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End-of-Life Cancer Care Redesign: Patient and Caregiver Experiences in a Lay Health Worker–Led Intervention

Manali I. Patel, MD, MPH, MS[1,2,3], **David Moore, PhD**[4], **Tumaini R. Coker, MD, MBA**[5,6]

[1]Division of Oncology, Stanford University School of Medicine, Stanford, CA, USA

[2]Medical Services, Veterans Affairs Palo Alto Health Care System, Palo Alto, CA, USA

[3]Center for Primary Care and Outcomes Research, Health Research and Policy, Stanford University School of Medicine, Stanford, CA, USA

[4]Clinical Excellence Research Center, Stanford University School of Medicine, Stanford, CA, USA

[5]Seattle Children's Hospital, Seattle Children's Research Institute, Seattle, WA, USA

[6]Department of Pediatrics, University of Washington School of Medicine, Seattle, WA, USA

Abstract

Importance: The Engagement of Patients with Advanced Cancer (EPAC), comprised of a lay health worker (LHW) who assists patients with advance care planning, is an effective intervention for improving patient experiences and reducing acute care use and total health-care costs. The objective of this study was to assess patients' and caregivers' experiences with the intervention.

Methods: We invited all patients enrolled in EPAC and their caregivers to complete an 8-item survey at the end of the intervention and a random 35% sample to participate in a qualitative interview to assess their experiences. At 15-month follow-up, we invited all caregivers of patients who died during the study to participate in a qualitative interview. We analyzed survey responses using bivariate methods and recorded, transcribed, and analyzed interviews using qualitative content analysis.

Results: Sixty-nine patients were alive at completion of the intervention and all 30 identified caregivers completed the survey. All viewed the intervention as a critical part of cancer care and recommended the intervention for other patients. In qualitative interviews, among 30 patients, all reported improved comfort in discussing their end-of-life care preferences. In qualitative interviews with 24 bereaved caregivers, all viewed the intervention as critical in ensuring that their loved ones' wishes were adhered to at the end of life.

Corresponding Author: Manali I. Patel, MD, MPH, MS, Division of Oncology, Stanford University, 1070 Arastradero Road, Suite 233, Palo Alto, CA 94306, USA, manalip@stanford.edu.

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Supplemental Material
Supplemental material for this article is available online.

Conclusions and Relevance: Incorporating an LHW into end-of-life cancer care is an approach supported and viewed as highly effective in improving care by patients and caregivers. The LHW-led EPAC intervention is one solution that can significantly impact patient and caregiver experiences.

Keywords

end of life; cancer care; caregiver; patient experiences

Background

Discussions regarding patients' care preferences can improve the quality of end-of-life (EOL) cancer care.[1–4] These conversations between patients and health-care providers are critical for patients to understand their prognosis[5,6] and formulate and discuss their care preferences.[1,3,7] Barriers include provider and patient reluctance to engage in discussions,[8,9] limited provider time to conduct discussions,[8] professional workforce shortages,[8,10] and limited reimbursement and infrastructure to support the needs of patients at the EOL.[8,9,11] These barriers result in variations in the delivery of EOL cancer care services and lead to high rates of unwanted acute care use,[12] poor patient and caregiver experiences,[13] and high health-care spending.[2,14]

In prior work, we used redesign methods to develop and evaluate a novel approach to delivering some EOL cancer care services among veteran patients ("Veterans") with advanced cancer.[15] The Engagement of Patients with Advanced Cancer (EPAC) program uses a lay health worker (LHW) to educate and encourage patients to formulate and communicate their EOL care preferences with their families/caregivers and health-care providers. In a randomized trial at the VA Palo Alto Healthcare System, we found improvements in patient satisfaction, decreased acute care utilization, and decreased total costs of care as compared to Veterans assigned to the usual care group.[16] In this study, we sought to understand Veterans' and caregivers' experiences with the intervention and how the intervention influenced caregivers' experiences after the Veterans' death.

Methods

The EPAC Intervention

The EPAC intervention, described elsewhere,[16] was comprised of an LHW assigned to all patients randomized to the intervention group. In a 6-month structured intervention, the LHW provided 15- to 30-minute weekly telephone-based education on goals of care and assisted patients in identifying a surrogate decision maker, completing advance directives, and communicating preferences with their health-care providers and care-givers. Caregivers were invited to participate jointly in all intervention activities. The LHW who had a Bachelor of Arts and no prior medical experience participated in an 80-hour online training[17] supplemented by 4-week structured observation. The LHW was supervised by an oncology nurse practitioner and had no direct interaction with the oncology providers who were blinded to the patients' assignments. The study, funded by the VA Office of Patient-Centered Care, was registered on clinicaltrials.gov ().

Patient Sample

All Veterans with newly diagnosed advanced stages of cancer or recurrent cancer were invited to enroll in the study at their first oncology visit. Exclusions were limited to patients without capacity. Those who agreed were consented and randomized to either the intervention or the usual care (Supplement Figure 1). The LHW contacted patients randomized to the intervention group by phone and introduced himself/herself as the "VA health-care coach whose role was to assist with ensuring the highest quality care possible." Patients remained in the intervention for 6 months or until death, whichever was first.

Quantitative and Qualitative Patient Assessments

At the time of enrollment, we asked all Veterans randomized to the intervention to participate in a quantitative survey and qualitative interview at the end of the 6-month study period to assess their experiences. Veterans self-reported their race/ethnicity and marital status and one identified caregiver and his or her relationship with the Veteran. Age, sex, cancer diagnosis, stage, and recurrent cancer were obtained from the electronic health record. Veterans who were still alive completed an 8-item survey administered by a trained research assistant. Questions included whether and how often the patient used the intervention, if they felt the intervention was helpful, and if they would recommend it to others (Supplement Appendix 1).

We used computer-generated random numbers to randomly sample 35% of Veterans who were still alive and had completed the intervention to participate in a qualitative interview regarding their experiences. A trained research assistant conducted the in-person interviews between February 2, 2014, to November 25, 2015, with the use of a semistructured interview guide (Supplement Appendix 2). Participants received both a travel and a food voucher to participate. The protocol addressed general experiences with cancer care and the intervention and the extent, if any, to which the intervention assisted the patient in establishing and communicating care preferences.

Quantitative and Qualitative Caregiver Assessments

The objective of caregiver assessments was to understand care-giver experiences with the intervention and whether the intervention influenced caregivers' experiences with patients' deaths. At the time of enrollment in EPAC, Veterans in the intervention group provided permission for the research team to approach one identified caregiver to participate in assessments. When permission was granted, we contacted the caregiver to obtain consent for the quantitative survey. We also invited the consenting care-givers to participate in a one-on-one interview if and when their loved ones died. At the end of the intervention, caregivers who provided consent were asked to complete an 8-item survey administered by a trained research assistant to assess experiences with the intervention. These questions included whether and how often caregivers used the intervention, if they felt the intervention was helpful, and whether they would recommend the intervention for others (Supplement Appendix 1).

At 15-month follow-up, we recontacted all consented care-givers of participants who died to participate in a 1-hour interview either in person or by telephone. A trained research assistant conducted the post-death interviews between November 1, 2014, and November 15, 2016, with use of a semistructured interview guide (Supplement Appendix 2) and addressed these topics: (1) general experiences with cancer care, EOL care delivery, and the intervention; (2) if and how the intervention may have impacted EOL care; and (3) whether they would recommend the intervention to others. All methods were reviewed and approved by the institutional review board of Stanford University.

Analytic Methods

Quantitative methods.—We examined participant responses to survey questions and report responses for all intervention patients. Analyses were conducted by STATA version 13.1.[18]

Qualitative methods.—We digitally recorded, transcribed, and imported all interviews into Atlas ti (qualitative data management software [Version 8]). Two members of the research team read and coded text samples to create a codebook through an iterative process. Two experienced coders independently and consecutively coded full transcripts, discussed discrepancies, and modified the codebook with the first author. To measure coder agreement, we calculated a Cohen k score using all quotes from the major code categories.[19] The range of k scores (90%−98%) suggested excellent consistency.[20] We performed a conventional approach to qualitative content analysis of the 263 unique patient and 225 unique caregiver quotations provided during interviews.[21]

Results

A total of 105 Veterans were randomized to the intervention. Sixty-nine (66%) were alive at completion of the intervention; all completed the quantitative 8-item survey. Table 1 demonstrates the demographic characteristics of the quantitative survey participants. The mean age was 68.2 years, all male, and mostly self-reported race/ethnicity as non-Hispanic white (n = 52, 76%). The majority were unmarried, had no identified caregiver, had stage IV disease, and diagnosed with thoracic malignancies.

Eight-Item Survey Responses of Intervention Participants

All participants reported talking with the LHW at least 3 times during the intervention, found the intervention to be very helpful, and recommended continuing it (Table 2). Fifty-three (n = 37) percent reported initiating one or more contact with the LHW, all of who noted the ease in making contact and recommended the intervention for other patients.

Qualitative Interviews of Intervention Participants

Twenty-four Veterans were contacted to complete an in-person interview and all participated in person. Thematic analysis revealed 3 main themes regarding patients’ experiences with the intervention. These themes included: (1) establishing trust, (2) provision of consistent and reliable guidance, and (3) frequent, timely discussions (Table 3).

Theme 1: Establishing trust.—All participants noted the trusting relationship that the LHW intervention helped to establish. One patient stated, “This program made me feel better by having someone there. The [LHW] was my instant friend. She, made it easy to talk about these important things." Another patient noted, "You could feel that everyone cared about you. The team always called, checked in when they said they would and I could say anything to [the LHW]."

Theme 2: Provision of consistent and reliable guidance.—All interviewees noted the importance of the intervention in assisting patients to formulate their care preferences. One participant stated, "You don't want to think you could die. I didn't want to think like this so I didn't. This program made me realize why and how to think and talk about these things … the same messages over and over so that I finally got it." Another participant noted, "This program gave me my safe place to talk about dying. Things that were important to me … how I wanted to live and die. It's better I make those choices for myself when I can."

All interviewees noted the importance of the intervention in providing consistent, reliable encouragement to discuss their preferences with their health-care providers and loved ones. One participant noted, "[Usually] you just go along with whatever the doc says. [But] this program said it was my life and I had a say and to speak up." Another patient stated, "I didn't want to talk to my wife. I was scared she wouldn't be able to handle it. This program helped me understand why I needed to talk to her and helped me to. I got to know her care goals too. If I can't beat this, my wife will know what to do and I will know what to do for her too."

Theme 3: Frequent, timely discussions.—Many patients noted that conversations regarding their EOL care preferences became easier over time. One patient stated, "The more I was in [the program], the easier this got. [When] the question 'has anything changed' [was asked] it was easy to say 'no, if I have to die, please make sure I do at home.'" Another patient stated, "This program spells it out for you, makes you think about lots of things over and over. The program made me ask questions and made it so much easier to think and talk about."

Caregiver Experiences With the Intervention

Only 30 Veterans identified a caregiver at the time of enrollment, all of whom provided consent for their caregiver to be contacted. All 30 caregivers agreed to participate in the 6-month follow-up 8-item quantitative surveys and in qualitative interviews if and when the Veteran died.

Eight-Item Survey Responses of Caregivers

All 30 caregivers completed an 8-item survey administered by a trained research assistant. All reported talking with the LHW at least 1 time during the intervention (Table 4) and reported that the LHW was very helpful and would recommend continuing the intervention. Three caregivers initiated one contact with the LHW and reported it was very easy to make contact. All caregivers would recommend the LHW for others.

Qualitative Interviews of Caregivers

Twenty-four of the 30 caregivers who consented to participate in a post-death interview had a loved one died at 15-month follow-up. All 24 participated in post-death interviews and opted for a telephone interview. Three main themes emerged regarding caregivers' experiences with the intervention, which included: (1) preparation for death; (2) clear, honest discussions regarding EOL; and (3) goal-concordant care at the EOL (Table 5).

Theme 1: Preparation for death.—All caregiver participants noted that the intervention prepared them for their loved one's death. One participant noted, "You hear horror stories about people surprised when their loved ones die … how awful it is. But this wasn't the case. This program made us talk about it. It was hard to think and hard to talk about, but at the end, I feel so thankful that I was prepared." Another stated, "This program gave me real expectations. I wasn't blindsided about him dying. Because we talked so much about what he wanted during the last couple of months, I felt at peace when it, did because I knew exactly what he wanted."

Theme 2: Clear, honest discussions regarding EOL.—All caregivers noted the importance of the intervention in encouraging clear and open discussions with their loved ones about their care preferences. One participant noted, "He came home after talking with the program and told me straight up that he wanted me to know that he didn't want to die but if it happened he wanted it to be at home." Another stated, "He was honest and direct in a way that he had never been before. He was very clear that he wanted to stop chemotherapy and go to Hawaii to die. So, we packed our bags and went, as he had wished."

Theme 3: Goal-concordant care at the EOL.—All caregivers reported that the care their loved ones received at the EOL was aligned with the patient's goals. One participant noted, "He did not want to die in the hospital. After doing the program this was what we heard from him over and over. He did what the program said, and told the doctor "time out" when the doctor was planning to start a new treatment. He started hospice and was on it for a good month before he finally passed. He was happy with this decision and it made us happy too."

Another noted, "He was worried we were all going to have to watch him die at home and he never wanted to be a burden to us. He didn't want to stop the treatments and told us that because he was making that choice that he wanted to die in the hospital rather than at home. It wasn't what we wanted but he died in the way he wanted."

Discussion

The EPAC intervention is an effective approach to improving cancer care delivery at the EOL.[16] The EPAC uses an LHW to assist patients and caregivers in formulating and discussing their EOL cancer care preferences with their families and health-care providers. In this study, we found overwhelming patient and caregiver support for the intervention. Participants viewed the intervention to be highly important in encouraging patients to discuss their EOL cancer care wishes. In post-death interviews with caregivers, the intervention assisted care-givers with preparing for their loved one's death and in ensuring that patients received EOL cancer care that matched their stated wishes.

In our prior development work, patients,[9] caregivers,[9] health-care providers,[8] and health-care payer organizations[11] endorsed the concept of LHWs in assisting with EOL cancer care services. However, they also expressed concern regarding the extent to which LHWs would be accepted by patients and caregivers and the effectiveness of LHWs in this capacity. In a prior publication, we demonstrated the positive effects of the EPAC intervention, one of the first interventions to utilize LHWs in EOL cancer care,[15] on patient satisfaction with care and decision-making, health-care use, and costs.[16] We provide evidence in this study that patients and caregivers overwhelmingly accepted this service and found that it successfully encouraged patients to think about and discuss their care preferences. Caregivers in post-death interviews noted the importance of this intervention in ensuring that EOL cancer care was concordant with their loved ones' wishes. It is possible that the LHW's social support, given that many of the Veterans in our study had no identified caregiver, led to the development of a meaningful, interpersonal relationship. This interpersonal relationship may have further encouraged patients to engage in their care. The overwhelming perception of the LHW as an integral role of the care team, despite no direct interaction between the LHW and the oncology providers, supports this supposition.

There are some limitations to this study. First, we were only able to include data on the patients who completed the intervention and were not able to collect data on those who died during this period. Patients who died may have important experiences with the intervention that we were not able to report. These challenges in evaluating EOL care have been reported previously.[22,23] Despite this limitation, we were able to obtain 100% response rate of the patients who were still alive to understand the impact of this EOL care intervention on their experiences. Furthermore, given the multidimensional aspects of EOL care, such as the impact on caregivers,[24] we ameliorated some of the challenges in evaluating EOL cancer care by interviewing caregivers as well.[24] Second, because we focused on patient experiences with the intervention, we did not elicit data from patients who were not enrolled in the intervention. Our analysis of other aspects of patient experiences in both the intervention and control groups is presented elsewhere.[16] Although we are unaware of other initiatives at this VA during the time of the study, it is unclear whether the patients and caregivers may have been exposed to information from other sources regarding these topics. Third, there were few patients in the study who had an identified caregiver at the time of enrollment. Therefore, we had to limit our caregiver assessments to the Veterans who died and had caregivers. Among the eligible caregivers, however, we were able to successfully conduct an interview with 100% of them. Finally, the EPAC intervention utilized only 1 LHW in 1 VA facility, and it is unclear whether the experiences reported by patients and their caregivers were due to the interpersonal skills of the LHW in this intervention or due to potential unmeasured factors within this VA and/or among the Veterans in this study. Therefore, it is unclear whether the experiences we report can be replicated across other LHWs and practices. Although this VA facility is continuing this work, a larger study utilizing multiple LHWs in other settings can help to elucidate whether the experiences we report can be replicated across other LHWs and practices.

Despite limitations, our study found that patients and care-givers supported an LHW-led intervention that aimed to elicit patients' care preferences at the EOL and encourage patients to discuss their care preferences with their caregivers and medical teams. After completing the intervention, patients and caregivers highly recommended it for other patients and patients felt more at ease with discussing their EOL cancer care preferences with their caregivers and oncology providers. Caregivers of decedents noted that the intervention also led to improvements in EOL cancer care for patients while also helped to prepare them for their loved one's deaths. These findings support this effective intervention as one solution that can greatly improve the experiences of patients and their care-givers with cancer care at the EOL.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Demographics of Patient Survey Respondents.

Participant Characteristics	Patient n = 69	Caregiver n = 30
Age, years, mean ± SD	68.2 ± 9.2	66 ± 4.3
Sex, n (%)		
Male	69 (100)	3 (10)
Female	0 (0)	27 (90)
Race/ethnicity, n (%)		
Non-Hispanic white	52 (75.3)	11 (36.7)
Non-Hispanic black	5 (7.3)	2 (6.7)
Hispanic	2 (2.9)	5 (16.7)
Asian/Pacific Islander	4 (5.8)	12 (40)
American Indian/Alaskan Native	0 (0)	0 (0)
Chose to not provide	4 (5.8)	0 (0)
Other	2 (2.9)	0 (0)
Marital status, n (%)		
Married	24 (34.8)	28 (93.3)
Caregiver identified, n (%)	30 (43.4)	
Spouse		20 (66.7)
Ex-spouse		3 (10)
Sibling		2 (6.7)
Son or daughter		3 (10)
Friend		1 (3.3)
Other		1 (3.3)
Cancer stage at diagnosis, n (%)		
I	3 (4.3)	1 (3.3)
II	12 (17.4)	3 (10)
III	20 (28.9)	11 (36.7)
IV	34 (49.4)	15 (50)
Recurrent cancer, n (%)	24 (34.8)	12 (40)
Anatomic site of cancer diagnosis, n (%)		
Thoracic	20 (28.9)	12 (40)
Gastrointestinal	16 (23.2)	11 (40)
Genitourinary	8 (11.7)	2 (6.7)
Head and neck	13 (18.8)	2 (6.7)
Skin	7 (10.1)	1 (3.3)
Other	5 (7.3)	2 (6.7)

Abbreviation: SD, standard deviation.

Table 2.

Experiences With the Intervention—Patient Responses.

Intervention Participant Responses	n(%)
1. Since enrollment, did you talk to the lay health worker?	
☐ Yes → Go to question #3	69 (100)
☐ No → Go to question #2 only	0 (0)
2. Why didn't you talk with the lay health worker?	
☐ You weren't interested	N/A
☐ You didn't have the time	
☐ You already had enough information	
☐ You didn't think it would be helpful	
☐ You didn't know about it	
☐ You called her but she did not call back	
☐ Other reason	
3. Since enrollment, how often did you talk with the lay health worker?	
☐ One time	0 (0)
☐ Two times	0 (0)
☐ Three times	2 (2)
☐ Four times	1 (1)
☐ Five times	3 (3)
☐ Six times	8 (8)
☐ Seven times	11 (11)
☐ Eight times	17 (17)
☐ Nine times	27 (27)
☐ Ten times	15 (15)
☐ >Ten times (write in _______)	16 (16)
4. Since enrollment, how helpful did you find the lay health worker to be during your cancer care?	
☐ Very helpful	69 (100)
☐ Helpful	0 (0)
☐ Somewhat helpful	0 (0)
☐ Not at all helpful	0 (0)
5. Would you recommend that the VA continue to have the lay health worker available during your cancer care?	
☐ Yes	69 (100)
☐ No	0 (0)
6. How often did *YOU* initiate contact with the lay health worker aside from when the lay health worker contacted you?	
☐ None → Go to question #8	32 (46)
☐ 1 time	21 (30)
☐ 2 times	5 (7)
☐ 3 times	2 (3)
☐ 4 times	4 (6)
☐ 5 times	4 (6)
☐ 6 or more times (write in _______)	1 (2)

Intervention Participant Responses	**n(%)**
7. How easy was it to make contact with the lay health worker?	
☐ Very easy	37 (100)
☐ Easy	0 (0)
☐ Somewhat easy	0 (0)
☐ Not at all easy	0 (0)
8. Would you recommend that the VA provide a lay health worker for other patients?	
☐ Yes	69 (100)
☐ No	0 (0)

Abbreviations: N/A, not available; VA, Veteran Affairs.

Table 3.

Patient Interview Themes.

Theme 1: The lay health worker intervention established a trusting and positive relationship between the patient and the care team.
The program at the VA made me feel special and taken care of during one of the most vulnerable states of my life. Getting diagnosed with a terminal illness like cancer is a shock to the system and this program let me trust the VA team taking care of me.
I think it's sad that other patients don't get this program at the VA because it really made me trust the docs and nurses that they are there for me. The program made me feel like 1 could be honest with what I wanted.
The lay health worker was so positive and a breath of fresh air, making me think about things and letting me know that they [the team] was all there behind me every step of the way.
It was so easy to talk to [the lay health worker] and it seemed like that was settin' me up to talk to my doctors and it helped me to do that, I think.
I'll be honest, I thought, this program was going to really waste my time. But a couple of minutes on the phone, I warmed up to it That phone number for [the LHW] was my go-to number 'cause there was always someone to answer it right away for anything.
What's different about this program is it made me feel cared for and made me feel like I could trust my cancer docs
You don't know what to think, you know, after you get hit with this cancer thing. Then [the lay health worker] calls you up and gets you to feel better about the whole thing just by being there and listening.
Theme 2: The lay health worker intervention provided consistent and reliable guidance to patients when formulating and discussing decisions and preferences for care.
Well, it was good, this program, because it gave me a lot of education and materials to help me to make my own choices.
These things are tough. I don't know how other people do it without a program like this. I didn't realize that others have to do this on their own. It was nice to set goals and to go through all the forms like the directive and deciding who would make my decisions for me with [the lay health worker]. It made it seem less scary and kinda relieved once you did it.
Gettin' a phone call at least once a week to go through what was important to me and whether I know why I got chemo was good. At first I thought it was duh I know but then there were times that I didn't really know what was going on and if! really wanted all of it This program helped me to ask when I was confused and then make decisions for myself based on what and where my cancer was going.
I don't like to talk about it—dying. Who does? But, I do like to talk about how I want to live. And that's how the program framed it for me. In the time I have here on Earth, how do I want to live.
We all have to die and these things like talking about our wishes are important. But, unless this program forced me to do it, like really make me think and talk about what I wanted, I don't think I would've done it I definitely would not have asked the doctor to help me to do it
Theme 3: Discussions about end-of-life care preferences need to be held frequently and become easier the more you have them.
Talking about dying and what I want when I die or how I want to die is going to change. And this program showed me this. When I was first diagnosed, I wanted to go through all the chemo and radiation and then when it stopped working after a month, I changed what I wanted. It was easier to think about what I wanted because I asked the tough questions like what is this for and is it going to make me live longer and how much longer. Getting the answers to these questions helps me to make these decisions.
We talked about it a lot during the program. What I wanted, when that may change, when would I want to talk about it again and how. And, we did, over and over and over, it seemed. Which was good for me. Now, if l live a bit longer, I will probably be able to do this on my own because it seems to be in my head to think about these things.
I could answer the questions before [the lay health worker] even asked because we went through it a couple of times. It was hard at first, to think about. But, then when you think about a time when you could be sicker and you know what you want at that time, then you come to that point when you are sicker, you don't have to think about it because you had already thought about it when you weren't at that point
These things [end of life care preferences] change. They aren't the same the first time. The first time, I wanted to do everything to live, and that was it. Then when I ended up in the hospital for a week and then in a nursing facility for a couple of weeks, my wishes changed. I realized I wanted to just be at home to take care of my dog. I didn't want to do anything that would make it so I would end up back in the hospital in that downward spiral. So, these things change and unless we are asked time and time again, the doctors won't know.

It seems weird when you get these questions thrown at you right after you get cancer. But I was happy that I got these questions asked a lot because the first time my answers were different I wanted to live. But then I got sicker and my answer changed to, ‘do things to allow me to continue taking care of my dog.’ I have to think about these things a lot of different times for them to stick and my docs need to know how my feelings change after I go through something and especially when I get closer to the end.

It’s like, I don’t know. Something you really don’t want to do like talking about what you want when you croak. Or, rather, right before you croak. But, if you don’t do it, someone else will do it for you. And, if you don’t do it often, someone else will take what you said when you weren’t so close to croaking and think that’s what you wanted. The good think about this program is it taught me to speak up a lot and to speak up often, ‘specially when I change my mind about something.

Table 4.

Experiences With the Intervention—Caregiver Responses.

Caregiver Responses	n (%)
1. Did you talk to the lay health worker?	
☐ Yes → Go to question #3	30 (100)
☐ No → Go to question #2 Only	0 (0)
2. Why didn’t you talk with the lay health worker?	
☐ You weren’t interested	N/A
☐ You didn’t have the time	
☐ You already had enough information	
☐ You didn’t think it would be helpful	
☐ You didn’t know about it	
☐ You called her but she did not call back	
☐ Other reason	
3. How often did you talk with the lay health worker?	
☐ One time	18 (60)
☐ Two times	2 (7)
☐ Three times	4 (14)
☐ Four times	2 (7)
☐ Five times	1 (3)
☐ Six times	1 (3)
☐ Seven times	1 (3)
☐ Eight times	1 (3)
☐ Nine times	0 (0)
☐ Ten times	0 (0)
☐ >Ten times (write in_____)	0 (0)
4. How helpful did you find the Lay Health worker to be during your loved one’s cancer care?	
☐ Very helpful	30 (100)
☐ Helpful	0 (0)
☐ Somewhat helpful	0 (0)
☐ Not at all helpful	0 (0)
5. Would you recommend that the VA continue to have the Lay health worker available during your loved one’s cancer care?	
☐ Yes	30 (100)
☐ No	0 (0)
6. How often did *YOU* initiate contact with the lay health worker?	
☐ None → Go to question #15	0 (0)
☐ 1 time	3 (10)
☐ 2 times	0 (0)
☐ 3 times	0 (0)
☐ 4 times	0 (0)
☐ 5 times	0 (0)
☐ 6 or more times (write in_____*)*	0 (0)

Caregiver Responses	**n (%)**
7. How easy was it to make contact with the lay health worker?	
☐ Very Easy	3 (100)
☐ Easy	0 (0)
☐ Somewhat easy	0 (0)
☐ Not at all easy	0 (0)
8. Would you recommend that the VA provide a Lay health worker for other patients?	
☐ Yes	30 (100)
☐ No	0 (0)

Abbreviations: N/A, not available; VA, Veteran affairs.

Table 5.

Bereaved Caregiver Interview Themes.

Theme 1: The lay health worker intervention helped caregivers to prepare for their loved one’s death.
The VA program, well, I don’t know what would’ve happened if we didn’t have it… but, it made a difference in how [patient] lived and how he died. We were all ready… and he was too.
We knew what [the patient] wanted. We knew when he would want to stop treatment and we knew that he didn’t want to spend his last days coming to the clinic. We were really prepared when it [death] got close because this program made us talk about it a lot
The lay health worker program made me feel more comfortable asking [the patient] those hard and tough questions. And, I am so glad I did. I think if we hadn’t done that we would have never gotten home hospice so early.
I think it made [the patient] live longer… I really do. The program made him seem more carefree. It got all of us thinking and talking and preparing for the end.
I go to a caregiver support group, and, I just think about how different my experience was and I think it’s because of this program. I felt like I knew what to expect and was happy that we had a chance to really talk these things through so I wouldn’t be blindsided at the end.
Theme 2: The lay health worker intervention assisted patients to engage in clear, honest discussions with their caregivers about their end-of-life care preferences.
I really didn’t want to face that [the patient] was going to be gone … you know for good. But he went through this program, and that [lay health worker] called and called and then he would get off the phone and start going through what he understood was happening, what he wanted when it happened, and when he would want to change his mind. And, he talked about it so matter offactly that I was just forced to have to go along with it and listen. I didn’t know that it would make such a difference at the end… knowing that he lived the way he wanted and died the way he wanted.
The first thing we talked about was that I would be his decision-maker when he was too sick to make decisions for himself. Then, we talked about what things would make him want to stop chemo. Then we talked about stopping chemo and then we talked about hospice and that he would rather go to the VA hospice and not be at home. There were no gray areas here… very decided and clear.
It was good that we talked about it in detail. I wouldn’t have known that he didn’t want to go to clinic every week had he not told me. We were pushing for him to go through all the treatments but when he told us what it was doing to him and how it wasn’t what he wanted, that he didn’t want to rely on us tor drive him back and forth, that he didn’t want to be a burden, that he really wanted to go to the lake one last time … well, that hit home for us.
I heard him talking on the phone several times, that he didn’t want to stop his boating business at all if he was going to die. He was trying to figure out how all of this—meaning life—was going to work out with the every week chemotherapy and every day radiation if he was really going to die in the next year. He really struggled about this and it was crazy that he was talked about his struggles with us and with the program that he was in at the VA. It was good to talk about some of these things we never probably would have talked about.
It’s so hard when they don’t talk about it and then you are left wondering what you should do in that situation when your dad can’t talk for himself. This program made us talk about it well before he died and it was not fun but now I am so glad we did it because I am not left wondering if l made the right decision for him.
I went through this with my mom and now with my step-dad. I don’t ever remember mom’s doctors asking these things. So, this was a totally different experience with my step-dad. The fact that my step-dad had a program to help him with all the decisions, and talking about what he wanted, and helping him at the end, also with the advanced directive forms … this was very very different than what I experienced with my mom. He had to make decision for himself and then talk to me about it and this was a big change from how I thought it had to be.
Theme 3: The care received by patients at the end-of-life matched their stated wishes.
He wanted to keep pushing—keep getting treated—hoping that he would be able to beat this thing. He made this decision knowing the treatments weren’t going to help and could even worsen things. But he wanted to keep pushing and he did until the very end.
I don’t think we would have ever known what he wanted at the end had it not been for this program. We are at ease knowing that the great care he got when he was dying was exactly what he wanted.
I am always hearing bad stories about people having these awful things happen at the end of their lives. I feel like we are lucky that this program helped my husband get what he wanted.
I wanted him to keep going because there was a research study that he could have joined up with but he didn’t want that He wanted hospice at home, wanted to spend time with his grandchildren, wanted to move his bed to the living room so he could be more a part of the family, and wanted to spend his remaining time like this. He died at home on Labor Day, surrounded by all of his family and friends, just the way he wanted.
I read all the time about how many patients with cancer never get the chance to tell their families what they want in the end. And when we joined this program, it was scary at first to talk about it, but, he had the chance to tell us what he wanted not once but many times. And, that’s what mattered the most because he was able to get what he wanted at the end and wouldn’t have been able to get that if he hadn’t spoken up and talked to us about it.

This program made a big difference for us, all of us, really, [the patient’s] family because we got to hear what he wanted at the end and got to see him get exactly that. I think we are all at peace and the grieving process was hard but we all know he went the way he wanted to.