Published in final edited form as:
Dementia (London). 2020 August ; 19(6): 1955–1973. doi:10.1177/1471301218814121.

The Care Ecosystem: Promoting Self-efficacy Among Dementia Family Caregivers

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Abstract

Objectives: To illustrate specific psychosocial interventions aimed at improving self-efficacy among family caregivers enrolled in the Care Ecosystem, a model of navigated care designed to support persons with dementia and their primary caregivers. Enrolled family caregivers work with un-licensed care team navigators who are trained in dementia care and provide information, linkages to community resources, and emotional support by phone and email.

Method: we conducted focus groups and interviews with the care team navigators to identify the approaches they used to target caregiver self-efficacy. We assessed mean self-efficacy scores in a sample of 780 family caregivers and selected three exemplary cases in which the caregivers had low self-efficacy scores at baseline with significantly higher scores after six months of participation in the Care Ecosystem intervention.

Results: Multiple psychosocial strategies were utilized by care team navigators working with patients with dementia and their family caregivers. Using thematic coding we identified three categories of Care Team Navigator intervention: emotional, informational, and instrumental support. These are consistent with a psychosocial approach to building self-efficacy.

Discussion: Self-efficacy represents a family caregiver's knowledge and preparedness in managing the challenges of care. Psychosocial support shows benefit in improving caregiver self-efficacy that in turn, may positively influence caregiver health and well-being. The findings in this manuscript demonstrate how a model of navigated care can positively impact self-efficacy among dementia family caregivers.

Introduction

Dementia is a progressive neurodegenerative condition affecting millions of people around the world (Plassman et al., 2007; Prince, Wimo, & et al, 2015; Querfurth & LaFerla, 2010;). The course of dementia involves deterioration of cognitive, behavioral, emotional and physical function. The care of a person with dementia involves advocacy, practical assistance with day to day function, strategies for dealing with dementia-related behaviors, protective supervision, and shared decision-making regarding health, safety, and finances. Family caregivers shoulder the bulk of this care, and most feel unprepared to meet the associated challenges and responsibilities (Jennings et al., 2015). Thus, there is great interest in discovering effective ways to prepare caregivers for these responsibilities and support them as they navigate dementia-related challenges.

Self-efficacy refers to the perception of one’s capacity to successfully and confidently manage responsibilities and tasks (Bandura, 2005) and is a factor in how people feel, think and behave in response to situational demands (Bandura 1997). Self-efficacy has been measured in broad categories; such as caregiving in general to more specific concerns, such as providing personal care or managing problematic dementia-related behavioral symptoms. Self-efficacy is considered modifiable and subject to change (Bandura, 1997). Increasingly, self-efficacy has become an important variable in the study of family members caring for a person with dementia because ratings of self-efficacy have been associated with measures of caregiver health and well-being. Caregivers with higher ratings of self-efficacy are more likely to have lower ratings of burden (Gallagher et al., 2011; van der Lee, Bakker, Duivenvoorden, & Droes, 2014) and a more positive outlook about caregiving (Semiatin & O’Connor, 2012). Higher self-efficacy for managing symptoms and for finding and arranging for services is associated with less depression and fewer physical symptoms such as headaches or pain among those caring for a person with dementia (Fortinsky, Kercher, & Burant, 2002). Feeling prepared has been associated with lower levels of distress (Wawrziczny et al., 2017). Alternatively, low ratings of self-efficacy are associated with increased biomarkers of stress (Mausbach et al., 2011) and elevated blood pressure (Harmell et al., 2011).

Self-efficacy has been shown in the literature to be influenced by psychosocial support interventions. The types of psychosocial interventions that have been studied in dementia among family caregivers are multiple and varied. These range from provision of education and skill building, case management, emotional support. and make use of cognitive, behavioral, or social mechanisms to protect and promote caregiver well-being (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Dahlrup, Nordell, Carlsson & Elmstahl, 2014; Whitlatch & Orsulic-Jeras, 2018). Specifically, education and skills training, case management, and interventions that target caregiver’s negative emotions have been associated with improvements in self-efficacy (Samia, O’Sullivan, Fallon, Aboueissa, & Hepburn, 2018; Tang & Chan, 2016). Classes that focus on building skills in managing behaviors and other caregiving tasks improve self-efficacy among dementia family caregivers (Huang, Shyu, Chen, Chen, & Lin, 2003). Caregivers who received coaching via tele-health had improved self-efficacy for obtaining respite and managing dementia-related behaviors (Steffen & Gant, 2016).

The Care Ecosystem is a dementia-capable model that provides personalized and proactive care for people with dementia and their caregivers that is currently being tested in a large single-blind controlled trial. Upon consent and randomization to the intervention group, dyads (persons with dementia and their caregivers), are assigned to a care team navigator who identifies needs and concerns, provides education and information, linkages to resources, care coordination, and emotional support by phone and email. Care team navigators are supported and supervised by a multidisciplinary team of clinicians (advanced practice nurse, social worker, and pharmacist) with dementia expertise. Details on study design and methods can be found in Possin et al, 2017 (Possin et al., 2017). The purpose of this manuscript is to illustrate specific Care Ecosystem interventions provided by care team navigators aimed at improving caregiver self-efficacy using focus groups, interviews, and review of exemplay case studies. We demonstrate that the approaches used by care team navigators in the Care Ecosystem are compatible with a model of psychosocial intervention that involves the provision of emotional, informational, and instrumental support.

Methods

The Care Ecosystem

The Care Ecosystem model was informed by other dementia care coordination programs that provide information, support and resources for persons with dementia and their families (LaMantia et al., 2015; Reuben et al., 2013) with an emphasis on personalizing the intervention to meet the needs of each dyad. In the Care Ecosystem, care team navigators guide dyads through proactive care protocols focused on issues critical to quality dementia care such as caregiver support and education, strategies for dealing with dementia-related behaviors, safety counseling, medication review, advance care planning, and links to community resources. Care team navigators provide emotional support and active listening. Care is delivered over the phone, by email, postal service mail, and in-person (if the dyad comes to the clinic for an appointment with their physician). The care team navigators provide educational handouts that were developed as part of the Care Ecosystem clinical trial (to protect author identification, we can add this link later).

While unlicensed, the care team navigators receive 80 hours of training designed for their role in dementia care. The training includes clinical observation as well as reading assignments, lectures, and discussions. During their training, they learn about issues salient to dementia and family caregiving. Care team navigators learn to locate information and community resources. They learn appropriate ways to communicate and listen to people with dementia and family caregivers and how to be emotionally supportive. Their training includes strategies for repeating or reflecting what the person said, validating or affirming the person’s emotional experience, acknowledging and appreciating what the person is doing well, clarifying goals and values, and collaborative consideration of the potential risks and benefits for different care strategies and decisions. The care team navigators focus on proactive planning to prevent common problems and improve quality of life and health outcomes. They participate in weekly clinical debriefing meetings with other care team navigators, advanced practice nurses, a social worker, and a pharmacist with expertise in dementia. An advanced practice nurse provides ongoing supervision (through observation and documentation review). Complex issues and any medical concerns that are beyond the scope of the care team navigator are triaged to a dementia specialist nurse, social worker, or pharmacist (by phone, email or in-person); thus extending the reach of dementia specialists to people with dementia and their family caregivers.

Care is initiated by the care team navigators through a comprehensive phone interview that is structured to elicit the dyad's needs and concerns. The person with dementia and the caregiver are both invited to participate; however, if the person with dementia has speech or comprehension deficits that create barriers to talking on the phone, the care team navigator communicates with the caregiver only. The intake interview includes a screen for safety concerns, behavior challenges, any unmet caregiving needs, financial and legal concerns, and issues with medication management. The care team navigator works with the dyad and the clinical team to come up with a plan to address the dyad's identified needs and issues. The care plan typically includes aspects of psychosocial support, for example, information and educational resources, strategies for caregiver support and respite, linkages to community services, and ways to address patient and caregiver health and well-being. The care plan may also include clinical or medication related recommendations from the nurse or pharmacist. Typically, the care team navigator communicates with the caregiver over the phone on a monthly basis although the frequency of contact is scaled up or down depending on the needs and preferences of the dyad. The Care Ecosystem "Dashboard" software is a workflow management tool used by the care team navigators to document encounter notes, care plans, and other relevant information such as the names of medical providers, back-up caregivers, and community service providers. The Care Ecosystem is designed to be a telephone- and web-based intervention: in most cases, care team navigators do not meet their dyads in-person, which enables a broader geographical reach of the program.

The Care Ecosystem Caregiver Self-Efficacy Scale

At baseline (prior to randomization) and at 6- and 12-month follow-up, dyads complete a telephone interview that includes the Care Ecosystem Caregiver Self-Efficacy Scale, as well as measures of caregiver burden (Zarit, Reever, & Bach-Peterson, 1980), caregiver depression (Kroenke, Spitzer, & Williams, 2002), and caregiver report of the person with dementia's quality of life (Logsdon, Gibbons, McCurry, & Teri, 2002). Participants are randomized to either the intervention (Care Ecosystem) or control (standard of care) group in a 2:1 ratio. Research coordinators, blinded to treatment group assignment after randomization, collect these data over the phone. Our measure of self-efficacy was created out of a desire to have a rating tool that measured the caregivers' perceived level of knowledge of where to find needed resources, social support, and confidence managing caregiving and behavioral challenges. At the same time, the measure needed to be brief and easy to administer over the phone. We reviewed existing measures (Fortinsky et al., 2002; Steffen, McKibbin, Zeiss, Gallagher-Thompson, & Bandura, 2002) consulted with other groups conducting similar projects (Jennings et al., 2015) and then selected those items and rating methods that could provide the most knowledge about caregiver self-efficacy while keeping within the goals of what is possible to deliver through the Care Ecosystem. Caregivers rate their self-efficacy on a 5-point scale of whether they strongly agree, agree, neutral, disagree, or strongly disagree (maximum score of 20, with higher score indicating higher self-efficacy) with the following four statements:

1. I know where to get the services I need.
2. I have people I can turn to when I need help with my problems.
3. I feel confident that I can manage future caregiving challenges.
4. I feel confident that I can manage (name of the person with dementia)'s changes in behavior.

Focus groups and interviews

The medical anthropologist working on the project facilitated a 1-hour focus group with the care team navigators in order to identify common actions, and strategies involved in psychosocial approaches to addressing caregiver self-efficacy, which include providing emotional, informational, and instrumental support. Care team navigators were asked to identify strategies they used to foster self-efficacy and preparedness among their caregivers. Three key thematic areas emerged from the qualitative research, and were used to organize care team navigator responses within subthemes to reflect how they implemented their work in practice. The goal of the focus group and interviews was to include strategies utilized among the entire cohort and incorporate these findings into the larger analysis. The medical anthropologist also conducted qualitative interviews with the care team navigators responsible for each of the three case studies selected for this review and members of the clinical team in order to fully understand the nature of the dyad's needs and how the team formulated their interventions. The focus group and interview data were analyzed using thematic coding, which is a process of analysis that involves coding for themes, iterative analysis, and memo writing to validate themes across research analysts (Corbin & Strauss, 2015; Creswell, JW & Poth, CN, 2018; Miles, Huberman, & & Saldana, 2014). Cases presented here are based on real dyads but identifying information and details have been modified to maintain anonymity.

Case Study Selection and Analysis

We examined baseline survey data to assess caregivers' ratings of their self-efficacy. In the baseline sample of 780 caregivers, the mean self-efficacy score was 13.38 +/− 3.04, and was similar between the caregivers enrolled at the California (13.24+/−3.20) and Nebraska / Iowa (13.58+/−2.8) sites. We selected three cases from the California cohort (intervention group) who had among the lowest caregiver self-efficacy scores at baseline (7 and 8) with marked improvement at 6 months (14 and 19) (see Table 2), and whose care exemplified the types of strategies employed by the care team navigators to boost self-efficacy. From clinical records in the Dashboard, we compiled characteristics about the dyads, their concerns, needs and questions, and the interventions delivered by the care team navigators. In each case study we describe concerns from the dyad's perspective, care team navigator care planning and interventions, and follow-up. The cases exemplify ways that the care team navigators addressed the specific needs of caregivers and people with dementia with a focus on psychosocial interventions to address caregiver self-efficacy and preparedness.

Results

Demographics of the three dyads are presented in Table 1. Self-efficacy scores for the three caregivers (along with itemized scoring) are shown in Table 2 and illustrate the specific domains that improved over 6 months. Self-efficacy for all the sub-items improved in 6 months. The only exception occurred for the caregiver described in Case #2: 2 sub-items (confidence in managing future caregiving challenges and changes in behavior) remained the same from baseline to 6 months.We identified three overarching themes from the qualitative data that are represented in Table 3, along with subthemes and actionable examples of care team navigator approaches within each thematic area. Broad themes included the areas: (1) emotional support (i.e. building rapport, encouraging caregiver to take care of his or her own wellbeing); (2) informational support (i.e. education to prepare caregiver to handle current and future challenges); and (3) instrumental support (i.e. helping create linkages to supportive services). Subthemes and examples emerged in responses when care team navigators reported strategies they used to foster self-efficacy and preparedness among the caregivers they worked with. These results reflect psychosocial strategies and approaches care team navigators used to address caregiver self-efficacy.

Case Studies

In each case study we discuss the dyad background, care team navigator interventions, and follow-up. The cases exemplify ways that the themes and actions identified during focus group and interviews were implemented in practice to address the specific needs of caregivers and people with dementia with a focus on psychosocial interventions to address self-efficacy and preparedness. Each dyad reported very different needs. Thus, the ability of the care team navigator to work closely with the dyad and identify and respond to these needs through the supportive relationship facilitated the tailored intervention that included anticipatory guidance and personalized resources and services.

Case #1

Background

The person with dementia is a 62-year-old Latino male in the moderate stage of dementia (unspecified). In addition to dementia he also had other complex medical conditions that included heart disease and diabetes. He exhibited short-term memory loss (repetitive questions throughout the day about what was planned and misplacing personal items), severe word-finding deficits and frustration when he was unable to communicate with others. Family reported bouts of anxiety and physical aggression (would push family members when angry and frustrated). His typical day was spent at home or accompanying family members on errands. The person with dementia’s 33-year son is the primary caregiver. He works fulltime. While he is named as agent in his father’s Durable Power of Attorney for Healthcare, several family members participated in care and decision-making for their father. The person with dementia lived with several family members (adult children and grandchildren) on a rotating basis. He generally stayed a week at a time with each family. His son expressed concern about the impact of his father's care on his occupational goals and worried about his ability to manage his physical aggression in the home. The son's self-efficacy score at baseline was 7.

Clarifying Needs and Goals:

There were several initial concerns reported by the family during their intake call with the care team navigator. They felt there was a lack of consensus on the best way to prevent and manage their father's anxiety and physical aggression. Some family members tried to use logic and reasoning, "You are in the right home: this is your daughter's house. Don't you remember being here last month?" Others attributed his anxiety and physical aggression to the frequent changes in his living situation yet felt this represented the best way to balance everyone's needs. The family had been very resourceful already: he was enrolled in the In-Home Supportive Services (IHSS) program, a county-based program that pays for some in-home care services in California. They had also found an adult day program in their area, but he had not started attending yet. The son was interested in learning about long term care placement options that were covered by Medicaid because his father's care was becoming more than they could safely manage at home. The care team navigator identified a need for: 1) support around dealing with family conflict, 2) information about how to respond to anxiety and aggression associated with dementia, 3) assistance with long term care placement, and 4) a need for acknowledgment and appreciation for the family's resourcefulness and strong advocacy skills in caring for their father.

Care team navigator interventions

Emotional: The care team navigator focused on providing psychosocial support and acknowledgement regarding the son and family's strong advocacy skills in caring for their father.

Informational: The care team navigator provided coaching and educational materials regarding more effective ways to communicate with him (for example, refrain from correcting or challenging him). The family was provided information from Disability Rights California (http://www.disabilityrightsca.org/pubs/549301.pdf) about how to advocate for 'protective supervision' to maximize the in-home support hours for dementia. In addition, the care team navigator provided a brief summary of ways that Medicaid pays for long term care in facilities in California and sent a website from California Advocates for Nursing Home Reform (CANHR) that includes detailed information about Medicaid for long-term care and searches for nursing homes by county: http://canhr.org/NH_Data/index.html. The care team navigator explained how challenging it can be to find a nursing home that will accept a person with dementia on Medicaid and encouraged the son to be diligent in calling facilities and submitting applications.

Instrumental: The family was provided with an application packet for a county-subsidized nursing home in their area.

Follow-up: After two months of calling and applying, the family was able to get their father into the county subsidized nursing home. The care team navigator provided educational handouts and coaching to help facilitate a smooth transition to the long-term care facility. Family members took turns visiting every day and told staff members their strategies to best manage his repetitiveness and anxiety. When the family described the experience as “exhausting” their care team navigator worked with the Care Ecosystem nurse to help the family identify a point person at the facility to communicate with about issues. The care team navigator also sent the family a Care Plan template that the family could use to document important information about their father’s needs and preferences and recommended posting the Care Plan in his room to help the facility staff provide more personalized care. The Care Ecosystem pharmacist consulted with the care team navigator to optimize the medication regimen; especially the medications prescribed to try to reduce aggressiveness. At 6 months, the son’s self-efficacy rating had improved to a score of 19.

Case #2

Background

The person with dementia is a 75-year-old Caucasian female in the mild stage of Alzheimer’s disease (AD). She had recently stopped working due to trouble learning the new technology required for her job. She drives her husband to work (recently passed the examination by the Department of Motor Vehicles) and meets him daily for lunch. She enjoys watching certain TV shows and taking care of the family’s dogs. Behavioral symptoms include mild irritability and frustration largely focused on her diagnosis of AD and feeling like a burden to her husband. Her 75 year-old husband is the primary caregiver and he works full-time. They had recently lost some of their savings due to the person with dementia’s poor judgment with a scam. The couple resides together in their own home. The caregiver’s self-efficacy score at baseline was 7.

Clarifying needs and goals:

The person with dementia searches the Internet daily for information about AD. She expressed a desire to be more active and would like to contribute financially. She manages her medications independently yet recently arrived to a medical appointment wearing two rivastigmine patches. The caregiver endorsed concerns about his own health, diminishing social life, his anxiety, and feels he has no one to turn to. He is nervous about their financial situation, safety issues surrounding his wife’s driving, and is looking for suggestions of appropriate activities for her during the daytime. Both are unsure whether they ever completed advance directives.

The care team navigator identified the following goals: 1) help preserve independence and promote a sense of purpose for the person with dementia, 2) minimize safety risks for the person with dementia without significantly compromising their quality of life, 3) get legal and financial affairs in order, 4) help improve the caregiver’s health and wellbeing.

Care team navigator interventions

Informational: The caregiver was offered several book titles about caring for a person with dementia and he elected to read *The 36 Hour Day* (Mace, NL & Rabins, PV, 2012) The care team navigator also provided documents and educational handouts on medical, legal and financial planning. Working closely with our pharmacy team, the care team navigator provided a reconciled medication list and educational handouts about medications and encouraged the caregiver to supervise his wife's medications.

Instrumental: The care team navigator identified support groups including a web and a telephone-based option for the caregiver to accommodate his work schedule and an in-person early stage support group for the person with dementia. The care team navigator provided options for activity engagement for her that included: a volunteer program at their local animal shelter and the Silver Sneakers exercise program. The care team navigator provided options to help the person with dementia stay engaged, including a volunteer program at their local animal shelter and the Silver Sneakers exercise program. The care team navigator referred them to their local Health Insurance Counseling and Advocacy Program (HICAP) to see if they would benefit from a Medicare Part D plan and provided information about additional strategies for reducing the costs of medications and resources for drug cost savings programs such as www.rxassist.org, www.needymeds.org and https://www.goodrx.com/.

Follow-up: The person with dementia continued to take care of the family dogs, started working out at the gym, and enrolled in a clinical trial for people with early stage Alzheimer's. The couple completed their advance directives and durable power of attorney for finances forms. The care team navigator talked with the caregiver about different options to help with transportation when his wife would have to give up driving. Options included: taxis, ridesharing applications, volunteers or friends, and county Para transit services. At 6 months, the caregiver's self-efficacy rating had improved to a score of 14.

Case #3

Background

The person with dementia is an 81-year-old Asian male in the advanced stage of Alzheimer's disease. Functionally, he requires assistance with daily tasks including eating, bathing, toileting and dressing. He naps more frequently during the day and awakens multiple times during the night. He had been hospitalized recently for a urinary tract infection and dehydration and had a twenty-pound weight loss over the past 6 months. His 51-year old daughter is the primary caregiver. The person with dementia lives in his daughter's home: the daughter arranged to work from home in order to care for him. The caregiver feels overwhelmed by her father's care needs and wonders how long she can continue to provide this level of care. The caregiver does not feel that friends and other relatives appreciate the difficulties in providing care.

At baseline, the caregiver's self-efficacy score was 6.

Clarifying needs and goals:

The caregiver reported being overwhelmed because she could not leave the house or take a vacation. She had been encouraged to consider placing her father in a long-term care facility but did not trust facility staff to take good care of him since he required a lot of help with meals and incontinence care. The caregiver was also concerned about the cost of paying for in-home help and wanted to know how long her father was likely to survive. During her father's recent hospitalization, the caregiver felt pressured by hospital staff to put him on 'comfort care'. She felt conflicted about the concept of 'comfort care' because she thought it meant 'giving up,' and she had observed a dramatic recovery in the past when he was treated with intravenous fluids and antibiotics. She also felt that her father had a good quality of life and appeared happy and content even though he could only say a few words and was functionally dependent on others.

The care team navigator identified the following needs for: 1) acknowledgment and appreciation of the caregivers' efforts and her commitment to her father's care, 2) supportive listening and validation of emotional experiences, 3) information about advanced dementia, 4) support with making decisions regarding her father's care, 5) help accessing respite services

Care team navigator interventions

Emotional: The care team navigator provided supportive listening and acknowledged the caregiver's dedication and competence as a caregiver and they mutually agreed to talk weekly. The Care Ecosystem nurse was included in discussions about the person with dementia's prognosis and end of life care.

Informational: The care team navigator and nurse talked through issues the caregiver identified and brainstormed different strategies (for example, whether to consider hospice, placing her mother in a facility or keeping her home) and they provided written information when they thought it would be helpful. They talked about ways to prevent pressure sores, loss of mobility, and infections like pneumonia or urinary tract infections. They sent videos (available on YouTube) by dementia specialist Teepa Snow that show ways to assist people with advanced dementia with eating and positioning like this one: https://www.youtube.com/watch?v=sNPAESrllgQ. In addition, the care team navigator provided the caregiver with respite grant applications from the Alzheimer's Association, the Family Caregiver Alliance, and Hilarity for Charity as well as information about local support groups.

Instrumental: The primary care provider (PCP) was informed about the caregiver's distress around the past hospitalization and conducted a home visit to discuss prognosis and complete the Physician's Order for Life Sustaining Treatment (POLST).

Follow-up: The caregiver elected to manage her father's care at home. She received two respite grants and was able to hire and train a team of caregivers so she could take some time off. Hospice was not instituted; however, the PCP ordered home health that included home visits from a physical therapist. The caregiver chose not to join a support group; she preferred to use her time away to do things she missed such as having dinner with friends.

The person with dementia gained weight, regained the ability to walk with assistance, and his sleep improved. The caregiver takes pride in her father's improved health in spite of "all the doctors telling me he was going to die". The caregiver continues to appreciate monthly calls with her care team navigator to talk about caregiving and how she is doing. At 6 months, the caregiver's self-efficacy rating had improved to a score of 14.

Discussion

In this manuscript we present thematic findings from multiple qualitative methods that included a focus group with seven care team navigators regarding the types of strategies they employed to enhance caregiver self-efficacy, interviews with care team navigators about specific strategies they employed, and case study analysis. These findings reinforced that care team navigators relied on multiple psychosocial support strategies targeting education, links to community resources and services, and emotional support. Our findings are in line with prior research showing links between psychosocial support and self-efficacy and also demonstrate the feasibility of targeting such interventions as a method for improving caregiver knowledge, confidence, and preparedness in managing caregiving responsibilities.

In order to assess how these themes manifested in practice we describe three persons with dementia whose family caregivers, at entry into The Care Ecosystem, had low ratings of self-efficacy regarding their knowledge of where to find needed services, people to help them, and confidence with caregiving challenges and dementia-related behaviors. The dyads received assistance from a care team navigator whose role was to identify needs, provide linkages to community resources, and offer psychosocial support. The case reviews provide multiple examples, related to the themes identified, of the specific actions by the care team navigator to address psychosocial support relevant to the person with dementia and the caregiver's needs. Care team navigators addressed psychosocial support by connecting caregivers to resources that enhanced education, skill development, and respite. Care team navigators acknowledged the difficulty and challenges associated with caregiving and provided support and active listening. Within six months of receiving our intervention in Care Ecosystem, caregiver ratings of their self-efficacy were markedly improved. The only exception occurred for the caregiver described in Case #2: 2 sub-items (confidence in managing future caregiving challenges and changes in behavior) remained the same from baseline to 6 months.

An advantage of The Care Ecosystem is the emphasis on a multicomponent array of strategies and suggestions personalized for each dyad. Prior research has shown that single component interventions are less effective than multicomponent strategies (Gitlin, Marx, Stanley, & Hodgson, 2015). For example, patient education on its own is not as effective unless offered in combination with supportive services (e.g. counseling) or cognitive/behavioral (skills training) strategies. Providing personalized answers to caregiving situations was shown to improve feelings of competence among caregivers (Van Mierlo, Van der Roest, Meiland, & Droes, 2010). As illustrated in the case reviews, care team navigators provided psychosocial support and active listening to the caregivers while also offering personalized strategies and suggestions targeted to the dyad's specific needs. They offered education when needs were identified, including education about dementia and care management strategies, ways to manage transitions in care, advance planning for medical, legal and financial issues, and identifying and addressing medication related issues. They linked caregivers with support groups as a way to obtain psychosocial support and to build social networks. They provided coaching on ways to manage the changes in the person with dementia’s cognitive and functional decline and behavioral symptoms. Successful interventions also actively involve both the person with dementia and the caregiver (Maslow, September 2012) and our cases reflect that value.

In addition, much of the care team navigator work involved ways to expand the caregiver’s network. In one case, this was accomplished by obtaining a respite grant that allowed the caregiver to bring hired help into the home. In others, the care team navigator connected the caregiver with a support group or helped facilitate the move of the person with dementia into long-term care facility. These interventions expanded the supportive network for the family.

In our program of care navigation, care team navigators typically make contact with their dyads monthly although the frequency of contact is negotiated depending on dyad needs. It is noteworthy that effectiveness of interventions designed to improve self-efficacy may be tied to a “dose.” In earlier work Brodaty created an algorithm regarding intervention “dosage.” The number of sessions or contacts involved in the intervention received a rating: minimal (1–2 contacts), moderate (3–5 contacts), medium-high (6–10 contacts), or high-intensive (>10 contacts). A meta-analysis of psychosocial interventions designed to reduce psychological morbidity and burden, found that a dose of greater than 3.5 contacts was less effective than those involving around 3.5 contacts (Brodaty, Green, & Koschera, 2003). This suggests that interventions (e.g. contacts with clinic or research staff) could potentially introduce feelings of burden or stress for caregivers. Further analysis to be completed regarding our Care Ecosystem study may shed light on the most appropriate “dose” of time (on the telephone or on email) the care team navigator spends working with the dyad. Further work may also help to answer whether telephone or video-conferencing (versus in-person classes and sessions) provides an efficient and effective method for addressing caregiver’s needs.

Limitations

We hypothesize that the care team navigator’s provision of psychosocial supportive strategies influenced the improvement in caregiver’s rating of their self-efficacy but this relationship cannot be confirmed without analysis of the entire sample. It is possible that the passage of time and greater familiarity with caregiving demands influenced the self-efficacy ratings. It is also possible that caregivers who enrolled in our study were more open to or hopeful to have help in connecting with education, resources, and psychosocial support. While our new Care Ecosystem Self-Efficacy measure shows promise at being able to detect change in important factors of self-efficacy, it is brief compared to others that have been used, and it has not yet been validated. Also, while ratings of self-efficacy may influence factors such as burden and depression, we did not include these variables in this analysis. Future work will help determine the efficacy of using rating tools as a means for identifying care needs in the clinical (non-research) setting. Caregivers who are older and/or female have been shown to have lower ratings of self-efficacy (Pinquart & Sorensen, 2003) and

Caucasian females have reported lower self-efficacy compared to Hispanic and Latino female caregivers (Depp et al., 2005). Again, an analysis of our complete sample will help to identify the presence of mediating and moderating factors of self-efficacy. Finally, supportive services for caregivers may be more widely available in California compared to Nebraska and Iowa, thus the cases presented here may not be representative of a nation-wide sample. An analysis of the complete sample is pending and should help to clarify these issues.

Summary

Self-efficacy refers to the perception that one is able to succeed in a specific situation or accomplish a task and has become an important way of assessing a dementia family caregiver’s knowledge and preparedness in managing the challenges of care. Psychosocial support shows benefit in improving self-efficacy that in turn, may positively influence caregiver health and well-being. The cases reviewed in this manuscript demonstrate how care team navigators, who are unlicensed and trained in aspects of dementia care and supported by a clinical team of dementia experts, can positively impact self-efficacy among dementia family caregivers through psychosocial interventions (delivered by phone and the internet), and we provide detailed examples of how caregiver self-efficacy can be addressed. Family caregivers are the foundation of care for persons with dementia, and effective and scalable strategies that support caregivers are desperately needed to meet their complex needs.

Acknowledgments

This research was funded by grants from the Centers for Medicare and Medicaid Services (1C1CMS331346) and the NIH/NIA (5R01AG056715)

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Table 1.

Person with dementia and caregiver characteristics

PWD characteristics	**Case 1**	**Case 2**	**Case 3**
Gender	Male	Female	Male
Age	61	75	81
Cultural background	Latino	Caucasian	Chinese
Preferred language	Spanish	English	Cantonese
Diagnosis	Dementia (unspecified)	Alzheimer's disease/Vascular dementia	Alzheimer's disease
Stage of dementia*	Moderate	Mild	Advanced
Insurance	Medicare and MediCal	Medicare	MediCal
Income (range)	$15,000–24,999	$100,000–149,999	Less than $10,000
Caregiver Characteristics			
Gender	Male	Male	Female
Age	33	75	51
Cultural background	Latino	Caucasian	Chinese
Preferred Language	English	English	English
Relationship to PWD	Son	Husband	Daughter

Dementia stage was assessed using the Quick Dementia Rating System (QDRS), a 10-item questionnaire completed by the caregiver. Scores range from 0–30: higher scores represent greater impairment in cognition, function, communication, and behavior (Galvin, 2015).

Table 2:

Self-efficacy scores

Case	Sub-items	Scores Baseline	Scores 6 Months
1	I know where to get the services I need	1	5
	I have people I can turn to when I need help with my problems	2	4
	I feel confident that I can manage future caregiving challenges	2	5
	I feel confident that I can manage (person with dementia)'s changes in behavior	2	5
	Total	**7**	**19**
2	I know where to get the services I need	2	5
	I have people I can turn to when I need help with my problems	1	5
	I feel confident that I can manage future caregiving challenges	2	2
	I feel confident that I can manage (person with dementia)'s changes in behavior	2	2
	Total	**7**	**14**
3	I know where to get the services I need	2	3
	I have people I can turn to when I need help with my problems	2	3
	I feel confident that I can manage future caregiving challenges	1	4
	I feel confident that I can manage (person with dementia)'s changes in behavior	1	4
	Total	**6**	**14**

Table 3:

Care Team Navigator Psychosocial approaches to addressing caregiver self-efficacy (focus group and interviews)

Theme	Sub-theme	Examples of CTN Approachss
Emotional support	Build social and emotional rapport	• Supportive listening • Consistent contact through monthly or more frequent phone calls • Provide genuine acknowledgment of the caregiver's strengths and skills (e.g. they are organized, caring, have strong advocacy skills)
	Help caregiver take care of own emotional and physical health and wellbeing	• Foster the idea that protection of the caregiver's health is vital • Reinforce the idea that self-identity does not have to be only as a caregiver (e.g. connect to a social club to foster friendship and social network, connect to past activities such as kayaking, yoga) • Coach on ways to ask for and receive help from others (e.g. friends, families) • Refer caregivers to therapy, support groups, mindfulness classes, etc.
Informational Support	Prepare caregiver to handle what is going on	• Help caregiver reframe expectations about the abilities of the person with dementia • Provide strategies to enhance communication (limit choice, simplify content, limit use of logical reasoning) with person with dementia • Educate about the nature of dementia and the inevitability of deterioration despite good caregiving • Educate caregiver about approaches to understanding and responding to the person with dementia's behavior and personality changes
	Prepare caregiver to handle the future	• Provide book titles and information about support groups, therapists • Address financial questions and concerns about how to pay for care and linkages to respite grants, public benefits, and elder law attorneys • Explore all potential options for future scenarios in care delivery (e.g. home with paid care or long-term care in a facility) • Educate about potential safety risks (falls; wandering; household hazards) • Provide education on recognition of delirium
Instrumental Support	Linkages to supportive services	• Identify and facilitate respite (day programs; in-home care) • Identify and facilitate skills training • Referrals to community services (meal delivery; case management; technology; supplies and equipment; home safety assessments) • Referrals to medical services (palliative care; hospice; specialty providers; primary care providers)