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Caregiver self-efficacy improves following complex care training: Results from the Learning Skills Together pilot study

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ABSTRACT

Family caregivers to persons living with dementia increasingly provide complex care tasks, though most (53%) do so without any training. "Complex care" includes medical/nursing tasks, as well as personal care tasks that require disease knowledge. Of the 67% of dementia caregivers who provide complex care, nearly half worry about making a mistake. To help caregivers feel more confident when providing complex care tasks, we developed and conducted a pilot study of the 4-week Learning Skills Together psychoeducation program (LST; N=35). Participants in LST reported high satisfaction with the program and found the information shared about complex care was easy to understand. Pre- and post-test data demonstrated improvements in mean caregiver self-efficacy at both 4-weeks and 8-weeks post-intervention (mean difference (MD)=1.0, SD= 1.6, *p*-value=0.004 and MD= 1.0, SD=2.2, *p*-value=0.038, respectively). Results demonstrate the potential for a brief psychoeducational program to prepare caregivers to provide complex care to persons living with dementia.

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Introduction

Among the two-thirds of caregivers who provide complex care to a family member living with dementia, less than half received prior training (53%).[1] Complex care tasks include both *medical/nursing tasks* (e.g., managing medications, monitoring swallowing problems), as well as *personal care that requires knowledge of dementia and co-morbid conditions* (e.g., help with feeding when the care recipient experiences dysphagia).[2] Complex care is particularly challenging for family members to administer to persons living with dementia, 80% of who experience behavioral symptoms (e.g., resisting care).[3,4] Cognitive changes also make it more challenging for persons living with dementia to communicate needs, such as when they experience pain.[2] Further, the presence of co-morbidities with dementia may exacerbate the complex care demands (e.g., diabetes).[5,6] Although many interventions provide training on management of behavioral symptoms of dementia in the community (e.g., Care of Persons with Dementia in their Environments, Savvy Caregiver),[7] there are few available training programs to help family caregivers provide complex care, inclusive of medical/nursing tasks, to persons living with dementia in community settings.

Learning Skills Together (LST) is a psychoeducational program developed to improve caregiver self-efficacy with complex care tasks. "Self-efficacy" refers to a person's belief that they can accomplish a specific task.[8] LST was designed in alignment with Self-Efficacy Theory, wherein higher levels of self-efficacy facilitate skills practice and improved performance based on feedback.[8] Within this model and as demonstrated in observational studies, self-efficacy both mediates and moderates depressive symptomology, wherein higher levels of self-efficacy are associated with lower depressive symptomology.[9,10] As such, interventions to improve self-efficacy may also support caregiver health and offset the deleterious effects of caregiver stress on caregiver mental health.[11] Yet, most community caregiver interventions to improve self-efficacy focus on stress management and management of behavioral symptoms, rather than complex care.[12]

Psychoeducational interventions to improve caregiver self-efficacy

Current responses to caregivers' need for complex care training primarily rely upon information-delivery alone.[13,14] For example,

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following the seminal report on lack of support for medical/nursing tasks, AARP and partners launched the Home Alone Alliance video library to show caregivers how to perform tasks. Similarly, the *AlzMed* materials also provide advice on managing medical/nursing tasks, relying on passive learning approaches such as reading a book or website.[13] Yet, interventions to improve caregiver self-efficacy are most effective when they integrate skill-building, such as psychoeducational approaches.[12] Caregiver psychoeducational interventions are characterized by their integration of discussion and active learning components, in addition to information delivery.[15]

Prior studies of psychoeducational programs demonstrate their ability to improve dementia caregiver self-efficacy, although none have focused on the performance of complex care.[12,16] For example, Tele-Savvy is a six-week group-based online program made to develop caregivers' skills to manage behavioral symptoms of dementia using psychoeducational approaches, including active learning, caregiver coaching, and assignments to teach problem-solving.[17] Results from a recent randomized controlled trial of Tele-Savvy demonstrated that participation improved caregiver self-efficacy compared to both active and non-active control groups.[18] In addition, caregivers also reported improvements in caregiver mastery, lower levels of depression and stress, as well as less bother from behavioral symptoms of dementia following participation in Tele-Savvy.

The present study

The purpose of this study was to determine the feasibility of delivering LST with fidelity, acceptability among caregivers to people living with dementia, and to preliminarily examine the extent to which LST improved self-efficacy in accordance with the intervention's theoretical approach.[19] The investigators hypothesized that caregivers who participate in the Learning Skills Together program would report higher average self-efficacy following participation.

Materials and methods

Design

In this pilot study, we used a single group repeated measure design.

Procedures

Caregivers completed a self-administered baseline survey 1-week prior to when they were scheduled to participate in LST. The 4-session intervention took place over two weeks. A post-test survey was sent by an email survey link 4 weeks after the final session of the program, and a final survey was administered 4-weeks after that (8-week post-intervention survey). Caregivers completed an online satisfaction survey at the end of the program. Caregivers were recruited using flyers distributed at geriatric and memory clinic sites, social media posts, newsletter notifications with community partners, word-of-mouth, and the Alzheimer's Association Trial Watch website. Caregivers could complete eligibility screening either online or by telephone. Those who completed an online screening survey received a telephone follow-up call to consent into the study.

Sample

To be eligible to participate in the study, participants had to be at least 18 years old and provide unpaid care to a family member, including families of choice, living with mid-stage Alzheimer's disease and related dementias (ADRD). Participation was limited to those caring for someone living with mid-stage dementia, as program content was tailored to the care most often at mid-stage, such as management of behavioral symptoms of dementia. Caregivers had to self-report the care recipient received a diagnosis of ADRD from a physician. Staging was determined using the Global Deterioration Scale, administered by phone, wherein eligible participants characterized their family member's ADRD symptoms as fitting with Stages 4 to 6.[20] Caregivers further had to provide care to someone who required assistance with 1) at least two instrumental activities or 2) at least one activity of daily living.[21,22] Paid caregivers, those who could not read and speak English, caregivers who did not have reliable access to a computer or tablet device and internet, or who planned to place the care recipient in a skilled nursing facility in the next three months were not eligible to participate in the research study. Those who were not eligible to participate in the study could still attend Learning Skills Together.

Intervention

Learning Skills Together was delivered over 4, 1.5 h sessions held over Zoom videoconference. Four to ten caregivers attended per session, which was facilitated by a master's-level gerontologist. LST was developed by an interdisciplinary team of healthcare professionals, including nurses, occupational therapists, a dental hygienist, a nutritionist, a speech-language pathologist, and gerontologists. The program was originally delivered in-person during a 5 h workshop provided by a caregiver education program placed within a university. Prior to being tested as a research intervention, the program contracted with a local Area Agency on Aging to receive payment for delivering Learning Skills Together as a part of the National Family Caregiver Support Program. Prior to beginning the research study, LST transitioned online in response to COVID-19 social distancing requirements. The development of the online program was guided by lessons learned from this in-person workshop. For example, similar to prior studies on caregivers' preferences for intervention, we found that caregivers enjoyed learning from other caregivers and thus integrated more opportunities for group discussion into the LST.[23] Content addresses common training needs identified in national studies, as well as qualitative feedback from caregivers.[2,14,24] Each session covered 2 to 3 topics, including: managing behavioral symptoms of dementia, communicating with someone living with dementia based on cognitive changes, providing mobility assistance and home safety (e.g., using a gait belt, pivot transfers), preparing special diets and nutrition (e.g., address the loss of appetite), monitoring and managing swallowing problems (e.g., when to thicken liquid), maintaining oral hygiene (e.g., monitoring for sores), managing bowel and bladder incontinence (e.g., prevention of urinary tract infections), and managing medications (e.g., monitoring side effects). During the pilot study, the content was either delivered by healthcare faculty or doctoral students, or else via recorded video presentations that were prepared by these presenters. Participants were also welcomed to participate in an optional "booster" session administered 5 weeks after the initial program, wherein they reviewed key concepts.

Goal Setting. Prior to participating in the first group session, caregivers were asked to complete a goals worksheet using an online form, as individual goal-setting activities are hypothesized to improve caregiver self-efficacy.[25] Participants were asked to either select suggested goals pertaining to session objectives or write their own goals. After selecting 3 to 5 goals, a nurse interventionist called the caregiver to review goals one-on-one. During this call, suggestions were made to ensure goals were realistic and relevant to the caregiver's needs.

Measures

Primary Outcome Measures. We measured *caregiver self-efficacy* using the 3-item Caregiver Competence Scale (Cronbach's

alpha=0.74, range: 3 to 15).[26] For this scale, caregivers were asked to indicate their level of agreement with statements about their sense of confidence as a caregiver (e.g., "I feel confident that I am meeting the needs of my relative"). *Caregiver self-efficacy when providing complex care tasks* was measured using a 14-item author-generated measure, as the investigator team was not aware of any validated measures of caregiver self-efficacy when completing complex care tasks. Items were based on topics addressed during LST (e.g., managing incontinence) and thus reflected complex care tasks most often conducted by family caregivers. Caregivers rated how confident they felt with each item, with responses ranging from 0 ("Not confident at all") to 5 ("Very confident"; Cronbach's alpha=0.88, range 0 to 70).

Paricipant Engagement. Participant engagement, and important component of peer learning, was monitored in multiples ways. First, caregiver attendance at each session was recorded, such that we could learn the average number of sessions attended. Further, because attendance does not necessearily mean being engaged in discussion, in a post-intervention satisfaction survey emailed to participants, caregivers were asked the extent to which they found the Learning Skills Together Program to be interactive from 1 ("Strongly disagree") to 5 ("Strongly agree"). In addition, during two cohorts in February and March 2021, an observer monitored sessions and rated the level of engagement ("Not at all engaged," "Somewhat engaged," "Mostly engaged," or "Definitely engaged").[27] Though not a measure of participant engagement, this individual also rated the extent ot which presenters matched session objectives ("Definitely matched," "Mostly matched," "Somewhat matched," and "Not at all matched"). The observer could write notes regarding their observations.

Participant Characteristics. Information about participant demographics (e.g., gender, age, race/ethnicity, educational attainment) and their caregiving situation (e.g., relationship to the recipient of care, hours per week spent on caregiving) were collected in the baseline survey. Additionally, caregivers were asked to provide information about assistance provided with activities of daily living (ADL) and instrumental activities of daily living (IADL).[21,22]

Analysis

Descriptive statistics, including means, frequencies, and variances were used to describe participants' demographic characteristics, caregiving situations, outcomes, and satisfaction. To determine whether there was a statistically significant difference in selected outcome scores from the pre-test survey and post-tests, we conducted paired t-tests to compare 1) baseline scores to the 4-week post-intervention survey and 2) baseline scores to the 8-week post-intervention survey. We did not control for covariates, as bivariate analyses showed no association between baseline characteristics and outcomes.[28] Further, as this was a pilot study, we focused on the directionality of results rather than testing statistical significance. All analyses were conducted in Stata 15.1. This study was determined by the UT Health San Antonio Institutional Review Board to be Exempt (HSC20200410E). This study is registered at ClinicalTrials.gov, Protocol NCT04428034.

Results

Intervention delivery

The Learning Skills Together program took place monthly from September 2020 to May 2021. Two programs were held in May 2021 due to high demand. Monthly sessions were attended by 8.2 participants on average, among whom half were study participants. Session monitoring was successfully completed in 14 of the 16 possible intervention sections (87.5%). Presenters "Mostly matched" (6) or "Definitely matched" (8) session objectives in all sections.

Sample

The analytic sample included all eligible participants who completed the baseline survey and attended at least two of the four Learning Skills Together sessions (see Fig. 1). The baseline sample included 35 participants, of whom 29 completed the 4-week follow-up survey, and 25 completed the 8-week follow-up survey. One participant completed the second but not the first follow-up survey. Of those who responded to the 4-week survey, one caregiver reported that they were no longer a caregiver, such that the study had a retention rate of 83% at 4-weeks post-intervention and 71% at 8-weeks post-intervention.

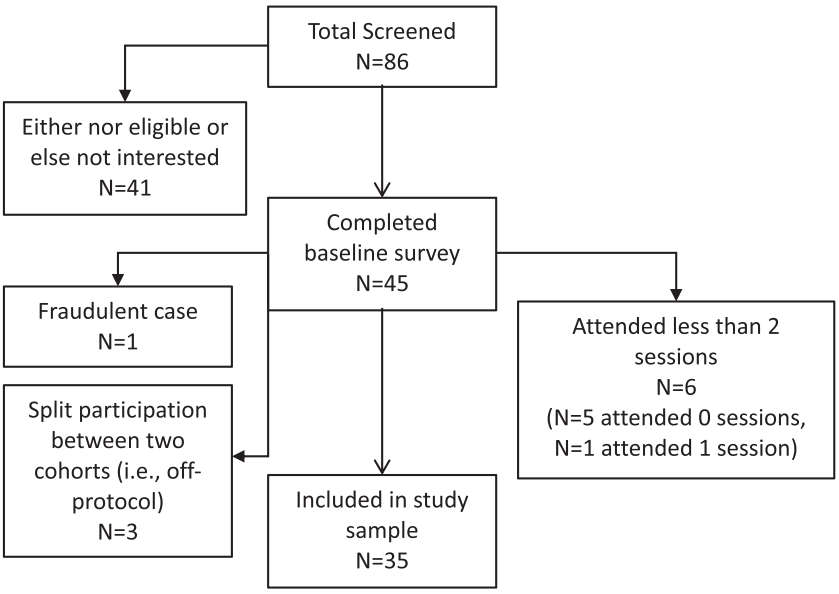

Fig. 1. Construction of study sample.
Note: All attendees were screened for eligibility. N=4 caregivers screened to participate in the program, were found to be ineligible for the study, and did not attend sessions.

Sample Characteristics

Participant Demographic Characteristics. Participants ranged in age from 25 to 85 years, with an average age of 63 (SD= 14.2). Most participants were women (83%). Fifty-four percent of the sample was Caucasian/white, followed by Hispanic (29%), African American/Black (9%), and Asian (9%).

Caregiving Situations. Nearly all participants were the primary caregiver (91%), and most shared a residence with the care recipient (82%). Spouses comprised the highest proportion of study participants (46%), followed by adult children (40%). As anticipated, given the focus on caregivers to persons with mid-stage dementia, most participants (67%) had been in this role for at least 3 years. Care recipients needed assistance with an average of 4 ADLs and 8 IADLs. Additional demographic information about the sample and their caregiving situations is described in Table 1.

Complex Care Tasks. Participants completed an average of 12.1 of 14 complex care tasks and had an average self-efficacy score of 3.7 out of 5 at baseline. The tasks which caregivers felt most confident completing included communicating with the care recipient's healthcare team (M=4.6, SD=0.6), making choices about the care recipient's healthcare if they are not able to (M=4.5, SD=0.7), and preparing foods that are nutritious (M=4.2, SD=1.4). Caregivers were least confident with managing incontinence issues (M=2.5, SD=1.7), managing behavioral symptoms of dementia (M=2.6, SD=1.4), and assisting with mobility tasks (M=2.8, SD=1.7). Supplementary Table S1 describes the caregivers' self-efficacy with complex care tasks at baseline.

Comparison of the Characteristics of Study Completers vs. Non-Completers. Bivariate comparisons of participants who completed and did not complete the 8-week survey demonstrated a statistically significant difference in scores for depressive symptomology at baseline. Participants who dropped out of the study reported higher depression scores (M=10.3, SD=2.3) than those who completed the 8-week survey (M=6.2, SD=0.9; *p*-value=0.049). There were no other statistically significant differences in demographic characteristics or other baseline measures.

Table 1
Sample Characteristics, N=35.

	N	%
Age[1]	62.6	14.2
Female	29	82.9
Race and ethnicity		
Caucasian/white	19	54.3
African American/Black	3	8.6
Hispanic	10	28.6
Asian	3	8.6
Educational attainment		
High school	2	5.7
Some college	3	8.6
College and/or post-graduate	15	42.9
Post-graduate	15	42.9
Employment		
Full-time	8	22.9
Part-time	5	14.3
Retired	17	48.6
Unemployed	4	11.4
Decline to state	1	2.9
Primary Caregiver	31	91.1
Caregiving relationship		
Spouse	16	45.7
Parent, incl. in-laws	14	40.0
Other	5	14.3
Shared residence	32.8	82.3
Length of time caregiving		
Less than 1 year	5	14.3
1 to 2 years	6	17.1
3 to 5 years	16	45.7
More than 5 years	8	22.9
Hours of caregiving per week[1]	62	46.5
Number of Activities of Daily Living (0 to 6)[1]	3.8	2.3
Number of Activities of Daily Living (0 to 9)[1]	7.7	1.4

[1] Mean and standard of deviation reported.

Outcomes

Caregiver Self-Efficacy. We observed statistically significant improvements in overall self-efficacy from the baseline survey to the 4-week post-intervention survey (MD=1.0, SD=1.6, *p*-value=0.004; Table 2). This was considered a medium/large effect size (Cohen's *d*= 0.61). Improvements from baseline were maintained at the 8-week post-intervention survey, though there was greater variation (MD=1.0, SD=2.2, *p*-value=0.038), and, as such, the effect size for this test was small to medium in size (Cohen's *d*= 0.43). Table 3 describes changes in the average scores, and Table 4 displays the result from the paired t-tests for each outcome. Summary statistics described in the text are from those cases included in t-test analyses.

Caregiver Self-Efficacy with Complex Care Tasks. We also found improvements in caregiver self-efficacy with complex care tasks from baseline to the 4-week survey. Scores increased from a mean of 3.7 to a mean of 4.2. This change remained at the 8-week survey. Both the 4-week and the 8-week changes in scores for self-efficacy with complex care tasks from baseline were statistically significant (*p*-value=0.006 and *p*-value=0.036, respectively).

Caregiver satisfaction with Learning Skills Together

Overall, caregivers reported a high degree of satisfaction with the Learning Skills Together program. Almost 97% of survey completers said they would be "Very likely" to recommend LST to another caregiver, with one caregiver reporting they would "Likely" recommend the program (N=32). All satisfaction survey completers said they "Strongly agree" (90.6%) or "Agree" (9.4%) with the statement "I enjoyed participating In the Learning Skills Together program." We also found that 96.7% found the information shared about complex care easy to understand (N=31). Additional satisfaction survey data can be found in Supplementary Table S2.

Participant engagement

Participants attended an average of 3.7 of the 4 LST sessions. Both participants and the observer indicted high levels of engagement during group sessions, an important condition for peer-learning to occur. All 32 satisfaction survey participants agreed or strongly agreed that sessions were interactive (100.0%). The observer reported that participants were "Definitely engaged" in half of the sessions (7), or else "Mostly" (4) or "Somewhat" (3) engaged. Comments also described sessions as interactive: "Group was interactive with sharing personal experiences and struggles similar to case studies presented."

Discussion

Findings from this pilot study support feasibility and acceptability of delivering a psychoeducational complex care intervention to dementia family caregivers online. Caregivers were highly satisfied with the program, and fidelity reports demonstrated high adherence to intervention objectives. Moreover, we observed preliminary evidence that participants scored higher on anticipated outcomes, including self-efficacy, following the participation in LST. Although evidence is not conclusive given the study design, this finding is important given the possibility that complex care training could have the opposite effect and potentially overwhelm families to diminish

Table 2
Summary statistics.

	T1 (N=35)			T2 (N=29)			T3 (N=27)		
	M	SD	N Miss	M	SD	N Miss	M	SD	N Miss
Competence	11.6	2.6	1	12.6	2.2	1	12.7	2.0	0
Self-efficacy with complex care tasks	3.7	0.8	3	4.2	0.6	4	4.1	0.6	3

Table 3
T-test results.[1]

	T1 to T2			T1 to T3		
	Mean Diff.	SD	p-value	Mean Diff.	SD	p-value
Competence	1.0	1.6	0.004	1.0	2.2	0.038
Self-efficacy with complex care tasks	0.6	0.9	0.006	0.4	0.8	0.036

[1] Results are reported only for those cases included in t-test analyses.

self-efficacy with complex care. Our findings suggest this did not occur, and most participants indicated information on complex care easy to understand.

The unanticipated transition to digital delivery sparked concerns about our ability to deliver training on how to provide "hands-on" care over video conference, which might have undermined the implementation of strategies consistent with Self-Efficacy Theory. In the initial, in-person version of LST, participants were given a chance to practice some skills (e.g., how to brush with a collis curve toothbrush).[24] Without the opportunity for direct feedback from healthcare experts on skill performance, we had to find alternative ways to improve self-efficacy, wherein practice and application are essential components. We did this using case studies, quizzes, group discussions, and other interactive activities to encourage practice and application of new skills. Notes from fidelity reports and satisfaction surveys suggest these strategies were successfully implemented, such as the observation of overall high engagement in discussion amongst participants and participants themselves reporting that sessions were interactive. Evidence of improved self-efficacy scores strengthens this conclusion. The finding that caregiver self-efficacy can be improved using digitally-delivered multicomponent psychoeducation is consistent with prior studies, such as the Tele-Savvy intervention that focuses on managing behavioral symptoms of dementia.[18,29] We are not aware of programs that use this approach focused primarily on complex care tasks.

Although effects from this pilot study are preliminary, and thus conclusions we can draw are limited, the change in mean self-efficacy departs from findings of the evaluation of *AlzMed*, where caregivers received a resource book or informational website on complex care alone and no change in confidence was observed. It is possible that the more active learning components within LST may have contributed to greater improvements in caregiver self-efficacy.[13] Holding Learning Skills Together over multiple sessions may also be important to maintaining changes in self-efficacy. DiZazzo-Miller et al. (2020) observed a decline in improvements with caregiver confidence 3-months post-intervention after a 2 h event focused on mobility, nutrition, and communication.[30] In contrast, higher levels of self-efficacy from baseline largely remained 2-months after participation in Learning Skills Together.

Our pilot study results indicate Learning Skills Together is an acceptable intervention to dementia family caregivers, most of whom indicated high levels of satisfaction. Not only were caregivers satisfied with the intervention, but participants attended most sessions. High levels of attendance are particularly notable given the 6 h time commitment to participate. It also appears recruitment methods rendered a sample of caregivers for whom LST would be most relevant, as most participants reported high levels of personal care, such as ADLS, and provision of complex care topics covered in the intervention. Still, it is notable that we found a difference in retention for caregivers with high depressive symptomology. It is possible that persons with severe depression may benefit from more acute forms of mental health intervention prior to participation in Learning Skills Together. This is consistent with self-efficacy theory, wherein poor mental health may negatively impact a person's ability to engage in learning processes.[8]

Limitations

This study has several limitations. First, for this pilot study, we applied a pre- and post-test design with 35 participants, such that it is not clear that changes in self-efficacy can be attributed to the intervention alone due to both limited statistical power and the possibility of confounding factors. It is possible that self-efficacy would have improved regardless of intervention participation, as caregivers gained more experience managing complex care tasks. Further, given the extent of participant dropout, results from this study are subject to selection bias. Lower-than-anticipated retention by 8 weeks may be attributed to our survey data collection method, wherein participants' self-administered surveys were sent by email and thus did not engage sufficiently with study staff. Familiarity with staff is known to improve retention in longitudinal studies.[31] In future research, we plan to administer surveys by Zoom with consistent members of the study team.

Conclusion

Brief complex care psychoeducation delivered online to family caregivers to persons living with dementia appears to be a feasible and acceptable approach to improve caregiver confidence with complex care tasks. Results from this pilot study may reveal an added-value of group-based learning guided by self-efficacy theory, similar to prior caregiver interventions, to support confidence with complex care. To further test the hypothesis that group-based psychoeducation can improve caregiver confidence with complex care tasks, the authors plan to further test the efficacy of Learning Skills Together in a randomized controlled trial with an active control group. In this trial, we will also conduct further psychometric testing to examine the validity of measuring self-efficacy with the complex care instrument. First designed as a service program reimbursable by the National Family Caregiver Support Program, LST is responsive to recent national reports that call for intervention models that can be readily translated and scaled.[32,33] Given the growing number of older adults expected to experience Alzheimer's disease or related dementia during their lifetime, interventions are needed to prepare family caregivers to confidently provide care while maintaining their own wellbeing and without fear of making a mistake.[32,34]

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Declaration of Competing Interest

None.

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Supplementary materials

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