Family caregivers’ perceptions and experiences of participating in the learning skills together intervention to build self-efficacy for providing complex care

Carole L. White, RN, Ph.D, FAAN\textsuperscript{a,b,*}, Aleera Barrera, OTD, OTR\textsuperscript{a,c}, Sarah Turner, BSc\textsuperscript{a}, Ashlie Glassner, RN, BSN, Ph.D(c)\textsuperscript{a}, Jennifer Brackett, Masters in Gerontology\textsuperscript{a}, Sheran Rivette, Family Caregiver\textsuperscript{a}, Kylie Meyer, Ph.D\textsuperscript{a,b}

\textsuperscript{a} School of Nursing, UT Health San Antonio, 7703 Floyd Curl Drive, San Antonio, TX 78229, United States
\textsuperscript{b} Glenn Biggs Institute for Alzheimer’s and Neurodegenerative Diseases, UT Health San Antonio, 7703 Floyd Curl Drive, San Antonio, TX 78229, United States
\textsuperscript{c} School of Health Professions, UT Health San Antonio, 7703 Floyd Curl Drive, San Antonio, TX 78229, United States

\section*{Introduction}

Family caregivers are providing intense and complex care, taking on medical and nursing tasks, with over half of caregivers worrying about making a mistake.\textsuperscript{1-4} In addition to basic activities of daily living (ADLs; e.g., assisting with mobility) and instrumental activities (IADLs; e.g., managing finances), caregivers are taking on more medical/nursing tasks (e.g., managing complex medication regimens). These tasks require specialized knowledge of disease processes and medical/nursing procedures, such as using mobility devices and preparing special diets.\textsuperscript{2-8} Complicating conditions, comorbidities, and progression of disease in recipients of care can further add to the complexity of care needed from caregivers.\textsuperscript{9} Caregivers report limited disease management including giving injections, preparing special diets, managing incontinence and operating specialized medical equipment. Performing medical/nursing tasks for persons living with dementia is particularly challenging related to difficulties care recipients may have understanding instructions, in communicating their needs, and behavioral symptoms including resistance to care.\textsuperscript{1} People living with dementia experience more chronic health conditions than cognitively-intact older adults,\textsuperscript{5} further complicating the caregiver in monitoring and managing of these co-morbid conditions, such as diabetes, adding to caregiver stress.\textsuperscript{9,10}

Over 11 million Americans provide unpaid care to a family member or friend living with Alzheimer’s disease and related dementias (ADRD).\textsuperscript{6} Notably, current caregivers to persons with dementia provide, on average, 20% more hours of care per week than dementia caregivers a decade ago.\textsuperscript{6} In an integrative review examining medical/nursing tasks among caregivers of older adults with dementia,\textsuperscript{2} in those studies that reported prevalence, more than two-thirds of caregivers were performing medical/nursing tasks. These tasks included medication management including giving injections, preparing special diets, managing incontinence and operating specialized medical equipment. Performing medical/nursing tasks for persons living with dementia is particularly challenging related to difficulties care recipients may have understanding instructions, in communicating their needs, and behavioral symptoms including resistance to care.\textsuperscript{1} People living with dementia experience more chronic health conditions than cognitively-intact older adults,\textsuperscript{5} further complicating the caregiver in monitoring and managing of these co-morbid conditions, such as diabetes, adding to caregiver stress.\textsuperscript{9,10}

Providing care in situations where caregivers feel inadequately prepared is associated with increased stress, anxiety, and depression.\textsuperscript{11} Building caregiver self-efficacy to provide complex care is...
important to support overall caregiver wellbeing.12–14 Self-efficacy is defined as a person’s beliefs in their ability to capably and confidently perform specific activities.15 Caregivers with a high sense of self-efficacy are more likely to view the complex care tasks as challenges to be mastered, while caregivers with low self-efficacy are more likely to perceive these tasks as strains that exceed their capabilities.14,16 Low self-efficacy is associated with increased caregiver burden,12,16 depression17 and decreased health-related quality of life.18 Importantly, self-efficacy is a modifiable attribute which can be learned and enhanced and, as such, a targeted outcome for caregiver interventions.19

The effects of psychosocial interventions on self-efficacy were summarized in a systematic review and based on their findings, the authors concluded that self-efficacy can be modified among dementia caregivers, particularly by those interventions that involve interactive activities.20 While the reviewed studies did not examine interventions to build self-efficacy around complex care provision, given the positive findings for psychosocial interventions, it would be important to examine the effects of an intervention for complex care on caregiver self-efficacy. The findings from a recent integrative review on complex care tasks provided by caregivers of persons living with dementia, taken together with the national data on caregivers providing complex care, emphasizes the need for interventions that support caregivers in providing complex care tasks.

Based on the lack of interventions focused on caregiver self-efficacy in the context of performing basic care and medical/nursing tasks for persons living with dementia, we developed and tested an intervention, ‘Learning Skills Together’. The objective of this study is to describe the caregivers’ experiences with and perceptions of the intervention to build our understanding of how the complex care intervention may contribute to building self-efficacy.

Methods

Study design

This qualitative descriptive study was embedded in a pilot clinical trial to evaluate the effects of the Learning Skills Together (LST) intervention on caregiver self-efficacy.21 The Institutional Review Board (IRB) approved all study procedures. The study requirement for written consent was waived by the IRB but all participants were provided with verbal and written information about the project and verbal consent was obtained.

Learning skills together intervention

A team of health care professionals, including nursing, occupational therapy, speech-language pathology, gerontology, nutrition, and dental hygiene, developed the psych-educational program for family caregivers. In designing the intervention, consideration was given to the nursing/medical care tasks caregivers reported performing most frequently and/or the tasks reported as difficult in the Home Alone Report.8 The context considers care for a person living with dementia in mid-stage, where caregivers are taking on more care and where communication difficulties and disruptive behaviors increase the challenges around complex care provision. For example, the care recipient may be unable to communicate swallowing difficulties and assisting with feeding, an ADL, also includes identifying swallowing difficulties and preparing a special diet or using behavioral clues to identify pain and determine the cause and treatment (e.g., urinary tract infections). Modules provide interactive content on behavioral challenges, communication, home safety, transfers including the use of durable equipment, swallowing and nutrition, managing incontinence, oral hygiene, medication administration, and monitoring co-morbidities including pain. Five principles: safety, hygiene, comfort, dignity, and independence, underpin the intervention content. The intervention was initially delivered as a 5 h in-person workshop. An initial evaluation of this format showed that the intervention was feasible and caregivers reported high satisfaction.22 With COVID-19 and the need for social distancing, we transitioned the in-person workshop to an online, 4-session synchronous intervention. Both the in-person and online versions of the intervention were led by the interprofessional team who designed the modules. In the in-person version, there was time built into the intervention for caregivers to practice performing some of the complex care tasks whereas in the online version we had caregivers practice skills at home and report back or, for example, bring medication lists for discussion. The online sessions were provided over two weeks, with a booster follow-up five to six weeks later, all delivered synchronously over Zoom. In this online version, four sources that lead to self-efficacy as identified in Bandura’s self-efficacy theory were deliberately incorporated into the content and delivery of the intervention as mechanisms for behavior change (see Table 1).

<p>| Table 1 Activities integrated into Learning Skills Together (LST) intervention targeting specific mechanisms for building self-efficacy. |
|-------------------------------------------------|---------------|-----------------|-----------------|</p>
<table>
<thead>
<tr>
<th>Mastery</th>
<th>Modeling</th>
<th>Coaching and Feedback</th>
<th>Emotional State</th>
</tr>
</thead>
<tbody>
<tr>
<td>Development of goals that caregiver wished to achieve</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Lecture content about complex care taught by experts</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Group activities to reinforce learning and to access feedback (e.g., identify fall risk in an illustration)</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Peer demonstration of problem-solving approaches and strategies during group discussion of case studies, including opportunity to provide and receive feedback on strategies</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Suggested assignments to practice implementing skills and follow-up opportunities to discuss (e.g., monitoring hydration)</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Creating interactive environment where caregivers felt safe and comfortable to share and ask questions</td>
<td>X</td>
<td>X</td>
<td>X</td>
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</table>
Participants and procedures

Participants were family caregivers of persons living with dementia. They were recruited from community-based and clinical settings. To be eligible for participation in the LST intervention study and subsequently the semi-structured interviews, participants were: (i) a family member/friend of an individual living with ADRD who had received a diagnosis from a physician (self-report by caregiver), (ii) caring for individual with mid-stage dementia as identified as a score between 4 and 6 on the Global Deterioration Scale,23 (iii) aged 18 years or older, (iv) providing complex care as defined by assistance with at least two instrumental activities of daily living or one activity of daily living, and (v) not paid to provide care. Following completion of the intervention, caregivers were invited to participate in a semi-structured interview.

In the month after completing the LST and final data collection, we invited participants to take part in a semi-structured individual interview. We used purposeful sampling to ensure diversity in gender, kin relationship, and ethnicity. For example, when there were 3 women who had completed LST, we invited the first two women to participate and then waited until there was a male participant to invite. All 15 participants who were approached agreed to the interview. An interview guide was developed by the interprofessional team with experience in family caregiving, including nursing, gerontology, and occupational therapy. Interview questions were designed to elicit caregivers’ experiences with the intervention components and strategies they are able to apply, as well as the delivery format (see Supplemental Table S1). All interviews were conducted by a doctoral student, with supervision from a researcher, via Zoom software and were audio-recorded with participant permission. Interviews were transcribed verbatim using transcription software.

Data analysis

The data analysis was conducted by members of the study team which included a nurse, occupational therapist, family caregiver, and gerontologist. Content analysis was used to analyze the transcribed data, with comparison across interviews.24 To begin, each member of the analysis team independently reviewed the first transcript and began to assign codes to the text. Team members met to review the first transcript together and to generate the list of codes using both a deductive and inductive coding approach. The codes were discussed among the team members until we reached a consensus on the initial codes and the meaning of each code. Following this initial coding session, each transcript was independently reviewed by two team members who then presented their coding to the team for clarification and additional coding. The process was iterative with new codes integrated into the original list during the analysis. The team then reviewed and grouped the codes into themes, using Bandura’s theory of self-efficacy15 as a guiding framework. Saturation of the themes was reached with the 15 interviews. Credibility was enhanced through the inclusion of a family caregiver who brought her expert knowledge to the analysis of the data as well as team members representing different professions who provide service and education to support family caregivers.

Results

The mean age of the 15 caregivers who participated in this study was 66 +/- 14 years, 73% were female, 60% were non-Hispanic white and 40% self-reported Hispanic ethnicity. The majority were spousal caregivers (67%), followed by adult children (20%) and 2 caregivers reported other relationships. Most had been providing care for at least 3 years. Table 2 provides detailed information on the 15 individual caregivers. Interviews were held between 2 and 5 weeks after completion of the intervention and lasted between 25 and 45 min.

The following themes and sub-themes were identified from the interviews: (1) helpfulness of the content, (1a) expertise in the delivery of the content, (1b) environment for learning, (1c) validation of my caregiving; (2) if they can do it, so can I, (2a) receiving feedback from other caregivers, (2b) giving feedback to other caregivers, (2c) emotional support from other caregivers; (3) applying what I am learning. (3a) setting goals and achieving them, (3b) sharing information with others. Fig. 2 shows the themes and sub-themes, mapped to the four sources of self-efficacy.15

1. “Helpfulness of the Content”

Consistent across interviews, caregivers described the helpfulness of the content in building their confidence around complex care provision, which included expertise in the delivery, environment for learning, and the validation of their caregiving. Most caregivers had been providing care for between 3 and 5 years and with the progression of the disease, they were taking on more care tasks and were concerned about performing these tasks. “The helpfulness of the content... a lot of stuff that I really wanted to know about and didn’t know... it was very helpful.” (CG3) Although all modules were referenced during at least one of the interviews, caregivers consistently

Table 2

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Marital Status</th>
<th>Race/Ethnicity</th>
<th>Education Level</th>
<th>Employment Status</th>
<th>Recipient of care</th>
<th>Years of caregiving</th>
<th>Number of ADLs*</th>
<th>Number of IADLs*</th>
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<tbody>
<tr>
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<td>28</td>
<td>Single</td>
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<td>Working</td>
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<td>3–5 years</td>
<td>6</td>
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<td>62</td>
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<td>Hispanic</td>
<td>Some college</td>
<td>Working</td>
<td>Father</td>
<td>&gt;5 years</td>
<td>6</td>
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<td>CG3</td>
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<td>72</td>
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<td>Wife</td>
<td>1 to 3 years</td>
<td>3</td>
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<td>White</td>
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<td>Unemployed</td>
<td>Friend</td>
<td>&lt;1 year</td>
<td>3</td>
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<td>CG5</td>
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<td>77</td>
<td>Married</td>
<td>White</td>
<td>Post-graduate degree</td>
<td>Retired</td>
<td>Wife</td>
<td>3–5 years</td>
<td>5</td>
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<tr>
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<td>77</td>
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<td>White</td>
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<td>Husband</td>
<td>3–5 years</td>
<td>6</td>
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<td>White</td>
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<td>Wife</td>
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<td>6</td>
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<td>White</td>
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<td>Wife</td>
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<td>5</td>
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<td>Hispanic</td>
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<td>Hispanic</td>
<td>Post-graduate degree</td>
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<td>Mother</td>
<td>3 to 5 years</td>
<td>6</td>
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<td>High School</td>
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<td>&gt;5 years</td>
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<td>Married</td>
<td>White</td>
<td>High School</td>
<td>Retired</td>
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<td>3 to 5 years</td>
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<td>Female</td>
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<td>Hispanic</td>
<td>College</td>
<td>Retired</td>
<td>Husband</td>
<td>&gt;5 years</td>
<td>7</td>
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<td>CG14</td>
<td>Female</td>
<td>73</td>
<td>Married</td>
<td>White</td>
<td>College</td>
<td>Retired</td>
<td>Husband</td>
<td>3 to 5 years</td>
<td>5</td>
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<tr>
<td>CG15</td>
<td>Female</td>
<td>76</td>
<td>Married</td>
<td>Hispanic</td>
<td>Post-graduate degree</td>
<td>Retired</td>
<td>Husband</td>
<td>1 to 3 years</td>
<td>4</td>
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</tbody>
</table>

*Number of Activities of Daily Living (ADLs) out of a possible 6 that caregivers performed; number of Instrumental Activities of Daily Living (IADLs) out of a possible 9 that caregivers performed.
commented on the importance of modules that addressed challenging behaviors, home safety, transfers, medications, and managing incontinence as information they needed to provide care. Several caregivers commented specifically on safely transferring the recipient of care. “Taking the person from a sitting position to standing up and knowing what to do, and the bathing the safety precautions for bathing. So, to me, that was very helpful because I didn’t know anything about it.” (CG6) A spousal caregiver discussed her concerns before enrolling in the intervention and how what she had learned helped to reduce her stress, “How am I going to deal with my husband? How can I keep him at home? I’m not a nurse, wasn’t trained to be a nurse, didn’t want to be a nurse. But I knew I needed some basics, to where I could extend the time that we’re here at home. After taking this class, it was that instant, I can do this. I’m so grateful because I can sleep a little bit better, that those stressors have lessened quite a bit.” (CG13)

a. Expertise in the delivery of the content. Caregivers commented on the opportunity to learn from and interact with a team of health care professionals. “I don’t feel as anxious as I was, you know, just a few months ago. And I think hearing from professionals who are experts in their areas, the course, has a lot to do with it. So I just feel, I think my competence is, it’s night and day.” (CG9) Although you can look up some of the material on the internet, caregivers commented on the importance of the discussion that was part of the intervention. “And just because I could look something up on the web, it’s not sufficient. I have to have that person to person, ask questions and there were experts that could help me. Like when we talked about swallowing, we can extend more on questions like well, what if and what if?” (CG10)

b. Environment for learning. Across interviews, caregivers described an environment that enhanced their learning, with material presented in a way that supported their learning. “I felt, I felt very comfortable. They got it across very simple, in plain language, it was easy to understand. And it was great having all these different experts like nurses, the therapists, nutrition, that was very important.” (CG2) Caregivers also highlighted the materials that accompanied each module and reinforced what they were learning including the case studies and videos. “I saw it presented in the class and then I watched the video again after to use the gait belt to get my husband up. I tried and I could do it.” (CG14)

c. Validation of my caregiving. Caregivers described that validation of the care they were providing gave them more confidence. “It allowed me to reflect on the care I am providing, how I have progressed. And it gave me a little more reassurance and confidence that I am doing something right and ways to improve.” (CG7) They also learned how to modify the care they are providing to address the changing needs of their family member. “This is, this is no longer something he can do on his own [managing his medications]. So we do it together. I suggested to him, why don’t we sit at the table and do it together. I am gonna sit next to him. Well, so that’s what we’re doing now.” (CG6)

2 “If they can do it, so can I”

Caregivers appreciated the group setting and felt that this format enhanced their learning and their confidence. Sub-themes that related to this social persuasion or modelling included the interaction with other caregivers in receiving from giving feedback as well as the emotional support they received from the group. “No, it helped very much. It made me feel I wasn’t alone and I realized, if they can do it, so can I.” (CG15) It was validating to know that other caregivers share similar concerns and worries about providing complex care but also reassuring when they heard success stories from their peers. “And the reason I like the group format is because I feel I feel so alone as it is. So being with other people and listening to them and hearing things that they have been able to do or have tried, I find that helpful, I guess. Everyone sharing I think is very helpful, very much so.” (CG6)

a. Receiving feedback from other caregivers. Caregivers valued the feedback from other caregivers. “It was good getting feedback from the others too, from their own personal experiences.” (CG5) They also reported that they learned from the questions of other caregivers, bringing up situations they may have not encountered as well as things they had tried that worked or did not work. “There are those that have been doing this longer and the sharing of what they’re doing or not doing, you know, so I felt that was really good.” (CG13)

b. Giving feedback to other caregivers. In addition to receiving feedback, caregivers wanted to be able to share their experiences with other caregivers. Participants found being able to provide feedback enhanced their own confidence in the care they are providing. “I like the group because they may highlight something that I might forget or not acknowledge but it also helps me to be able to give them a suggestion or advice from what I have learned. This is how I handle it, you know, you might want to try it.” (CG10) They appreciated the interaction with other caregivers. “There was an opportunity for interaction, and I felt, I felt like being able to contribute some of the things that I have learned and were important to me.” (CG5)

c. Emotional support from other caregivers. Caregivers described the environment as supportive to their leaning and were able to give and receive support from their peers. “A group like this kind of lets us all unload and I want to be able to give support to the other people in the group.” (CG11) They described and were appreciative of getting to know other caregivers in their cohort and the support they felt was there. “I really felt that I had friends that I really could call if I was stressing too bad. And that helps and gives you confidence.” (CG12) The comparison with other caregivers and knowing they were not the only ones who were learning to provide complex care supported their learning. “But it’s always nice to know that you’re not the only one sitting out there going, well am I the only one who doesn’t know this. It makes it easier on you. Because you see there are other people facing the same things that you are facing.” (CG3)

3. “Applying what I am learning”

Being able to apply what they learned during the LST intervention was important to building caregiver confidence. Sub-themes related to the application included setting goals and achieving them and sharing the information with others. “It’s not that I wasn’t confident before, but I am applying what I am learning now. There’s a different tone, like I know how to do it and I know I can do it. Not necessarily what’s best in every situation but I know more and am bringing it to the care of my grandmother and it has helped in my situation.” (CG1) They recognized the changing care environment and feeling better equipped to deal with it. “I just feel a little more confident. You know, because I know more. And the more the more you know, the more confident you are and the better you are to, to cope with the challenges that change and present themselves every day.” (CG7)

a. Setting goals and achieving them. Caregivers reported that setting goals and successfully accomplishing them built their confidence. “One of my goals was as, as he progresses and gets worse, the environment that we’re going to need to create here at home and I know how to do it now and am already being able to make some changes.” (CG6) Another caregiver described her goal to learn
about transfers. "And my goal was to know about transfers and that belt was, oh, it was another aha moment." (CG13)

b. Sharing the information with others. Caregivers described being able to pass on what they learned with other people involved in the care of their family member and they felt that being able to share the information increased their confidence for complex care tasks. "What I ended up doing was I ended up sharing it with my family. It empowered me to be like, okay, I feel confident enough to be able to share this with them. And they also get to learn. So it's kind of a win, win." (CG1) Another caregiver described feeling confident to share the information with a home aide. "Very much, very much it has increased my confidence and I'm trying to figure out a way to maybe extend this to the lady that comes to help." (CG10) A male spouse described having his son come over and practice the transfer belt with him so they both would know how to use this for his wife. "I had my son come over and I was able to practice using the belt with him so that I now know we can both be comfortable to use this." (CG8)

Online delivery of intervention

Within the guide, we also asked caregivers to comment on how they thought participating in an online delivery of the intervention impacted their learning. Most caregivers appreciated the convenience of an online program. "It was great for me because I really can't leave my husband that long. Or at least I'm not comfortable doing that. And so Zoom has just been awesome for that." (CG6) Caregivers commented that the case studies and having the chance to report back to the group enhanced their learning within an online environment. Several caregivers commented that content such as managing equipment may have been better in person. One caregiver requested that we develop a video that shows in more detail how to safely use a transfer belt. Finally, a comment from several caregivers is that it may have been better in person. One caregiver requested that we develop a video that shows in more detail how to safely use a transfer belt. Furthermore, their mastery was demonstrated in sharing the information with others. And they also get to learn. So it's kind of a win, win." (CG1) Another caregiver described feeling confident to share the information with a home aide. "Very much, very much it has increased my confidence and I'm trying to figure out a way to maybe extend this to the lady that comes to help." (CG10) A male spouse described having his son come over and practice the transfer belt with him so they both would know how to use this for his wife. "I had my son come over and I was able to practice using the belt with him so that I now know we can both be comfortable to use this." (CG8)

Discussion

Caregivers manage increasingly complex care as the dementia of the care recipient progresses yet receive limited training to undertake these complex care tasks.1,3,4 Caregivers worry about making mistakes, with low confidence with complex care tasks contributing to feelings of stress, anxiety, and guilt.2 Skill-based interventions have been shown to improve self-efficacy20 and have been found to be superior to education alone.25 Yet support caregivers' need for complex care training have been focused on delivery of information alone.26,27 The results reported here provide insight into how this psycho-educational intervention may contribute to self-efficacy among caregivers for complex care provision.

Self-efficacy is the strength of one’s belief in being able to complete specific tasks or behaviors.15 Confidence or belief in the ability to perform specific task predicts the performance of those behaviors and tasks. Coaching in self-efficacy is important as it has been shown to improve health and well-being for family caregivers of persons living with dementia.12,18,26,29 Four sources of self-efficacy: mastery, modeling, coaching and feedback, and emotional state,15 provided a guiding framework for the 3 themes and 8 sub-themes identified from the semi-structured interviews (Fig. 1).

Mastery or performance outcomes is an influential source of self-efficacy.15 with strong efficacy expectations developed through the successful completion of specific tasks, in this case complex care provision. Lee and colleagues, in an integrative review of care tasks undertaken by family caregivers, reported that family caregivers find these tasks difficult and challenging, and require support from healthcare professionals to master these tasks.2 Having caregivers develop goals and, in turn, achieve those goals led to self-efficacy. Homework was built into each session where caregivers had the opportunity to practice and master the specific complex care tasks. The theme “applying what I am learning” demonstrated the caregiver’s mastery of the caregiving tasks. Caregivers described setting goals and achieving them, for example mastering the use of the transfer belt. Furthermore, their mastery was demonstrated in sharing the information with other family members and professional care assistants.

The group format for LST targeted the modelling domain in building self-efficacy. While caregivers described learning from experts, they consistently valued learning from their peers. Hearing their peers describe successful performance raised their expectations that they could also master comparable complex care tasks, “if they can do it, so can I”. Caregivers commented positively on learning from other caregivers, receiving and giving feedback which contributed to their self-efficacy. Samia et al. conducted a qualitative study to understand caregiver training needs in a program designed to build caregiver self-efficacy.30 Caregivers consistently emphasized the importance of group training, opportunities to interact with other caregivers, and the wealth of information available from their peer caregivers.

Caregivers of older adults with dementia identified the need for more and better structured information, training and support from healthcare professionals.4 In the current study, caregivers described the "helpfulness of the content" and valued the feedback they received from the experts. Coaching and feedback was used throughout the

<table>
<thead>
<tr>
<th>Themes</th>
<th>Sub-Themes</th>
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<tbody>
<tr>
<td>Helpfulness of the content</td>
<td>• Expertise in the delivery of the content</td>
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<td></td>
<td>• Environment for learning</td>
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<tr>
<td></td>
<td>• Validation of my caregiving</td>
</tr>
<tr>
<td>If they can do it, so can I</td>
<td>• Receiving feedback from other caregivers</td>
</tr>
<tr>
<td></td>
<td>• Giving feedback to other caregivers</td>
</tr>
<tr>
<td>Applying what I am learning</td>
<td>• Emotional support from other caregivers</td>
</tr>
<tr>
<td></td>
<td>• Setting goals and achieving them</td>
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<td></td>
<td>• Sharing the information with others</td>
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[Fig. 1. Themes and sub themes mapped to elements of Bandura's self-efficacy theory.]
intervention to support self-efficacy, including group activities designed so that caregivers could succeed and case studies, similar to situations caregivers may be facing in caring for a person with mid-stage dementia. Furthermore, caregivers described validation of their previous caregiving experiences as building their confidence. Similarly, Soroka et al., examining caregiver confidence with end-of-life care, reported that prior experiences and validation of their caregiving increased mastery for new tasks around supporting their family member. They commented on the importance of supportive feedback from their peers as well as the experts.

A supportive environment for learning that considers the emotional state is essential for building self-efficacy. Caregivers described the supportive “environment for learning”, that included support from their peer caregivers. Intentional time was built into the intervention to facilitate communication among caregivers and to consider their individual learning and self-care needs. Although there was not a module focused specifically on self-care, it was built into each of the modules. In examining how the Care Ecosystem Model promotes self-efficacy among caregivers, the investigators reported that providing personalized strategies and suggestions targeted to the caregiver’s specific needs may have contributed to feelings of competence. Other investigators have also discussed the importance of therapeutic interventions as a means of enhancing caregiver confidence.

Related to the pandemic, the delivery format was transitioned to an online delivery. We were concerned that the format would continue to support learning complex care tasks and results of the quantitative data reported elsewhere support the effectiveness of the virtual delivery. Caregivers in this study reported satisfaction with the online intervention and expressed increased confidence in performing complex care tasks. The results from two systematic reviews show a positive impact of online caregiver interventions, particularly when they are tailored to caregiver needs and multi-dimensional, such as including opportunities to practice skills and discuss with other caregivers. In-person events may be difficult for family caregivers to attend related to their caregiving responsibilities. Furthermore, their reach is limited to family caregivers within certain geographical areas and are usually not accessible to caregivers in rural areas.

Limitations

The sample represents 15 participants from the LST intervention clinical trial. The sample represents those agreeing to participate in a clinical trial and as such may represent caregivers who already feel sufficiently confident about their abilities and wanted to learn more. As the intervention was delivered online through Zoom, we were able to include both rural and urban family caregivers. The online delivery, however, limits the sample to family caregivers who have access to and are able to utilize technology to find information about caregiving. Their perceptions of the intervention and self-efficacy may not reflect those caregivers who are unable to utilize technology.

Conclusions and implications

There is growing evidence for self-efficacy as a mediator in supporting caregiver well-being. Yet little research exists on how best to build self-efficacy for complex care provision among family caregivers. The strategies used here to build self-efficacy and the support for sources of self-efficacy identified from the semi-structured interviews can serve as examples that can be included in other interventions to enhance self-efficacy. Caregivers emphasized the value of the group mode of delivery which can be a more cost-effective approach to intervention delivery and also enhanced caregiver self-efficacy. Implications for practice from the results reported here underscore the need for healthcare professionals to recognize the role that caregivers take on in providing complex care and to systematically assess caregiver knowledge and confidence in performing this care. The Caregiver Advise, Record, Enable (CARE) Act requires provision of education and instruction of medical/nursing tasks prior to hospital discharge. There is a need for health professionals in the community to also recognize and support the training needs of family caregivers of persons living with dementia. Future research is needed to examine the sustainability of self-efficacy, whether it translates into better outcomes for persons living with dementia, and the effectiveness of delivering the intervention within a community setting.

Funding

The project described was supported by the National Institutes on Aging and National Center for Advancing Translational Sciences, National Institutes of Health, through Grant T1L TR002647 (awarded to K. Meyer), P30AG064200-02 (through the Emory University Center on Dementia Caregiving Mastery, awarded to C. White) and P30AG066546 (South Texas Alzheimer’s Disease Research Center, C. White receives funding through this award). The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

Ethical approval

Ethics approval was obtained from UT Health San Antonio Institutional Review Board; Protocol: HSC0200410E.

Declaration of Competing Interest

The author(s) declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.gerinurse.2022.04.012.

References


