









ORIGINAL ARTICLE

Impact of an automated, remote monitoring and coaching intervention in reducing hospice cancer family caregiving burden: A multisite randomized controlled trial

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Abstract

Background: Care for those with life-limiting cancer heavily involves family caregivers who may experience significant physical and emotional burden. The purpose of this study was to test the impact of Symptom Care at Home (SCH), an automated digital family caregiver coaching intervention, during home hospice, when compared to usual hospice care (UC) on the primary outcome of overall caregiver burden. Secondary outcomes included Caregiver Burden at weeks 1 and 8, Mood and Vitality subscales, overall moderate-to-severe caregiving symptoms, and sixth month spouse/partner bereavement outcomes.

Methods: Using a randomized, multisite, nonblinded controlled trial, 332 cancer family caregivers were enrolled and analyzed (159 SCH vs. 173 UC). Caregivers were primarily White (92%), female (69%), and spouse caregivers (53%). Caregivers provided daily reports on severity levels (0–10 scale) for their anxiety, depressed mood, fatigue, disturbed sleep, and caregiving interference with normal activities. These scores combined constituted the Caregiver Burden primary outcome. Based on reported symptoms, SCH caregivers received automated, tailored coaching about improving their well-being. Reports of moderate-to-severe caregiving symptoms also triggered hospice nurse notification. Secondary outcomes of Mood and Vitality were subcomponents of the Caregiver Burden score. A combined bereavement adjustment tool captured sixth month bereavement.

Results: The SCH intervention reduced overall Caregiver Burden compared to UC ($p < .001$), with a 38% reduction at 8 weeks and a medium-to-large effect size ($d = .61$). SCH caregivers experienced less ($p < .001$) disruption in both Mood and Vitality. There were higher levels of moderate-to-severe caregiving symptoms

overtime in UC (OR, 2.722). All SCH caregivers benefited regardless of caregiver: sex, caregiver relationship, age, patient diagnosis and family income. SCH spouse/partner caregivers achieved better sixth month bereavement adjustment than UC ($p < .007$).

Conclusions: The SCH intervention significantly decreased caregiving burden over UC and supports the maintenance of family caregiver mood and vitality throughout caregiving with extended benefit into bereavement.

KEYWORDS

bereavement, cancer caregivers, caregiver burden, hospice, self-care, telemedicine

INTRODUCTION

Family caregivers play a significant role in providing care for patients with cancer, particularly as their symptoms increase during advanced cancer.^{1,2} Despite positive benefits, including finding meaning in the caregiving role, most say they were unprepared and had little reserve for the demands of caregiving. As a result, family caregivers experience both physical decline and psychological distress.^{3,4} Higher levels of perceived caregiving burden correlates with elevated levels of anxiety and depression.^{1,5} Furthermore, caregiver distress heightens as the patient approaches death, with the final weeks noted as the most burdensome, often continuing into bereavement.^{1,6} Home hospice care is a supportive option for patients and their families during the final months of life. Although hospice is a partnership between clinicians and family caregivers, the greatest burden for round-the-clock patient monitoring falls to caregivers.^{1,5} These caregiving demands, combined with the anticipation of the family member's death, compromises caregivers' health and well-being.⁴

There is a growing body of intervention research aimed at assisting cancer caregivers to provide care to their family member, and/or maintain their well-being while caregiving. Overall, systematic reviews conclude that these interventions have demonstrated benefit for several caregiver outcomes.⁷⁻⁹ However, when statistical benefits are identified, the effect sizes are often small and inconsistently sustained across time. In addition, the frequency and timing of these supportive interventions may not align with current family caregiver needs. Existing caregiver interventions often require multiple, in-person, or individually delivered telephone sessions that are difficult and costly to scale.⁹ Technology-aided interventions are less resource-intensive and offer a scalable and sustainable delivery mechanism.^{10,11} In addition, digital tools can tailor interventions to match the dynamic nature of end-of-life care and fluctuating family caregiver needs.¹² This tailored approach responds to immediate temporal needs reported by caregivers while dynamically monitoring physical and psychosocial caregiver outcomes. Digital tools enable stepped interventions that provide automated caregiver coaching and in-the-moment support with escalation to the hospice team if caregiver burden exceeds a preset threshold. To date, there is limited research with digital technology aimed at assisting hospice

caregivers.¹³ The purpose and primary outcome of this randomized controlled trial was to determine the efficacy of Symptom Care at Home (SCH), an automated, digital tool using telephone interactive voice response (IVR) technology, to decrease daily Caregiver Burden (anxiety, depressed mood, fatigue, disturbed sleep, and caregiving interference with normal activities) over the course of home hospice care. Secondary outcomes included determining if there was early and sustained SCH Caregiver Burden benefit at weeks 1 and 8, improved Mood and Vitality and decreased rates of moderate and severe symptoms overall and for the five individual caregiver symptoms. We also compared spouse/partner bereavement outcomes at 6 months after patient death. We hypothesized that SCH caregivers would have reduced caregiving and bereavement burden when compared with usual cancer hospice care. Patient outcomes related to the SCH intervention have been reported elsewhere.¹⁴

MATERIALS AND METHODS

Study design

We conducted a prospective, nonblinded, randomized controlled, multisite study with parallel group assignment to the SCH intervention or usual hospice care (UC). Newly admitted home hospice patients with cancer and their primary family caregiver were enrolled from one of 13 participating hospices in Utah (eight hospices), Oregon (one hospice), Massachusetts, and Illinois (two hospices each).

Study objectives

The primary objective was to determine SCH intervention efficacy to decrease overall Caregiver Burden, evaluated throughout the hospice trajectory. For secondary outcomes, we evaluated the potential early and sustained benefit of SCH at weeks 1 and 8, and two sub-components of the overall Caregiver Burden scale: Mood (anxiety, depressed mood) and Vitality (fatigue, disturbed sleep, caregiving interference with normal activities). To provide additional clinical relevance and interpretability, rates of moderate-to-severe (4 or

greater on a 0–10 scale) caregiving symptoms were compared overall and individually. We also evaluated spouse/partner bereavement adjustment at 6 months as a distal outcome. Finally, we conducted a sensitivity analysis to determine whether key subgroups (caregiver: sex and age, caregiver relationship, patient diagnosis, and family income) equitably benefitted from any SCH reduction received in Caregiver Burden. The trial was approved by the University of Utah institutional review board (IRB) and two hospices that had separate IRBs. The study was registered with [ClinicalTrials.gov](https://clinicaltrials.gov) (NCT02112461).

Participant recruitment

Recruitment took place at 13 hospices in four states (Oregon, one hospice; Utah, eight hospices; Illinois and Massachusetts, two hospices each) with seven profit and six nonprofit agencies. Hospices determined their preferred method to notify families of the study opportunity when a patient was admitted to their service. Most chose an opt-out flyer with study staff follow-up for those who did not opt out. For hospices not using a flyer, verbal approval to contact the family was obtained by hospice staff. Flyer or verbal introduction occurred within the first week of hospice admission.

Interested and eligible families received a home visit to complete an informed consent with subsequent baseline data collection, followed by randomization. Caregiver inclusion criteria were age 18 or older, English speaking/writing, daily phone access of any type (landline, smart, mobile), and caring daily for a person with cancer from a participating hospice. Caregivers were compensated \$100 for participation. Only one caregiver was enrolled per family. Consent was also obtained from the patient to obtain access to disease and demographic data from their hospice medical records. No patient-reported data were required.

Study procedures

All caregiver participants, both SCH and UC, used the automated system for daily caregiver symptom reporting until patient death or 6 months of hospice care, reflecting the typical maximum period of insurance coverage. The automated IVR telephone system used a digitized human voice that allowed for “conversations” with the caregiver, who indicated responses using their telephone keypad to enter data. IVR systems transmit data through telephone lines and do not require internet access.

SCH Intervention

The SCH intervention evaluated the caregiver self-report symptom data and, based on algorithms, provided automated coaching messages tailored to the severity and pattern of the caregiving symptoms reported. Reports included the five caregiving symptoms for the past

24 hours using a 0–10 scale. Further details about the SCH system and its development have been previously reported.^{15,16} Following caregiver reporting, automated coaching was immediately provided during the call. Coaching was developed by a panel of clinical experts in end-of-life care and based on national evidence-based guidelines. For caregiver responses that exceeded pre-set thresholds for severity, generally moderate-to-severe symptoms (four or greater on 0–10 scale), SCH generated automated notifications to their hospice nurse. Nurses viewed notifications via a web-based system. They were not directed how to respond to notifications but were asked to indicate their plan of action: visit the family, call the family, or waiting and monitoring future reports. Report viewing was considered compliant within 48 hours from generation of the alert. The SCH group also received usual hospice care. The intervention was terminated at patient's death.

UC

The UC group received usual hospice care and was reminded at consent and each following reporting call, that their reports were not shared and that they should contact their hospice nurse for concerns. The UC group reported caregiver symptoms daily but did not receive self-care coaching, nor were symptom notifications sent to their nurse. This approach controlled for the time and attentional demands of calling and for the possibility that reporting symptoms alone altered the caregiver's experience.

Measures

Caregivers were asked to provide their demographic and health-related data (Table 1). Patient demographic and disease-related variables were collected from the hospice medical record.

Caregiver symptoms were assessed daily and served as the Caregiver Burden measure that included five items: anxiety, depressed mood, fatigue, disturbed sleep, and caregiving interference with normal activities. Caregiver Burden overall and at week 1 and week 8 were calculated as the mean unweighted composite of the five 0–10 caregiving symptom items for the time period, expressed as a percent of maximum possible scale severity. The Caregiver Burden measure demonstrated excellent overall reliability of .91 (Cronbach's α). For additional clinical interpretation, we similarly computed the subscale scores of Mood (anxiety, depressed mood) and Vitality (fatigue, disturbed sleep, caregiving interference), which exhibited high reliabilities (.90 and .87, respectively).

Because this study was part of a three-project grant, spouse/partner caregivers were followed during the first 6 months of bereavement, enabling us to evaluate the potential longer-term benefit of SCH. The bereavement measures included: 1) active coping competency (“Perceived Self-Care and Daily Living Competencies Scale” subscale^{17,18}), 2) loss and restoration orientations (“Inventory of Daily Widowed Life” scale^{19,20}), 3) grief (“Texas

TABLE 1 Caregiver demographics and patient diagnosis (n = 332 caregivers/patients).

Caregiver gender	Symptom care at home, n = 159			Usual hospice care, n = 173			Combined total, No. (%), n = 332
	M, n = 47	F, n = 112	Total, n = 159	M, n = 55	F, n = 118	Total, n = 173	
Caregiver relationship to hospice patient/caregiver							
mean age							
Spouse or partner	33	53	86	36	54	90	176 (53)
No.	65	63	64	67	66	66	65
Mean age (years)							
Adult child	12	43	55	13	51	64	119 (36)
No.	50	50	50	52	50	50	50
Mean age (years)							
Sibling	0	4	4	3	3	6	10 (3)
No.	—	70	70	59	54	57	62
Mean age (years)							
Other relationship	2	12	14	3	10	13	27 (8)
No.	—	—	—	—	—	—	—
Mean age (years)							
Caregiver race (combined % non-Caucasian)			8%			3%	6%
Caregiver Hispanic ethnicity			7%			5%	6%
Caregiver education							
7–11 years			6			5	11 (3)
High school			30			34	64 (19)
Some college ^a			54			64	118 (36)
College graduate			33			36	69 (21)
Some professional or graduate education			7			6	13 (4)
Professional or graduate degree			29			28	57 (17)
Caregiver annual household income							
<\$10K			7			6	13 (4)
\$10K–\$25K			17			17	34 (10)
\$25K–\$40K			19			26	45 (14)
\$40K–\$50K			12			21	33 (10)
\$50K–\$75K			27			41	68 (21)
>\$75K			50			41	91 (27)
No answer			27			21	48 (14)
Caregiver employment							
Not employed			25			81	153 (46)
Part-time			50			23	48 (15)
Full-time			12			51	101 (30)
No answer						18	30 (9)
Patient cancer diagnosis							
Lung			28			37	65 (20)
Breast			14			19	33 (10)

TABLE 1 (Continued)

Caregiver gender	Symptom care at home, n = 159			Usual hospice care, n = 173			Combined total, No. (%), n = 332
	M, n = 47	F, n = 112	Total, n = 159	M, n = 55	F, n = 118	Total, n = 173	
Colon			18			11	29 (9)
Blood			11			13	24 (7)
GU			12			12	24 (7)
GYN			9			13	22 (7)
Pancreas			13			14	27 (8)
Prostate			7			16	23 (7)
Brain			16			5	21 (6)
Head, neck			9			9	18 (5)
Liver			2			11	13 (4)
GI			5			4	9 (3)
Other			15			9	24 (7)

Abbreviations: F, female; GI, gastrointestinal; GU, genitourinary; GYN, gynecological; M, male.

^aMedian category.

Revised Inventory of Grief-Present Feelings²¹⁻²³), 4) depression ("Geriatric Depression Scale"^{24,25}), 5) hope ("Hope-State Scale"^{26,27}), 6) meaning finding ("Finding Meaning Scale" subscale^{28,29}), and 7) satisfaction with daily life.

Randomization and power

Randomization was conducted within the 13 hospice sites. Computer-generated assignment to SCH or UC was accomplished in blocks of six for each hospice by the biostatistical staff. Individual assignments, in sealed envelopes with sequential numbering, were opened after consent and baseline data completion. We estimated a sample size of 346 to provide 90% power to reject the null hypothesis that an effect size of $d = .35$ (small-to-moderate) was zero in the population.

Statistical analysis

Descriptive and baseline analyses

Demographic and disease characteristics were described using relative frequencies and cross-classifications for categorical variables, with central magnitudes and standard errors for continuous variables. We used the Kaplan-Meier log-rank procedure to test the hypothesis of equal treatment population durations, defined as time from enrollment to end of study or withdrawal. Reasons for dropout were classified as possibly informative of the intervention or not; we tested for proportional differences using an exact permutation test.

Analysis of the primary outcome

Our primary outcome was overall Caregiver Burden. To test our main hypothesis that SCH reduced Caregiving Burden, we analyzed the daily longitudinal Caregiver Burden composite scores as a function of treatment assignment and time from randomization.

Analyses of secondary outcomes

Similar to the primary outcome, we compared the immediate and sustained impact of Caregiver Burden at 1 and 8 weeks. To provide additional clinical context, we evaluated the two Caregiver Burden subscales: Mood and Vitality. The analysis incorporated responses from all time points available over 6 months for each caregiver, but for interpretive clarity, we grouped the time points into discrete periods: baseline (pretreatment study day 0), separately for weeks 1-8, combined weeks 9-12, and combined weeks 13-26. The key end point was defined as the maximum likelihood estimate of the mean baseline-adjusted difference in Caregiver Burden between SCH and UC across all time periods. Model and analysis details appear in Supporting Information S1.

For enriched interpretation, we secondarily tracked the percentages reporting at least one moderate (4-7) or severe (8-10) symptom per week³⁰ and estimated the weekly and overall probabilities of greater Caregiver Burden in UC versus SCH. We also examined the subscales Mood and Vitality using a generalized linear mixed effects model of the ordered symptom categories (Supporting Information S1).

Because some spouse/partner caregivers were randomized to a later bereavement intervention in another project, 6-month distal

outcome measures were available for 52 SCH caregivers and 57 UC caregivers allowing us to evaluate sustained impact. A vector comprising active coping competency, restoration and loss orientation, life satisfaction, finding meaning, hope state, depression, and grief was compared between groups in multivariate analysis of variance and tested with Pillai's Trace criterion.

Sensitivity analysis

To investigate any impact of key covariates on results, we examined the constrained longitudinal data analysis (cLDA) general linear mixed model result with the addition of caregiver sex, caregiving relationship, caregiver age, family income, and patient diagnosis as predictors and moderators in the model. This allowed us to determine whether all subgroups benefited equitably from SCH if benefit was found. To check for the systematic impact of drop-out on the results, we re-ran the analyses under the very conservative assumption those SCH caregivers who drop from the study would have responded as UC caregivers from that point forward, under multiple imputations to retain variability.³¹ Assuming that the intervention was not actively harmful, this constitutes a worst-case scenario for the effect of missing longitudinal data, a pragmatic lower bound of the treatment impact.

The cLDA analyses for caregiver burden and for ordered symptom categories were conducted with SAS Proc Mixed and SAS Proc Glimmix, respectively. The multivariate analysis of the sustained impact was conducted using SAS Proc GLM. Further detail is provided in Supporting Information S1.

RESULTS

Study sample and descriptive data

We approached 1180 paired caregivers/patients; 365 (30.9%) agreed to participate and were randomized to SCH (179) or UC (186) (Figure 1); 33 randomized caregivers (20 SCH intervention and 13 usual care) never provided assessments (often due to patient death), but 332 (SCH 159; UC 173) provided at least one response at either baseline or post-randomization and were analyzed (Figure 1). Demographics and baseline data are presented in Table 1. A total of 53% ($n = 176$) of caregivers were spouse/partner and 36% ($n = 119$) were adult children.

SCH caregivers called 73% of expected days versus UC, who called 66% of expected days ($p < .001$). Daily calls averaged approximately 9 min for UC versus 11 min for SCH ($p < .000$). Given variation in patients' death trajectories, time-on-study distributions were highly skewed, with 80% completed by 2 months, 90% completed by 3 months, and 98% completed by 6 months. Overall, 76% of participants were in the study more than 1 week and 18% more than 8 weeks. The mean times on study were similar between groups, approximately 37 days. The median times on study were also similar between groups, approximately 18 days ($p = .50$, log-rank test). The interquartile ranges were 44 for SCH and 31 for UC.

Moderate-to-severe caregiving symptoms were common; fatigue was reported at some point by 82% of caregivers, followed by caregiving interference (78%), anxiety (77%), trouble sleeping (74%), and depressed mood (69%). Reasons for withdrawal were classified

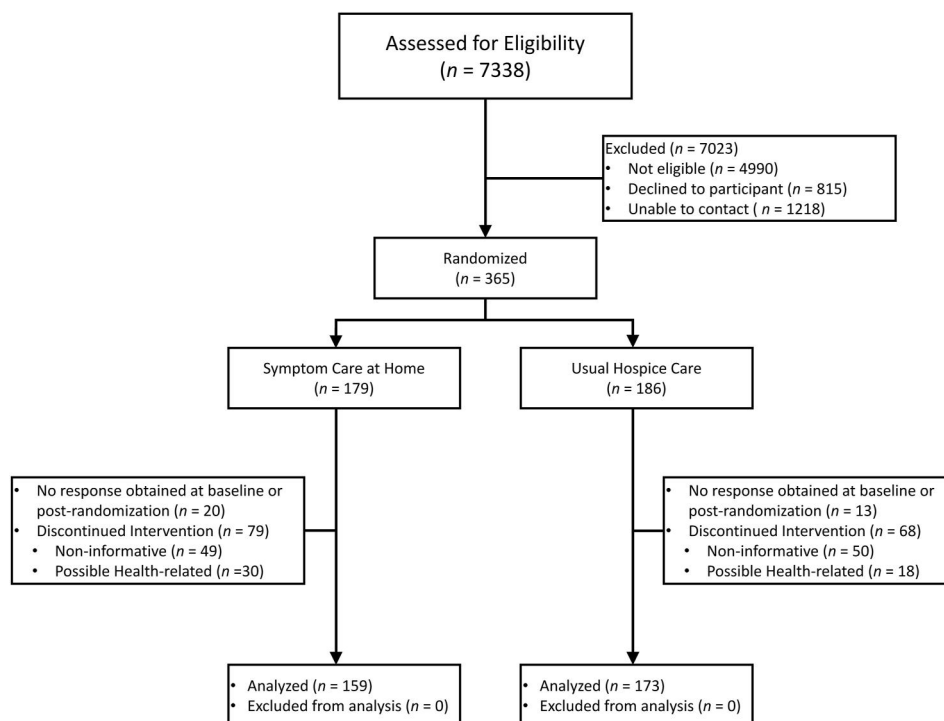


FIGURE 1 Consolidated Standards of Reporting Trials diagram.

as “completed or never dropped,” “presumably unrelated to health or intervention,” or “possibly related to study treatment condition or general health.” The distributions of reasons for withdrawal did not differ by group ($p = .228$, exact test). Withdrawals unrelated to health or treatment included patients who moved to another residence, nonparticipating hospice, or an out-of-area caregiver returning home. Only three caregivers withdrew for possible study treatment-related reasons, identifying the reason as “overwhelmed or stressed with caregiving” or “too busy to participate.”

Primary outcome

For the primary outcome, Caregiver Burden, we calculated overall benefit, defined as the mean difference in total Caregiver Burden across all matched post-randomization time points (Figure 2). There was a mean estimated overall benefit of 9.32 points ($p < .001$, $d = .44$) for SCH compared to UC (Table 2).

Secondary outcomes

There was a rapid onset of benefit for SCH over UC of 5.90 points at week 1 ($p < .001$, $d = .28$). We found an enduring impact of SCH at week 8 of 12.89 points ($p < .001$, $d = .61$), a 38% relative reduction from baseline. Overall mean SCH benefit for Mood was 8.1 points ($p < .001$, $d = .33$) and 10.09 points for Vitality ($p < .001$, $d = .47$) compared to UC. Table 2 provides additional detail.

To explore the clinical impact of SCH on caregiver well-being for moderate-severe caregiving symptoms, Table 3 reports the probability of higher levels of at least one moderate-severe symptom in a week, both overall and separately for the Mood and Vitality

subscales. The cumulative logistic model demonstrated an overall odds ratio for higher caregiver burden in UC relative to SCH of 2.722 [1.625, 4.588], corresponding to a .731 probability that a randomly selected UC caregiver would have greater categorical burden than a randomly selected SCH caregiver. Findings for Mood and Vitality were similarly positive for SCH.

Sensitivity analysis

With one exception, the addition of key predictors and moderators contributed no significant changes in the model estimates. All SCH patients benefited over UC regardless of caregiver sex, caregiver relationship to patient, caregiver age, patient diagnosis and family income. Although all incomes benefitted from SCH, the intervention produced a significantly ($p = .013$) greater benefit of 15.00 mean Caregiver Burden points for lower-income (<\$50K) (Figure 3) versus 4.86 mean points for higher-income caregivers. Under the conservative scenario that the Caregiver Burden scores for SCH dropouts would immediately resemble those of UC participants from the dropout point forward, multiple imputation showed the worst-case SCH benefit changed minimally from 9.32 to 8.61 and remained highly significant ($p < .001$).

Six-month sustained bereavement impact

The final secondary outcome demonstrated the distal beneficial of SCH for spouse/partner caregivers 6 months into bereavement when compared in a multivariate analysis of variance to UC ($p = .007$, partial $\eta^2 = .245$). All significant univariate differences were in the direction of SCH benefit.

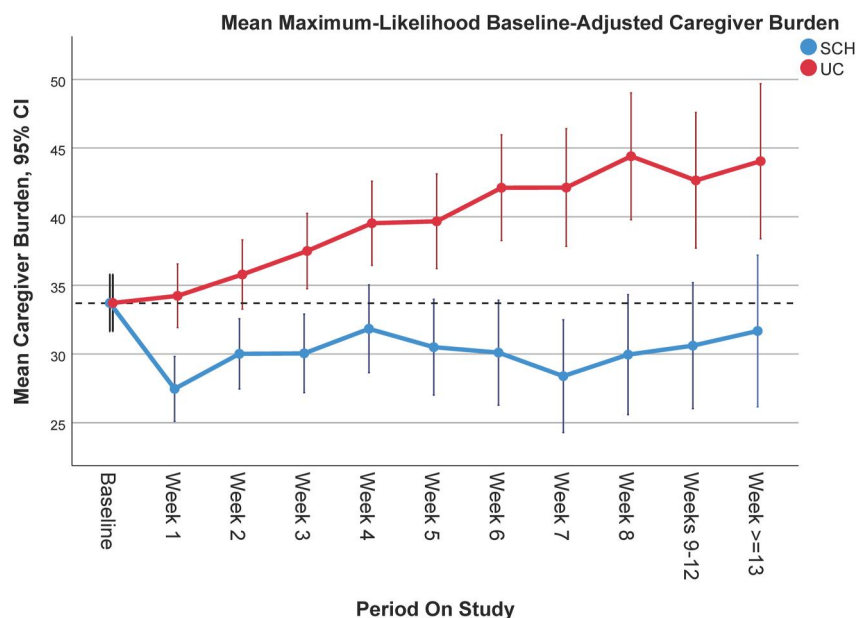


FIGURE 2 Mean maximum-likelihood baseline-adjusted caregiver burden.

TABLE 2 Estimated caregiver burden benefit^a for SCH intervention relative to usual care.

Effect	Estimated benefit (S.E)	95% CI	Cohen's d	t	Relative % improvement ^b	Prob > t	F (p > F)
Total caregiver burden							
Mean impact across periods ^c	9.32 (1.86)	(5.67, 12.97)	.44	5.01	—	<.001	
Week 1 impact	5.90 (1.35)	(3.25, 8.56)	.28	4.36	—	<.001	
Week 8 impact	12.89 (2.88)	(7.24, 18.54)	.61	4.48	38%	<.001	
Arm × time interaction ^d							3.36 (p < .001)
Mood component							
Mean impact across periods ^c	8.15 (2.07)	(4.09, 12.21)	.33	3.94	—	<.001	
Week 1 impact	6.36 (1.55)	(3.31, 9.40)	.26	4.10	—	<.001	
Week 8 impact	10.83 (3.21)	(4.55, 17.11)	.44	3.38	35%	<.001	
Arm × time interaction ^d							2.79 (p = .002)
Vitality component							
Mean impact across periods ^c	10.09 (1.89)	(6.37, 13.81)	.47	5.33	—	<.001	
Week 1 impact	5.67 (1.44)	(2.84, 8.50)	.27	3.94	—	<.001	
Week 8 impact	14.06 (2.94)	(8.28, 19.83)	.66	4.78	31%	<.001	
Arm × time interaction ^d							3.29 (p < .001)

Abbreviations: CI, confidence interval; Prob, probability; SCH, Symptom Care at Home; S.E, standard error.

^aAll estimates expressed as percent of scale severity maxima.

^b100× ratio of 8-week impact to mean baseline value.

^cEquivalent to the baseline-adjusted main effect across all post-randomization time points assuming equal population means at pre-randomization baseline.

^dTen-degrees of freedom test of coincident treatment arm trajectories, assuming equal population means at pre-randomization baseline.

TABLE 3 Probability of moderate or severe symptom burden by time point and treatment arm.

Period	Arm	Vitality			Mood			Symptom burden		
		Est	Lo CI	Hi Ci	Est	Lo CI	Hi Ci	Est	Lo CI	Hi CI
Baseline	UC	0.739	0.663	0.803	0.390	0.303	0.485	0.781	0.712	0.838
	SCH	0.739	0.663	0.803	0.390	0.303	0.485	0.781	0.712	0.838
Week 1	UC	0.924	0.802	0.962	0.730	0.626	0.814	0.944	0.911	0.966
	SCH	0.816	0.734	0.876	0.587	0.468	0.697	0.849	0.779	0.901
Week 1 OR		2.760	1.504	5.065	1.903	1.030	3.516	3.004	1.621	5.568
Week 8	UC	0.857	0.727	0.930	0.696	0.501	0.839	0.893	0.785	0.950
	SCH	0.540	0.356	0.714	0.374	0.212	0.571	0.656	0.472	0.803
Week 8 OR		5.079	1.752	14.724	3.820	1.260	11.576	4.352	1.482	12.781
Overall OR		3.121	1.868	5.216	1.926	1.123	3.304	2.722	1.625	4.558
Prob (UC sx > SCH sx) ^a		0.757			0.658			0.731		
Prob (SCH sx > UC sx) ^b		0.243			0.342			0.269		

Abbreviations: CI, confidence interval; Est, estimate; OR, odds ratio; Prob, probability; SCH, Symptom Care at Home; sx, symptom; UC, usual hospice care.

^aThe probability of higher symptom levels in UC than in SCH across all matched time points.

^bThe probability of higher symptom levels in SCH than in UC across all matched time points.

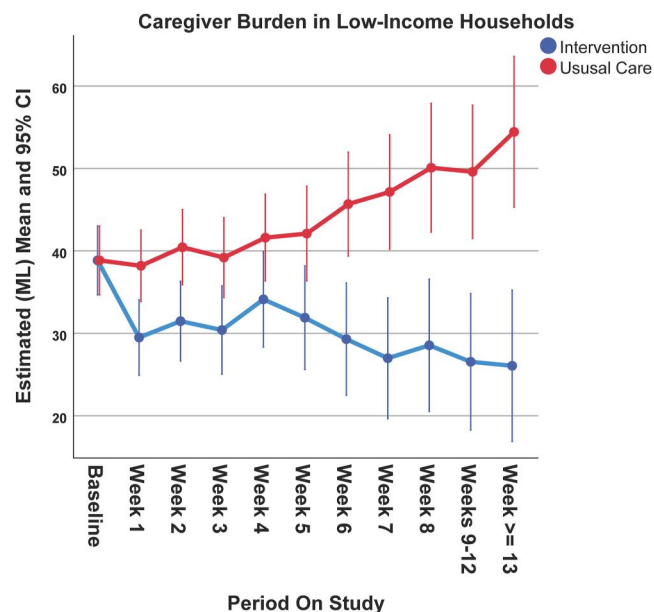


FIGURE 3 Caregiver burden in lower income households.

DISCUSSION

An automated digital monitoring and coaching intervention, SCH, for family caregivers reduces caregiving burden and maintains caregivers' mood and vitality over the course of home hospice care. The intervention added benefit within days of initiating use, with continued positive effect for spouse/partner caregivers 6 months into bereavement. Current literature clearly articulates caregiver health risks related to caregiver burden and its escalation at the end-of-life.³²⁻³⁴ Few intervention trials target key caregiver needs during home hospice, including how to care for their family member while concurrently maintaining the caregiver's physical and emotional well-being. In a recent focus group with caregivers, interventions to address caregivers' health and well-being were a pressing priority.³⁵ Previous literature has identified the need for new intervention approaches that span the cancer caregiving trajectory,³⁶ have equitable benefit for subpopulations, and can be scaled through digital delivery. The SCH intervention provides a model for addressing these gaps.

Although hospice care defines the patient and family as the focus of care, most of the hospice research is observational or examines interventions often limited to caregiver skills for managing patients' pain.^{17,37,38} Our findings demonstrated both robust statistically significant and clinically meaningful benefits for the maintenance of caregiver well-being. This is paired with our previously reported results demonstrating that the SCH caregiver intervention reduced patient symptom burden over UC.¹⁴ Our findings indicate significant improvement can be obtained in caregiver well-being when interventions such as SCH are added to usual hospice care. SCH served as a protective intervention for caregivers (Figure 2), helping maintain both mood and vitality, compared to the trajectory of increasing burden, depressed mood, and loss of vitality associated with UC. Although there was broad benefit from SCH across caregiver

demographics, there was greater benefit derived for low-income caregivers. This underscores the potential value of digital tools in addressing inequities, particularly tools that do not require the internet or a smartphone, such as our IVR-based system, and can be accessed by caregivers wherever they are providing care.^{39,40}

The use of digital technology to deliver the SCH intervention allowed us to address some of the shortcomings in caregiver interventions to-date.⁴¹⁻⁴³ SCH decreases the need for skilled professionals to deliver the coaching intervention because it is automated and efficient, providing support but involving the clinician only when caregiving symptoms are poorly controlled. It dynamically focuses on physical and psychosocial needs and caregiver burden, tailoring caregiver coaching to the individual reported pattern. Caregivers engaged with the SCH intervention with high reporting adherence and willingness to interact with SCH approximately 11 min/day throughout the caregiving trajectory.

There are several strengths to this study, including the multisite national sample of hospices allowing generalizability to other hospices, as well as the inclusion of both nonprofit and for-profit hospices. Another strength is the fidelity offered by each intervention caregiver receiving the identically delivered and worded, algorithm-based, automated coaching intervention. Our design included a usual care group who also reported caregiver symptoms. There are some limitations as well, including a lack of racial/ethnic diversity despite multi-site recruitment. However, the diversity in our sample is reflective of the hospice population nationally, where minority populations are less likely to enroll.^{44,45} Study enrollment was 30.9%, which aligns with reviews reporting approximately one-third of cancer caregivers enroll in intervention studies⁴⁶ with particular difficulty enrolling for end-of-life studies. Given the positive findings of SCH in the hospice setting, future studies should extend to other end-of-life care pathways, particularly those used by racially and ethnically diverse populations. Other limitations included our two-component intervention, with both coaching and provider notifications. We did not include groups to examine the relative contribution of each component. Further research is needed to identify the essential components and explore non-IVR digital interfaces (e.g., mobile text, passive sensor technology) that might further decrease caregiving stress by providing in-the-moment and on-demand coaching support and a variety of engagement approaches for caregivers.

There is a growing recognition that optimal cancer care must include family caregivers and extend to patients' homes. Given our positive findings, further research on digital interventions for cancer family caregivers throughout the cancer caregiving trajectory and in settings other than hospice is warranted. There are limited studies that address the integration of caregiver interventions into cancer care delivery and necessitates real-world implementation research.⁴⁶ Automated digital health interventions for caregivers are feasible, improve patient and caregiver outcomes, and can overcome inequities in access to care. It serves as a scalable approach to bridge the divide between clinic-based providers and family caregivers in the home.

In conclusion, the SCH intervention significantly decreased caregiving burden and supported family caregiver mood and vitality throughout hospice caregiving with extended benefit into bereavement. The benefit was equitably distributed among all SCH participants. Digital health interventions, such as SCH, hold promise to overcome current barriers to the development and implementation of efficacious and scalable approaches to improving cancer family caregiver well-being.

AUTHOR CONTRIBUTIONS

Kathi H. Mooney: Data acquisition and interpretation, conceptualization, analysis, study design, interpretation, writing—original draft, and writing—review and editing. **Lorinda A. Coombs:** Analysis, writing—original draft, and writing—review and editing. **Meagan S. Whisenant:** Analysis, writing—original draft, and writing—review and editing. **Christina M. Wilson:** Analysis, writing—original draft, and writing—review and editing. **Ann Marie Moraitis:** Data interpretation, conceptualization, and writing—review and editing. **Mary N. Steinbach:** Data interpretation, conceptualization, and writing—review and editing. **Elizabeth A. Sloss:** Data interpretation, conceptualization, and writing—review and editing. **Jennifer L. E. Lloyd:** Writing—review and editing. **Natalya Alekhina:** Data interpretation, conceptualization, and writing—review and editing. **Patricia H. Berry:** Analysis, study design, interpretation, analysis, writing—original draft, and writing—review and editing. **Youjeong Kang:** Data interpretation, conceptualization, and writing—review and editing. **Eli Iacob:** Analysis and data interpretation. **Gary W. Donaldson:** Study design, interpretation, analysis, data interpretation, conceptualization, and writing—review and editing.

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CONFLICT OF INTEREST STATEMENT









Jennifer L. E. Lloyd reports consulting fees from Pfizer. Kathi H. Mooney reports consulting fees from Reimagine Care. Mary N.

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DATA AVAILABILITY STATEMENT

The data underlying this article will be shared on reasonable request to the corresponding author.

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Additional supporting information can be found online in the Supporting Information section at the end of this article.

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