.0%	60.0%	52.9%	5.1(8), p=.8										
LBD	16%	7.7%	13.3%	16.7%	26.7%	17.6%											
Other	32%	38.5%	46.7%	33.3%	13.3%	29.4%											
Months caregiver has provided care	55.3(43.1), 4–220	62.4(21.5)	44.1(26.4)	56.56(48.4)	49.17(38.7)	72.94(55.4)	1.1(4), p=.4										
ADLs/IADLs (CAFU score)	62.0(22.6), 22–105	61.2(16.2)	61.1(24.1)	58.3(21.3)	63.4(28.0)	73.4(18.2)	1.4(4), p=.2										
BPSD (NPI-C score)	23.3(20.5), 0–100	35.5(26.5)	23.5(22.5)	20.4(16.7)	19.9(20.2)	22.9(18.8)	1.5(4), p=.2										
Dementia Severity Rating Scale Sum	24.9(11.1), 3–52	24.1(9.6)	23.9(10.9)	22.8(10.0)	26.7(12.2)	29.9(11.1)	1.5(4), p=.2										
Used formal care support	41%	46.2%	33.3%	36.1%	20.0%	70.6%	9.8(4), p<.05										

Note. Sample characteristics included: caregiver age in years, gender, race (non-white versus white), marital status (married versus non-married), educational attainment (college degree versus less than a college degree), current employment status, religious (reported religious affiliation versus no affiliation), relation to the person with dementia (whether the caregiver was a spouse, child, or other), months of care provision, and whether or not the caregiver utilized formal care services in support of their care. Caregivers were also asked how hard it was for them to pay for necessities such as food, housing, medical care and heating (dichotomized as difficult versus not difficult). The Dementia Severity Rating Scale offers an estimate by the caregiver of the level of dementia severity for the person with dementia summed across a number of facets relating to health and well-being (e.g. memory, ability to make decisions, personal care, social and community activity) (scale ranges from 0- normal to 54- maximally impaired) (Clark & Ewbank, 1996; Moelter et al., 2015). Finally, the person with dementia's dementia diagnosis was compared across caregiving styles with the most frequently reported diagnoses- Alzheimer's disease and Lewy Body Dementia, compared to other dementia diagnoses as one group.