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Supporting In-Home Caregivers in Symptom Assessment of Frail Older Adults with Serious Illness: A Pilot Study

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Abstract

Background: Many older adults with serious illness who depend on others for care have symptoms that are difficult to manage. Supporting caregivers in symptom assessment (SA) may reduce suffering.
Objective: Pilot an SA-Toolkit for caregivers to assess older adults' symptoms at home.
Design: Pilot study.
Setting/Subjects: English-speaking patients ≥65 years of age and their caregivers from a home-based geriatrics program in San Francisco.
Measurements: With multiple stakeholder input, we created a SA-Toolkit consisting of illustrations depicting symptoms, validated Faces Scale, and easy-to-use tracking system with phone numbers of family/friends/clinicians. At baseline and one week, we assessed change in patients' symptoms and caregivers' self-efficacy with SA (5-point scale) using Wilcoxon signed-rank tests. We assessed acceptability at one week.
Results: Eleven patient/caregiver dyads participated in the study. Patients were 84.7 years old (SD 5.7), 81.8% women, 27.3% non-white. From baseline to one week, mean number of symptoms decreased (3.7 [1.5] to 2.6 [1.8], $p = 0.03$). Specifically, patients with pain decreased from 63.6% to 36.4%, anxiety 54.6% to 18.2%, depression 45.5% to 27.3%, and loneliness 36.4% to 18.2%. Caregiver self-efficacy increased (4.6 [0.3] to 4.8 [0.3], $p = 0.09$). Patients found the symptom illustrations easy to use (8.7 on 10-point scale), but the Faces Scale less so (7.3/10) because it provided ''too many choices.'' Caregivers liked the SA-Toolkit because it was easy to use; nearly all (10/11, 90%) would recommend it to others.
Conclusions: The SA-Toolkit resulted in decreased symptom burden among patients and higher caregiver self-efficacy in SA. The SA-Toolkit is acceptable and may help reduce suffering in frail, older patients.

Keywords: caregiver burden; home-based care; symptom assessment; vulnerable populations

Introduction

MILLIONS OF OLDER ADULTS in the United States have serious illness and experience associated symptoms.[1] These symptoms can be challenging to manage, particularly for those who depend on others for care, and often result in emergency room visits.[2–4]

It is estimated that 2.3 million caregivers support 900,000 older adults who are seriously ill or at the end-of-life,[5] and this number is expected to increase as the population ages.[6] In-home caregiving has been associated with lower health care utilization and improved quality of life for older adults.[7–11] However, caregivers of patients with serious illness experience distress related to patients' symptom burden,[12–15] in part because of not knowing how to assess the severity of symptoms and when to reach out to patients' clinicians for support.[16,17] Although prior successful models have used telehealth and trained advanced practice nurses to

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provide symptom management,[18–20] this level of support is often not available, particularly for vulnerable populations. To our knowledge, no prior resources have been developed to support caregivers in the symptom assessment (SA) and to empower them to reach out for clinical help if needed.

In previous focus groups of frail older adults living in the community and caregiver stakeholders, we learned of the large unmet need of untreated symptoms, including pain and loneliness, and a lack of standardized SA methods for caregivers.[21] Stakeholders recommended the development of an easy-to-use tool to support caregivers in SA that would provide guidance on how caregivers could reach clinicians if needed but importantly no further instructions on symptom management. Therefore, we developed a brief, easy-to-read SA Toolkit to be used by caregivers at home. The SA Toolkit includes tools for assessing common symptoms and grading their severity. It also includes guidelines on the next actionable step caregivers could take, such as contacting clinicians if symptoms were progressing.

We piloted the SA-Toolkit among patient/caregiver dyads within a home-based geriatrics program to determine the feasibility of enrolling patients and their caregivers in this study, as well as the usability of the SA-Toolkit. We also evaluated effects of (1) the SA-Toolkit on patients' symptom burden and (2) caregivers' self-efficacy in assessment of common palliative care symptoms.

Methods

Setting and participants

To determine the best setting and participants to include in a pilot study, we conducted focus groups of multiple stakeholders (Medicaid In-Home Supportive Services [IHSS] administrators, case managers, caregivers, and patients), initially envisioning implementation of an SA program within a structured framework for paid caregivers and their clients, such as IHSS.[21] Paid caregivers and their clients welcomed SA, noting the strength of leveraging their established relationships. However, SA was recommended only for patients who have established relationships with responsive outpatient clinicians, given the potential need to arrange urgent follow-up visits. Therefore, we recruited a convenience sample of patients enrolled in a home-based geriatrics program at the University of California, San Francisco (UCSF), which has 24/7 telephone access to a clinician and the capability of urgently seeing patients when needed. Stakeholders were also concerned about "overmedicalization" of the role of home health workers and the potential for added burden to already overworked, underpaid nonclinician caregivers.[21] We therefore ensured materials were patient centered and focused on SA and support rather than management.

Patients were included if they were English speaking, at least 55 years old, and receiving in-home care by a paid (by personal or external sources) or unpaid family/friend caregiver. We excluded patients with a diagnosis of active drug or alcohol abuse, psychosis, or dementia, or who did not pass a telephone screen for cognitive impairment[22,23] or were unable to answer informed consent teach-back questions within 3 attempts.[24] Patients' caregivers were then contacted and screened for eligibility. Caregivers were excluded if they were unable to answer informed consent teach-back questions within three attempts. All study participants pro-

vided written informed consent and were reimbursed $50 for a baseline interview and $25 for a follow-up interview. This study was approved by the Institutional Review Board of the UCSF.

SA-Toolkit

We developed the SA-Toolkit based on Social Cognitive and Behavior Change theory,[25] as well as feedback obtained from focus groups and in-depth cognitive interviews with home health administrators, case managers, caregivers, and patients.[21] We used standard health literacy techniques to ensure materials were written at a fifth grade reading level, as health literacy of caregivers is similar to that of the United States adult average (e.g., a mean of the seventh to eighth grade).[21,26] The SA-Toolkit consists of a script for caregivers to introduce SA, tools for assessing symptom severity (Symptom Board, Symptom Cards, Faces Scale, Symptom Tracker sheet), and guidelines on the next actionable step for the caregiver. The Toolkit is meant to provide all needed education, and no additional education sessions were provided to the patient or the caregiver.

Based on input from the focus groups and using questions from the validated Edmonton Symptom Assessment Scale, Memorial Symptom Assessment Scale, the Palliative Care Outcome Scale, and the UCLA Loneliness Scale,[27–30] symptoms assessed in the SA-Toolkit include pain, shortness of breath, constipation, diarrhea, nausea, feeling tired, loneliness, anxiety, depression, and an option to include other symptoms. These symptoms were represented with illustrations (approved by stakeholders) and displayed on a "Symptom Board." Symptoms were also presented separately as "Symptom Cards," which contained illustrations and written descriptions. We used a monochromatic adaptation of a validated 6-point "Faces Scale"[31] for assessment of symptom severity, after testing three other Faces Scales in focus groups. The first Faces Scale[32] was felt by focus group participants to be "too scary." A second scale with colors,[33] ranging from green to red for low to high severity, created confusion as participants chose based on the color closest to their skin color. A third scale that used emojis[31] was felt to be "too cartoonish." The Symptom Tracker was developed with the focus groups and formatted similarly to existing tracking sheets used for other information (e.g., weight, blood pressure). The SA-Toolkit also provides guidelines for the next actionable step a caregiver could take in response to patients' symptoms, including scripts the caregiver can use to remind patients to take relevant medications, check on needed medication refills, obtain permission from patients for whom the caregiver can reach out to if needed (i.e., family, clinicians, emergency medical services), and discuss patients' symptoms with these parties if they need to be contacted. Space is provided to document family, clinician, and emergency contact information.

To use the Toolkit, caregivers were instructed to show patients the Symptom Board to assess which symptoms patients were experiencing; they could also use the Symptom Cards to read aloud descriptions of each symptom if needed. They then assessed the severity of each symptom using the Faces Scale and recorded this information daily on the Symptom Tracker. Finally, caregivers ensured patients had taken medications relevant to their symptoms, and if further

attention was needed, they contacted patients' clinicians and/or family members.

Measures and outcomes

Pre- and post-surveys were administered over the phone or in person to patients and caregivers at baseline (time of recruitment) and follow-up (one to two weeks after using the SA-Toolkit), respectively.

At baseline, we obtained sociodemographic data from caregivers and patients, including self-reported age, gender, race/ethnicity, education, finances (defined as adequate or limited if they reported not having enough to make ends meet), and health literacy (defined as adequate or limited) using a validated measure.[34] Additional information obtained from patients included, cognitive status using validated measures,[22,23] self-reported health status, 4-item depression and anxiety screen,[35] whether they lived alone, social support,[36] and self-reported quality of life. We also asked caregivers about their duration of caregiving experience in years.

Our outcomes were (1) feasibility of enrolling patients and caregivers in this study, (2) patients' symptom burden at baseline and follow-up, (3) caregivers' self-efficacy in SA at baseline and follow-up, and (4) usability of the SA-Toolkit.

Feasibility. We assessed feasibility by measuring the enrollment rate, reasons for refusal to participate, and the one-week retention rate of patients.

Patient symptom burden outcomes. We measured patients' symptoms and their severity using the 6-point Faces Scale in surveys as detailed above.

Caregiver self-efficacy outcomes. We measured caregivers' self-efficacy in SA using a 5-item survey adapted from a validated scale[37] to assess attitudes, knowledge, and confidence in both pre- and post-surveys. Each item used a 5-point ordinal response scale (1 to 5), with 5 representing the highest self-efficacy. The five items were averaged into an overall 5-point self-efficacy score.

Usability outcomes. We assessed usability of the Symptom Board, Symptom Cards, and Faces Scale from both patients and caregivers using closed and open-ended questions. Although four prior cycles of pilot testing led to the use of the 6-point monochromatic Faces Scale for this study, we received additional patient feedback that it was difficult to discern differences on the 6-point scale. Thus, we
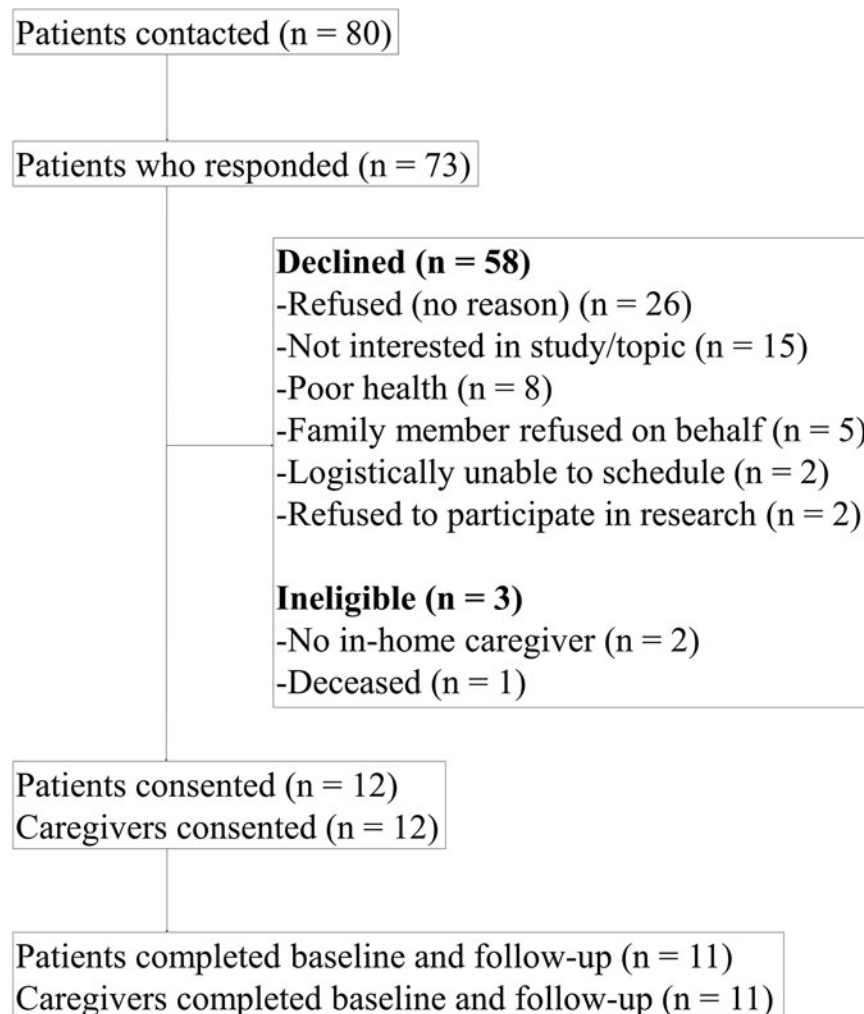

FIG. 1. CONSORT diagram detailing patient/caregiver enrollment and participation.

created a new scale with only four faces. All study participants used the 6-point Faces Scale; however, we also solicited feedback on a 4-point Faces Scale version from the last two patient/caregiver dyads that were enrolled in the study. Among caregivers, we also assessed usability of caregiver components of the SA-Toolkit, including the easy-to-read scripts to be read to patients and the Symptom Tracker sheets.

Analyses

We conducted descriptive analyses of all sociodemographic data, feasibility of enrollment, patients' symptom burden (number of patients experiencing each symptom, mean number of unique symptoms experienced by each patient, and mean level of severity of each patient's symptom burden), caregiver self-efficacy (mean responses to each item of the survey and the overall score), and usability by both patients and caregivers. We conducted Wilcoxon signed rank tests to assess changes from baseline to follow-up in patients' symptom burden and caregivers' self-efficacy.

Results

Feasibility of recruitment and participant characteristics

Eighty patients were contacted, of whom 67 (84%) responded. Fifty-four patients (81%) who responded declined to participate, 3 were ineligible, and 11 (16.4%) consented to participate (Fig. 1). Nearly half (26/54, 48.1%) of those who declined did not provide a reason, otherwise the most commonly cited reasons were lack of interest in the study/topic ($n = 15$), poor health ($n = 8$), and refusal by a family member on the patients' behalf ($n = 5$). All caregivers of participating patients agreed to participate. All 11 patients and 11 caregivers completed the 1-week follow-up.

Patient and caregiver characteristics are summarized in Table 1. Patients' average age was 84.7 years old (SD 5.7); 9 (81.8%) were women, 3 (27.3%) were racial/ethnic minorities, and 5 (45.5%) had limited health literacy. Caregivers' average age was 57.2 years old (SD 13.8); 6 (54.5%) were women, 3 (27.3%) were racial/ethnic minorities, all had adequate health literacy, and they had on average 7.8 years (SD 5.1) of caregiver experience.

Patients' symptom burden

The mean number of symptoms experienced by each patient decreased significantly from 3.7 (SD 1.5) at baseline to 2.6 (SD 1.8) at follow-up ($p = 0.034$; Table 2). Notably, the number of patients experiencing anxiety decreased significantly from 6 (54.5%) to 2 (18.2%; $p = 0.046$), pain from 7 (63.6%) to 4 (36.4%; $p = 0.083$), constipation or diarrhea from 5 (45.5%) to 2 (18.2%; $p = 0.083$), and loneliness from 4 (36.4%) to 2 (18.2%; $p = 0.16$). The mean severity of symptoms did not change significantly from baseline to follow-up (2.4 [SD 1.1] to 2.6 out of 5 [SD 1.3], $p = 0.37$). There was a trend toward an increased feeling of support at home for symptoms (3.9 [SD 0.5] to 4.4 out of 5 [SD 0.2], $p = 0.83$).

Caregiver self-efficacy

Overall caregiver self-efficacy in SA was high at baseline and follow-up (4.6 [SD 0.3] and 4.8 out of 5 [SD 0.3],

TABLE 1. PATIENT AND CAREGIVER CHARACTERISTICS

	Patients (N = 11)	Caregivers (N = 11)
Age, mean (SD)	84.7 (5.7)	57.2 (13.8)
Gender, n (%)		
Male	2 (18.2)	5 (45.5)
Female	9 (81.8)	6 (54.5)
Race/ethnicity, n (%)		
White	8 (72.7)	8 (72.7)
Black/African American	2 (18.2)	0 (0)
Asian/Pacific Islander	1 (9.1)	2 (18.2)
Other	0 (0)	1 (9.1)
Education, n (%)		
≤ High school	2 (18.2)	2 (18.2)
Some college or technical	4 (36.4)	3 (27.3)
College graduate	1 (9.1)	3 (27.3)
Graduate school	4 (36.4)	3 (27.3)
Limited finances, n (%)[a]	0 (0)	1 (9.1)
Limited health literacy, n (%)[b]	5 (45.5)	0 (0)
Cognitive status, n (%)[c]		
Normal mental function	9 (81.8)	—
Mild-to-moderate impairment	2 (18.2)	—
Self-reported health status, n (%)		
Fair/Poor	5 (45.5)	—
Good/Very good	6 (54.5)	—
Positive depression or anxiety screen[d]	4 (36.4)	—
Live alone, n (%)	4 (36.4)	—
Social support, mean (SD)[e]	17.2 (2.8)	—
Self-reported quality-of-life, n (%)		
Fair/Poor	3 (27.3)	—
Good/Very good/Excellent	8 (72.7)	—
Experience (years) working as caregiver, mean (SD)	—	7.8 (5.1)

[a]"Limited" if reported not having enough finances to make ends meet.

[b]"Limited" if answered not at all/a little/somewhat in response to confidence about filling out medical forms.

[c]By convention based on adjusted Short Portable Mental Status Questionnaire scores.

[d]Positive if Patient Health Questionnaire-2 or Generalized Anxiety Disorder 2-item scale score ≥3.

[e]Social support was measured using a 4-item version of the Medical Outcomes Study Social Support Survey. Scores range from 4 to 20, with 20 indicating higher support.

SD, standard deviation.

$p = 0.09$) (Table 3). Each item of the survey had a similar increase from baseline to follow-up; most notably, agreement that caregivers should be trained to assess patients' symptoms increased significantly from 4.5 (SD 0.7) to 4.9 (SD 0.3; $p = 0.046$).

Usability

All patients reported feeling comfortable with and liking their caregivers asking about their symptoms: ''I like the idea that I matter. I like that people like what I think,'' and ''I liked everything about it. I considered myself lucky to have my caregiver to have been here doing this with me.'' Patients similarly felt comfortable with their caregivers assessing

TABLE 2. PATIENT BASELINE AND FOLLOW-UP SELF-REPORTED SYMPTOM AND SUPPORT ASSESSMENT

	Baseline (N=11)	Follow-up (N=11)	p[a]
Number of unique symptoms per patient, mean (SD)	3.7 (1.5)	2.6 (1.8)	0.034
Severity of symptom burden per patient, mean (SD)[b]	2.4 (1.1)	2.6 (1.3)	0.37
Any symptom, n (%)	11 (100)	10 (90.9)	
Pain, n (%)	7 (63.6)	4 (36.4)	0.083
Shortness of breath, n (%)	4 (36.4)	4 (36.4)	1.0
Fatigue, n (%)	7 (63.6)	8 (72.7)	0.65
Constipation or diarrhea, n (%)	5 (45.5)	2 (18.2)	0.083
Nausea, n (%)	0 (0)	0 (0)	1.0
Loneliness, n (%)	4 (36.4)	2 (18.2)	0.16
Anxiety, n (%)	6 (54.5)	2 (18.2)	0.046
Depression, n (%)	5 (45.5)	3 (27.3)	0.32
Other symptom, n (%)[c]	3 (27.3)	4 (36.4)	0.56
Have support at home for symptoms, mean (SD)[d]	3.9 (0.5)	4.4 (0.2)	0.83

[a]Wilcoxon signed rank tests comparing baseline and follow-up.
[b]Measured for each symptom on an ordinal response scale (range 0–5; 5 signifying most severe) and averaged across all symptoms experienced by each patient.
[c]Other symptoms include knee discomfort, swallowing problems, arthritis, poor walking, and losing balance.
[d]Measured on an ordinal response scale (range 1–5; 5 indicating feeling supported all of the time).

symptom severity, stating that it provided "a sense of security," safety, and protection, and allowed for "open communication."

Patients reported that the Symptom Board with pictures and the Symptom Cards with descriptions were easy to use (8.8 [SD 1.3] and 8.5 [2.1] out of 10, respectively). However, patients reported feeling more comfortable using the Symptom Board (4.2/5, SD 0.8) versus the Symptom Cards (3.7/5, SD 1.5) (Table 4). One patient noted the Symptom Cards were "too graphic," and another would not recommend them because they did not find them to be necessary: "Most people know what these words are." Patients rated the 6-point Faces Scale lower than other tools for ease of use (7.3/10, SD 3.7) and comfort (3.4/5, SD 1.3). Patients reported difficulty understanding or identifying the facial expressions: "The in-between options are not easy to read, wouldn't know which one to choose [...] Too many choices." The last two patient/caregiver dyads who enrolled in the study were asked to compare the 4-point versus the 6-point Faces Scales. All preferred the 4-point version, reporting it was "simpler," "clearer," and "easier to use" than the 6-point version.

Caregivers rated all components of the SA-Toolkit highly because they "were simple and easy to use," and because they felt supported by the materials: "Nice to know that people care to help caregivers" (Table 5). All caregivers

reported the amount of time it took to assess symptoms using the SA-Toolkit and Symptom Tracker was appropriate. Eight of the caregivers felt the amount of information in the SA-Toolkit was appropriate, while three felt there was not enough information included. The information reported that lacking included the need to "Personalize these materials based on actual symptoms being experienced by individual clients," "[...] notes on the symptoms page of what these symptoms might be a bigger warning for," and "a section to keep track of medications to go along with symptoms." Nearly all (10/11, 90%) were fairly or extremely likely to recommend it to others; one caregiver was only somewhat likely, noting that the SA-Toolkit was "very general and may not be enough" for someone with advanced symptoms.

Discussion

This pilot study was feasible and demonstrated that an easy-to-use SA-Toolkit was acceptable, useable, and welcomed by patients and their caregivers. The SA-Toolkit also resulted in decreased symptom burden among patients. Asking patients about symptoms did not increase symptom burden, anxiety, or depression; rather, anxiety decreased significantly. Although caregiver self-efficacy in SA was high at baseline, it also increased. Acceptability

TABLE 3. CAREGIVER ENGAGEMENT IN SYMPTOM ASSESSMENT AT STUDY BASELINE AND FOLLOW-UP

	Level of agreement with the following statements, mean (SD)[a]		
	Baseline	Follow-up	p[b]
Assessing patients' symptoms is important	4.8 (0.4)	5.0 (0)	0.16
Assessing patients' symptoms can help with their quality of life	4.6 (0.7)	4.8 (0.4)	0.59
Caregivers should be trained to assess patients' symptoms	4.5 (0.7)	4.9 (0.3)	0.046
Know who to contact if patients are having severe symptoms	4.8 (0.4)	4.8 (0.4)	1.0
Confident in ability to assess and track patients' symptoms	4.3 (0.7)	4.6 (0.7)	0.18
Overall engagement score	4.6 (0.3)	4.8 (0.3)	0.09

[a]Measured on an ordinal response scale (range 1–5; 5 signifying highest level of agreement).
[b]Wilcoxon signed rank test comparing baseline and follow-up.

TABLE 4. USABILITY OF STUDY MATERIALS FOR PATIENTS (N=11).

Study material	Number (%) who used material	Easy to use, mean (SD)[a]	Comfortable using, mean (SD)[b]	Found helpful, mean (SD)[b]	Would recommend, mean (SD)[b]
Symptom board	6 (54.5)	8.8 (1.3)	4.2 (0.8)	3.2 (0.5)	3.2 (0.8)
Symptom card	6 (54.5)	8.5 (2.1)	3.7 (1.5)	4.2 (0.8)	3.0 (1.4)
Faces scale	7 (63.6)	7.3 (3.7)	3.4 (1.3)	3.4 (1.3)	3.4 (1.6)

[a]Assessed on a 1–10 ordinal response scale, with 10 representing "very easy."
[b]Measured on an ordinal response scale (range 1–5; 5 signifying most comfortable/helpful/would recommend).

of the Toolkit was high, with both patients and caregivers feeling more supported.

Symptom burden most notably decreased for anxiety, although other symptoms, including loneliness, depression, pain, and gastrointestinal symptoms also decreased. Our small sample size and short follow-up time frame limited our power to detect differences; nevertheless, these results suggest that SA can help to alleviate patients' symptoms. Only a subset of patients in our study reported feeling lonely, however, there was a trend toward a decrease, possibly as a result of increased interaction with caregivers. These findings are similar to other studies on loneliness. Loneliness among older adults is increasing and has been associated with anxiety and depression. However, addressing loneliness has been associated with reduced depressive symptoms and physician visits and better subjective health.[38–40]

The acceptability of the SA-Toolkit was high among both patients and caregivers. This suggests that the Toolkit may be a helpful resource for caregivers to assess symptoms of patients receiving paid or unpaid in-home care. Our findings are similar to prior research in demonstrating that standardized tools and guidelines allow caregivers to feel supported and activated.[17,41] However, to our knowledge this is the first intervention designed for caregivers to engage in the first step of SA for seriously ill older adults.[42,43] While other programs—including a telehealth palliative care model[19,20] and a peer-support program[44]—have been shown to reduce symptoms and provide emotional or spiritual support to patients, they require standardized training or advanced practice providers, which may not be feasible in resource-poor clinical settings. Patients in this study had the benefit of receiving home-based primary care with 24/7 telephone access to a clinician, which insured timely follow-up to caregiver-initiated concerns. For patients with established outpatient or home-based medical care, the SA-Toolkit may complement clinicians' efforts in relieving symptom burden. Further evaluation is needed to understand how the Toolkit can be integrated into existing home-based models and whether it reduces caregiver burden.

Participants also provided valuable feedback for improvement. Participants rated the 6-point Faces Scale as the most difficult component of the Toolkit; however, higher ratings of the 4-point scale are promising. Some patients felt the Symptom Cards were redundant. However, the study population was English speaking and without significant cognitive impairment, and illustrated cards may be useful in populations with communication barriers, thus warranting further evaluation. Caregivers' primary feedback was a desire for greater tailoring for only those symptoms the patients were experiencing. Some also requested more guidance on next steps in symptom management, which was beyond the scope as was recommended by our stakeholder advisory board and would require additional study.

This pilot study has limitations. The generalizability of our findings is limited given the small sample size, enrollment from one geriatrics practice, and convenience sampling with majority white and well-educated participants. We did not assess whether changes were made during the course of the study to clinical management of symptoms (e.g., changes to medication dosages) and whether that may have contributed to the decrease in symptoms. For patients who do not have stable or frequent access to a clinician, the feasibility of the SA-Toolkit is uncertain. Defining the population for further testing will be important to determine with community stakeholders.

Supporting caregivers of frail, older adults in SA is feasible and resulted in lower symptom burden and lower anxiety and loneliness among patients, as well as a greater feeling of support among caregivers. The SA-Toolkit may be a promising way to improve early SA among older adults with serious illness. Next steps include further refining the Toolkit and evaluating it over a longer period of time with racially/ethnically, socioeconomically, and linguistically diverse populations.

TABLE 5. USABILITY OF STUDY MATERIALS FOR CAREGIVERS (N=11)

Toolkit component	Ease of use,[a] mean (SD)
Symptom assessment script	8.8 (1.4)
Symptom board	8.9 (1.8)
Faces scale	8.5 (1.6)
Symptom tracking sheet	8.6 (1.6)
Knowing when to call	8.7 (1.6)
Knowing who to call	9.2 (1.5)

[a]Measured on an ordinal response scale (range 1–10; 10 signifying "very easy").

Author Disclosure Statement

No competing financial interests exist.

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