

A feasibility study of caregiver-provided massage as supportive care for Veterans with cancer

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Purpose To assess the feasibility of using a multimedia program to teach caregivers of Veterans with cancer how to offer basic massage for supportive care at home.

Methods Feasibility was assessed according to partner availability, compliance with watching training materials and practicing massage regularly, compliance with data collection; perceived study materials burden; clarity of instructional and other study materials. Pre- and post-massage changes in patients' symptom scores were measured using a numerical rate scale. A semi-structured exit interview was answered by patient and caregiver at the end of the study.

Results A total of 27 dyads were recruited. Veterans were 78% male. Forty-eight percent were diagnosed with hematologic malignancies (85%, advanced stage); 52% were diagnosed with solid tumors (64% advanced stage). Caregivers were 78% female; 81% were spouses. Out of the 27 pairs, 11 completed 8 weeks of data and practiced massage weekly. The majority of attrition (69%) was due to caregivers' burden. Caregivers reported instructional materials were clear, high quality, and easy to use. Patients were highly satisfied with receiving touch from their partners regularly. Post-massage symptom scores showed statistically significant decreases in pain, stress/anxiety, and fatigue. Perceived burden of data collection instruments was high, particularly for patients.

Conclusion It is feasible to use the TCC program to train caregivers of Veterans with cancer to offer massage for supportive care at home. Future studies should evaluate ways of providing support to caregivers, including offering massage to them, and easing the burden of data collection for patients.

Complementary therapies are widely used by cancer patients. Surveys indicate that 63%-91% of cancer patients have used some form of complementary therapy in conjunction with conventional cancer treatment.¹⁻³ Massage is considered a safe and well-accepted complementary therapy in supportive cancer care.^{4,5} It is also highly rated by cancer patients.⁶ There is evidence that massage may be an effective supportive intervention for pain, stress/anxiety, and fatigue in cancer patients.⁷ Some studies have reported that massage not only benefits the person receiving the massage but also the person providing it.^{8,9}

Surveys of Veterans have shown that Veterans use of complementary and alternative medicine (CAM)—in addition to their interest in having access to CAM—is high and similar to that of non-Veteran populations.^{10,11} A recent survey describing use and willingness to try CAM among 401 Veterans experiencing chronic non-cancer pain reported that the majority ($n = 327$, 82%) used at least one CAM modality. Nearly all ($n = 399$, 99%) were willing to try CAM interventions for pain. Massage therapy was the most preferred modality, with 96% of participants reporting willingness to try massage if the therapy was available.¹⁰ A previous survey of Veterans with cancer pain and chronic pain reported that 27.3% of participants used CAM within 12 months previous to the survey. Seventy-six percent of those not using CAM reported that they would use it if it was offered at a Veterans Affairs (VA) facility.¹¹ Higher income, supplemental non-VA insurance,

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and receiving care outside the VA system were associated with higher CAM use suggesting that lower CAM use may be related to lack of access within the VA system.

In spite of the wide implementation of massage within oncology and palliative care across non-VA cancer care centers and hospital-based oncology services,¹² massage is seldom offered to Veterans with cancer at VA facilities. A 2011 nation-wide survey of CAM modalities across VA facilities found that only 10% of providers using manipulative therapies (including massage and acupressure) were providing massage for cancer and palliative care patients. However, more than 40% of providers offered massage for Veterans diagnosed with back pain.¹³

Massage has been found to decrease pain in Veterans undergoing major surgery. A randomized controlled trial of massage provided by Licensed Massage Therapists (LMTs) in 605 Veterans showed that Veterans who received 3 sessions of massage within days 1-3 after major surgery experienced short-term decreases in pain intensity, pain unpleasantness, and anxiety compared with a control group receiving standard of care.¹⁴

The care needs of cancer patients are complex. Dealing with treatment-related symptoms involves many resources and is a time-intensive process that requires continual care at home by family and/or friends.^{15,16} With the large number of oncology patients seeking massage as supportive care and the unavailability of massage at VA facilities, instructing caregivers to offer basic massage at home could provide the therapeutic use of touch that cancer patients seek while at the same time enhancing the caregiver's quality of life (QOL) and sense of self-efficacy.^{7,16} Finding ways to train caregivers to offer supportive care at home may be relevant to VA oncology populations.

Studies have shown that QOL in caregivers of cancer patients is affected by their perceived inability to help reduce the patient's suffering.¹⁷ Some studies have reported that this impaired sense of self-efficacy could be decreased by providing caregivers with training on effective supportive interventions for symptom management.¹⁶ Veteran caregivers' have been reported to show high levels of stress. Veterans have a higher incidence of unmanaged pain and a higher incidence of cancer when compared to non-Veteran populations.¹⁸ Therefore, psycho-social interventions that enhance caregiver efficacy in symptom management and engage both patient and caregiver in meaningful interactions may be suitable to study in Veterans with cancer and their caregivers. Data exist about the use of such interventions in non-Veteran populations. A recent study reported the use of a multimedia program—the Touch, Caring and Cancer program. This program was developed with the goal of training caregivers of cancer patients to provide massage for supportive

care at home.¹⁹ A randomized trial of this program used a non-Veteran, community-based sample of 97 patient-caregiver dyads and showed decreased pain, fatigue, and anxiety in patients receiving massage when compared to those who participated in the attention control group. In this study, caregivers who offered massage regularly to the Veteran showed an increased sense of self-efficacy.²⁰ However, no studies have yet reported on the use of such a program within Veteran oncology populations. Therefore, we designed a study to test the feasibility of implementing the Touch, Caring, and Cancer program as well as the feasibility of using this program in future studies. In this paper, we report the results of a feasibility trial of the Touch, Caring and Cancer program with a cohort of Veterans who were receiving oncology and palliative care services at a VA hospital facility in Seattle, Washington.

Methods

The study was conducted at the Seattle Veterans Affairs Medical Center, VA Puget Sound Health Care System (VAPSHCS). The VAPSHCS Institutional Review Board approved the study and provided oversight.

Inclusion/exclusion criteria

Adult patients with a cancer diagnosis were included regardless of cancer site, stage, or active treatment modality. To participate in the study, patients were required to have a personal caregiver willing to learn and provide massage. In addition, both patients and their caregivers were required to speak English and to be able to complete written study materials in English. Patients and caregivers with any cognitive impairment that interfered with completing the study's forms were excluded from the study.

Recruitment

The initial recruitment was conducted by mail and resulted in no dyads recruited into the study over a 4-month period. The recruitment strategy was then revised to involve in-person recruitment at the Cancer Care Clinic and Bone Marrow Transplant Unit (BMTU). Patients and caregivers were approached while waiting for visits, after visits, and while receiving chemotherapy at the infusion room. Using this strategy, a sample of 27 outpatients with cancer diagnosis (all stages) was recruited along with their personal caregiver (friend, partner, or relative) at the cancer care clinic (n = 14) and BMTU (n = 13) over a 6-month period. Demographic characteristics of the study's cohort are included in Tables 1, 2 and 3.

Intervention/procedures

Upon enrollment, dyads were supplied with a training video and a written manual of the Touch, Caring & Cancer program. The development of these training materials was

TABLE 1 Demographic information of participant dyads

Dyads recruited (N = 27)	Veterans (N = 27)	Caregivers (N = 27)
Mean age	60.54	54.04
Median	62	57
Range	40-83	29-77
Gender	21 Male (78%) 6 Female (22%)	21 Female (78%) 6 Male (22%)
Ethnicity	White: 23 (86%) Hispanic: 1 (3.5%) Black: 2 (7%) Asian: 1 (3.5%)	White: 26 (97%) Hispanic: 0 (0%) Black: 0 (0%) Asian: 1 (3%)
Dyads who completed 8 weeks (N = 11)	Veterans (N = 11)	Caregivers (N = 11)
Gender	9 Male (82%) 2 Female (18%)	9 Female (82%) 2 Male (18%)
Ethnicity	White: 10 (91%) Hispanic: 0 (0%) Black: 1 (9%) Asian: 0 (0%)	White: 11 (100%) Hispanic: 0 (0%) Black: 0 (0%) Asian: 0 (0%)

TABLE 2 Cancer type, stages, and metastasis

Dyads recruited (N = 27)		
Type of cancer	Hematological: 13 (48%)	Advanced stage: 11 (85%)
	Solid tumor: 14 (52%)	Advanced stage: 9 (64%)
Dyads who completed 8 weeks (N = 11)		
Type of cancer	Hematological: 7 (64%)	Advanced stage: 5 (71%)
	Solid tumor: 4 (36%)	Advanced stage: 3 (75%)

TABLE 3 Caregiver relationship to Veteran

Dyads recruited (N = 27)	
Relationship type	Spouse: 22 (81%) Adult children: 3 (11%) Sibling: 2 (8%)
Dyads who completed 8 weeks (N = 11)	
Relationship type	Spouse: 11 (100%) Adult children: 0 (0%) Sibling: 0 (0%)

supported through a grant from the National Cancer Institute (NCI) and the program efficacy was previously tested in a randomized trial of 97 non-Veteran dyads.²⁰ After enrollment, an oncology nurse, nurse practitioner, or oncology physician's assistant was required to fill out a safety precautions form describing tumor site(s), presence of ports or other medical devices and symptoms that required precautions to insure the safety of participants during massage. The investigator and/or research coordinator marked the appropriate safety precautions on the training manual and ensured that caregivers understood the precautions that applied to them. Dyads were instructed to watch the video training

together to learn the massage techniques and to regularly check the safety guidelines.

The video instruction—entitled “*Touch, Caring, and Cancer*”¹⁹—is a 78-minute DVD featuring instruction by oncology massage-therapy researchers and clinicians filmed in a workshop context with 11 patient-caregiver dyads learning and practicing the techniques. The video addresses topics such as communication, safety precautions related to cancer, manual techniques for comfort and relaxation, acupressure, simple light touch/holding for comfort, and positioning on home furniture. A 70-page illustrated manual accompanied the DVD and served as a reference material for the dyads. Safety precautions were also explained in the manual. Dyads were instructed to read their safety precaution form and match the precautions to those listed in the manual. Participants were instructed to practice massage at least 20 minutes each time, a minimum of 3 or 4 times a week, but encouraged to practice every day if possible.

Data collection

Patients were provided with a simple daily log to track the number of sessions completed each week, the duration of

the session, and any possible adverse events such as skin irritation. Patients were asked to fill out pre- and post-symptom score cards once a week for a session of their choice that would last 20 minutes or longer. They were instructed to complete symptom score cards immediately before and 15 minutes after the session selected for reporting. This reporting method was successfully used by a randomized trial previously published by Collinge et al.²⁰ Patients reported the pre- and post-session ratings on a 10-point scale for pain; fatigue; stress/anxiety; and any optional "other symptom." Patients and caregivers were also asked to complete standardized survey instruments assessing QOL, stress and attitudes towards caregiving at baseline and 8 weeks with the purpose of testing the feasibility of using these forms in a future larger study. Table 4 describes the data collection instruments.

Demographic information (gender, age, marital status, type of relationship with caregiver) were collected from all patients and caregivers. Measures of disease severity (date of diagnosis, type of cancer, stage, and metastasis) were obtained from a medical report form completed by the oncology staff or palliative care physician.

Data analysis

Descriptive statistics were used to analyze the number and length of massage sessions. Data from all dyads that provided at least 4 weeks of data were included in the analysis. Descriptive statistics such as the minimum, median, mean, and maximum were found for each week for the number of times the caregiver used massage techniques on their partner and the average number of minutes the massage lasted each time. This provided information on whether there were any trends in the use and/or length of the massage. To test for a difference between the pre- and post-scores for pain, anxiety, and fatigue, a two-sided Wilcoxon signed rank test was conducted to investigate any differences in pain, stress/anxiety, and fatigue before and after massage sessions. The two-sided Wilcoxon signed rank test is a nonparametric paired test. The rank test was selected because of the small sample size and because the main hypothesis was whether there was a difference between the pre- and post-scores.

Results

Details about patient and caregiver population are provided in Tables 1, 2, and 3.

Recruitment issues and partner availability

In-person recruitment resulted in 27 dyads over a period of 6 months. Veterans were approached for recruitment while waiting for their cancer care clinic visit, after their

visit, or while receiving chemotherapy at the infusion room. Usually, patients who were approached together with their spouses were more likely to participate. Initially, inpatients from Palliative Care Service were included as a population for recruitment. However, these patients were usually too sick to participate in the enrollment process, which meant no inpatients were recruited.

The recruitment process was, in part, hindered by the number of Veterans who lacked available caregivers to provide massage at home and in some cases by skepticism that massage could help with symptom management. A total of 118 individuals were approached in person. Of these, 27 agreed to participate in the study; 21 were interested in participating but did not have a partner who was either able or willing to participate with them. An additional 16 expressed interest in participating and were followed up for 4-8 weeks as they sought partners to participate with them but never enrolled in the study (presumably because of lack of partners). Skepticism that massage could help with symptom management was easily overcome when patient and caregiver were given the opportunity to watch a 6-minute preview of the DVD training. All of the dyads who accepted to watch the DVD preview showed enthusiasm about participating. The remaining 54 Veterans approached did not show interest in the study.

From the 27 dyads recruited, 11 dyads completed the 8 weeks of the study. All of the 11 dyads who completed the study were in a spouse or partner relationship. In 9 of those dyads, the patient was a male Veteran. In all cases, caregivers were opposite-gender partners. Although we recruited 3 dyads that included female Veteran patients and their adult children as caregivers, none of them were able to complete the study. Informal data from their weekly calls indicated that the main reason for withdrawing was that the caregivers felt overwhelmed with their tasks (2); and/or were having health and work issues (1). In these cases, caregivers perceived the study procedures as burdensome and reported that they were unable to provide massage on an ongoing basis.

Compliance with training materials

Ten out of the 11 pairs who completed the 8 weeks of the study were compliant with the instructions to watch the DVD training and read the manual. The remaining dyad reported consulting the manual but did not watch the DVD training. The caregiver had previous massage instruction and determined that it was unnecessary to watch the DVD. Previous massage experience was not an exclusion criterion in our study because even if a participant had massage experience, they could still learn the particular safety precautions required for oncology massage

TABLE 4 Summary of data collection instruments

Data collection instrument	Instrument type	Construct measure	Data collection points	Approx. time to complete
Enrollment form	Developed by PI (LK)	Demographic information	Enrollment	15 min
Medical intake form	Developed by PI (LK)	Date of diagnosis, type of cancer, stage, metastasis, current treatment, and safety precautions inventory	After enrollment and before beginning participation	20 min
Functional Assessment of Cancer Therapy [FACT-G]	Validated	27-item compilation of general questions divided into four primary QOL domains: Physical Well-Being, Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being ²¹	Enrollment and 8 weeks	5 min
Pre-post patient session card	Based on validated instrument (ESAS)	Assessed patient-reported symptom burden (pain, stress/anxiety, fatigue and 'other' symptom) before and 15 minute post-massage. Instrument based on Bruera et al's Edmonton Symptom Assessment Scale (ESAS) ^{22,23}	Once a week	5 min
Weekly log	Developed by PI (LK)	7-day log with 3 questions/day: massage offered today (yes/no), if yes, how long it lasted, any adverse reaction present (skin irritation, discomfort, other)	Every day, for 8 weeks	2 min
Pre-post caregiver session card	Developed by Collinge et al ²⁰	Investigator-designed pre-post massage questions ^{20,24} Pre: assessed DVD and manual usage Post: assessed area of body that was massaged, length of session, and reference to DVD and/or manual during session	Once a week, for 8 weeks	5 min
Perceived stress scale [PSS]	Validated	Perceived stress scale (Cohen et al, 1983, 1988) ^{25,26}	Enrollment and 8 weeks	5 min
Caregiver reaction assessment subscale (CRA)	Validated	7-item Esteem Subscale of the Caregiver Reaction Assessment (CRA) ^{20,27}	Enrollment and 8 weeks	5 min
Caregiver survey	Developed by Collinge et al ²⁰	A 7-question investigator designed survey ^{20,24} asking about satisfaction with ability to help loved one, comfort with using touch, concern about making the patient's condition worse, comfort with providing massage, and confidence in ability to provide massage	Enrollment and 8 weeks	5 min
Semi-structured exit interview	Developed by PI (LK)	Investigator-designed to assess patient and caregiver experience with the "Touch, Caring & Cancer" program	End of the study	15-30 min

from our program. Caregivers who provided data for the 8 weeks of the study reported that they watched the DVD instruction an average of 6 times over the course of the 8-week period and consulted the manual an average of 16 times over the 8 weeks.

Compliance with using massage regularly

All of the dyads that returned at least 4 weeks of data forms ($n = 12$) practiced massage regularly according to instructions reporting a mean number of massages of 5.7 per week (median, 5.07; range, 0-14) with each massage

session lasting an average of 21 minutes (median, 18 minutes; range, 2-120 minutes). All dyads who participated in the exit interview (n = 10) reported continuing the practice after the 8 weeks of data collection at the time of the exit interview, which usually happened between 1 and 5 weeks after the last data collection was received.

Compliance with data collection and returning of data collection instruments

At enrollment, dyads were provided with a folder for each participant, patient and caregiver, which included 8 sets of forms – one set for each week. A summary of data collection instruments is presented in Table 4. Instruments were designed to avoid unnecessary burden and were simplified versions of the forms used by Collinge et al in a previous randomized trial of the Touch, Caring & Cancer program.²⁰ Patients were instructed to fill out 2 simple forms each week and return them in a self-stamped and self-addressed envelope provided along with the forms. One form was a daily log describing the days in which massage was provided, for how long, and if any skin irritation or other adverse event occurred by circling appropriate answers or entering check marks. The second form asked the patient to circle on a numerical rating scale of 1-10 the number associated to symptom burden for 4 different symptoms: pain, stress/anxiety, fatigue, and “other” (a symptom that was not listed but afflicted the patient). Patients were asked to fill out the log every day. A pre- and post-symptom score card was filled out once each week, immediately before and after the massage session the dyad had selected for reporting. Compliance with returning data collection was low in spite of weekly phone calls over the 8-week study period. These weekly calls inquired about the massage practice and the massage instruction, and reminded dyads about sending data collection forms back to the team. Of the 27 dyads recruited, 11 completed and returned the data collection forms over the 8 weeks; 5 dyads withdrew from the study for Veteran-specific reasons (2 dyads due to the Veterans’ deaths and 3 dyads due to worsening of the Veterans’ health). The remaining 11 dyads withdrew from the study due to caregiver-related reasons, either due to the caregivers feeling stressed/overwhelmed⁹ or illness.² Qualitative data from weekly calls showed that caregiver burden was a main barrier in the non-compliant dyads.

Exit interviews

A semi-structured exit interview was completed between 1 and 5 weeks after receiving data collection forms for week 8 of the study. Ten out of 11 pairs that completed the study took part in the exit interview. The remaining pair did not participate due to the sudden death of the

patient during the 8th week of the study. Four of the participating dyads expressed some degree of burden in filling out and returning forms, which was the only aspect of the study that caregivers and patients reported as burdensome. All dyads who completed the 8 weeks of the study reported easily learning the massage techniques from the instructional materials.

The following themes were identified from the exit interviews:

- Caregivers were very satisfied with the instruction, appreciated the clarity of the visual instruction and the descriptions included in the printed manual. *“The program was wonderful – the manual is textbook quality and was very helpful.”*

- Caregivers reported feeling increasingly confident in their massage skills as they practiced regularly, with a clear sense of self-confidence in their massage skills by the end of the 8 weeks. *“At the beginning it was a little difficult until I learned the technique . . . after a couple of weeks I felt more confident – we both really enjoyed the program and are very happy for the opportunity [to participate].”*

- Veterans and their caregivers consistently stated being grateful for the opportunity to learn massage techniques and expressed their appreciation of the Veterans Health Administration for making this training available to them. *“It was a good thing to go through the program together in such a difficult time, I want to thank you – we were very happy with the experience – it did a lot for both of us.”* *“I am very grateful for the opportunity to participate in this program through the VA.”*

- Some caregivers with health problems were surprised that they were able to participate in providing massage: *“I am also grateful that you have taken the time to explain to me that I could do this program even if I have arthritis. I thought I was not going to be able to do this but it not only worked out fine by learning the right techniques, but also it brought so much closeness to us. Thank you!”*

- Some caregivers expressed a sense of burden due to their full-time caregiving tasks, expressing their desire for receiving massage themselves. *“I would have liked to get a massage too, being a caregiver is so stressful and I am all alone to take care of him.”*

- Some Veterans found it difficult to fill out the data collection forms due to their illness. *“It was easy to participate except for the [data collection] forms, I (the caregiver) had so much on my plate.”* *“My husband had trouble sometimes filling out the papers, he was in such pain and sometimes I had to help him. I know it does not have to do with the actual program – the program was very helpful but the forms sometimes were a problem.”*

- Caregivers consistently described how the program taught them a way to help their loved one when

TABLE 5 Mean symptom scores pre- and post-massage for dyads providing 4+ weeks of data (n = 12 dyads)

Symptom	Minimum difference on scale of 1-10	Maximum difference on scale of 1-10	Median difference on scale of 1-10	Mean difference on scale of 1-10	Wilcoxon sign rank test statistic	P value (Two-sided Wilcoxon signed rank test)
Pain	0.2	2.143	0.875	1.061	78	.0005
Stress/anxiety	0.2	3	1.357	1.483	78	.002
Fatigue	-0.964	2	0.929	0.819	51	.019

he/she was in pain and/or experiencing anxiety, facilitating a sense of providing comfort in moments that the patient was feeling unwell. *“Massage really took away from the daily aches and pain of all I went through. Helped to take away the stress and fatigue.”* *“Being able to connect with him [the Veteran] when he was going through something so difficult and connect through the massage really helped us, because I could comfort him when nothing else brought comfort.”* *“Thinking that I could actually help my husband feel better [it brought comfort], it was very helpful.”*

- A sense of increased “closeness” and “connection” with their loved one, bringing them emotionally closer with their partners. *“...The program helped us to have a special bonding time together during those difficult times.”* *“...The program really helped us to stay connected through difficult times.”* *“It brought us closer in the midst of all the difficult times”* [What I liked best of this program was. . .] *“Being able to have that extra communication through touch and feel.”*

- Caregivers described providing the massage as bringing an opportunity for interactions that were unfocused on medical procedures or dealing with the cancer treatment but rather focused on “wholeness” and “wellness.” *“It was great that the program treated the whole person, not just the cancer, mind and body, so we could get our minds off from focusing just on the cancer – that was very important to us.”*

Secondary aims

As a secondary aim, we tested the ability of dyads to answer a set of data collection instruments previously used by Collinge et al²⁰ in a randomized trial of the *Touch, Caring & Cancer* program. The goal was to gain understanding about the feasibility of these dyads completing the instruments for a future randomized trial. Table 4 shows a summary of instruments and approximate time needed for filling them out. Caregivers were able to fill out the baseline instruments in 15-20 minutes consistently. However, the process was burdensome for some patients, particularly those who were receiving immune-suppressive regimes for bone marrow

transplant procedures and those who had more intense reactions to their chemotherapy treatment. Some patients needed up to an hour to fill out the baseline instruments and, in some cases, alternate times needed to be scheduled for completing the forms.

Changes in pre-post massage symptom scores

Table 5 shows the mean difference in symptom scores reported for Pain, Stress/Anxiety & Fatigue and the associated P values for all participants who provided at least 4 weeks of data. Table 6 shows mean symptom scores pre- and postmassage for all participants who provided at least 4 weeks of data.

Discussion

This study showed the feasibility of teaching caregivers of Veterans with cancer how to provide massage for supportive care at home as well as the feasibility of training these caregivers by using a multimedia program.¹⁸ However, as a research project, the feasibility of replicating this study may be limited due to the difficulty of maintaining the participants’ commitment to completing data collection forms. The data collection forms we used were considered burdensome by some participants. Any future project should address the need for collecting data by phone instead of using self-report forms.

Recruitment for this study was challenging. Recruitment strategy by mail proved to be completely unsuccessful, suggesting that personal contact may be an important factor in recruiting dyads for these types of interventions. While we were able to recruit 27 patient-caregiver dyads, another 21 patients expressed interest in participating but did not have an available caregiver. Recruiting volunteers to provide massage for these Veterans may be a feasible alternative that should be considered by future studies. Volunteers have been successfully used to provide hand and foot massage at various palliative care programs within VA and non-VA facilities, such as the Benevolent Touch program²⁸ and the Patient Comfort Ambassador program.²⁹

TABLE 6 Mean symptom scores pre- and post-massage for all participants who provided at least 4 weeks of data for pain, anxiety/stress and fatigue

Pain					
Cancer type	Advanced cancer	Metastasis	Pre-massage pain mean	Post-massage pain mean	Difference
Hematological	Yes	No	7.625	5.625	2
Hematological	Yes	No	6.000	4.375	1.625
Hematological	Yes	Yes (bone)	8.125	6.143	1.982
Solid tumor	Yes	No	2.571	2.167	0.404
Solid tumor	Yes	No	1.250	1.000	0.250
Hematological	Yes	Yes (bone)	5.250	4.750	0.500
Hematological	Yes	No	4.143	2.429	1.714
Hematological	Yes	Yes (Brain)	1.571	1.286	0.285
Solid tumor	No	Yes	6.125	4.875	1.250
Solid tumor	No	No	1.200	1.000	0.200
Solid tumor	Yes	No	1.375	1.000	0.375
Hematological	No	No	3.714	1.571	2.143
Overall			4.079	3.018	1.061
Stress/anxiety					
Cancer type	Advanced cancer	Metastasis	Pre-massage stress/anxiety mean	Post-massage stress/anxiety mean	Difference
Hematological	Yes	No	6.750	4.750	2
Hematological	Yes	No	1.625	1.250	0.375
Hematological	Yes	Yes (bone)	8.250	5.286	2.964
Solid tumor	Yes	No	3.000	2.333	0.667
Hematological	Yes	No	7.500	4.500	3
Hematological	Yes	Yes (bone)	4.125	3.750	0.375
Hematological	Yes	No	4.286	2.286	2
Hematological	Yes	Yes (Brain)	4.000	2.286	1.714
Solid tumor	No	Yes	6.000	5.000	1
Solid tumor	No	No	1.200	1.000	0.2
Solid tumor	Yes	No	1.500	1.000	0.5
Hematological	Yes	No	4.625	1.625	3
Overall			4.405	2.922	1.483
Fatigue					
Cancer type	Advanced cancer	Metastasis	Pre-massage fatigue mean	Post-massage fatigue mean	Difference
Hematological	Yes	No	7.375	5.375	2
Hematological	Yes	No	2.875	1.750	1.125
Hematological	Yes	Yes (bone)	7.750	8.714	-0.964
Solid tumor	Yes	No	2.857	2.333	0.524
Hematological	Yes	No	7.500	5.500	2
Hematological	Yes	Yes (bone)	6.250	6.250	0
Hematological	Yes	No	3.857	2.571	1.286
Hematological	Yes	Yes (Brain)	3.000	2.143	0.857
Solid tumor	No	Yes	6.000	5.000	1
Solid tumor	No	No	1.000	1.000	0
Solid tumor	Yes	No	1.250	1.000	0.25
Hematological	No	No	4.625	2.875	1.75
Overall			4.528	3.709	0.819

Population recruited was mostly male (78%), with 70% of the sample presenting advanced stage cancer and 97% receiving treatment at the time of the study. Roughly half of our population recruited (48%) had hematological malignancies (85% advanced stage). Some studies suggest that Veterans with hematological malignancies treated at VA facilities may be diagnosed at later stages than those from non-Veteran populations and therefore may be sicker at the point of diagnosis.³⁰ Veteran populations seeking care at VA facilities have also been described as more likely to have a poor health status and be older than non-VA populations with similar conditions.³¹ A previous randomized trial published by Collinge et al²⁰ in a non-Veteran sample showed lower attrition than our study. It is possible that the disease burden in our population was higher than the disease burden of the sample participating in Collinge et al's study,²⁰ affecting the ability of our caregivers to comply with the study procedures and/or with providing massage.

Furthermore, in our study we recruited dyads at a Veteran facility that is 1 of 3 Veteran Administration National Centers for Bone Marrow Transplant, which explains the high number of patients with hematological malignancies recruited in our study. Patients at our Bone Marrow Transplant Unit were traveling from great distances and were required to have partners with them while living at special VA accommodations for 2 to 6 months during treatment. Caregivers of these patients were particularly isolated as they lacked the support system that local patients may have. It is possible that these caregivers were more likely to be overburdened by their caregiving tasks. Unfortunately, our study did not collect data about these issues. We are planning a larger study that will include a more extensive qualitative component to understand the particular needs of our Veteran oncology populations.

Many Veterans did not believe that massage could be effective to decrease cancer-related symptoms. However, caregivers showed an awareness of the benefits of massage and were likely to express desire to participate in the study. Most of the Veterans (24/27) who were recruited into the study were those who had their partners accompanying them at the clinic. Only 3 out of the 27 dyads recruited were Veterans who were alone when approached for recruitment, suggesting that the presence of a partner when approached for recruitment may be a factor that influences the participation in these types of studies.

Our study showed that the data collection process was considered burdensome by this population. We used data collection forms that were simplified versions of those successfully used by Collinge et al²⁰ in a previous randomized trial of the same program. These forms were

revised with the goal to avoid unnecessary burden. The package was designed for easy identification of forms week to week, but the process of understanding which form to fill out and how as well as the process of returning forms once a week was confusing to many dyads. Only 11 of the 27 pairs completed and returned the data collection forms over the 8 weeks. Informal data from weekly reminder calls suggests that caregiver burden was a main barrier to filling out and returning the data forms in the noncompliant dyads. In addition, 4 of the dyads who completed the study described during their exit interview some degree of burden in filling out and returning forms, which was the only aspect completing dyads reported as burdensome. None of the younger caregivers (all of which were adult children of Veterans) were able to complete the study. Withdrawal due to caregiver-related circumstances (health issues, stress, and feeling overwhelmed by caregiving activities) accounted for 69% of subject attrition over the course of the study. Recruitment issues, high attrition, and adherence to data collection have been reported as a common challenge in other studies recruiting cancer patient-caregiver dyads.^{32,33} However, data collection burden did not emerge as an issue in the non-Veteran sample recruited by Collinge et al.²⁰ As stated above, some studies comparing Veterans to non-Veteran populations have suggested that unmanaged cancer pain may be more frequent in Veteran populations. Veteran caregivers in general also show high levels of stress.¹⁸ Therefore, it is possible that the high symptom burden in our study population and the caregivers' stress level may have had an impact on the perceived burden of data collection procedures.

From the 16 dyads who did not complete the study, 11 withdrew due to caregiver-related reasons either because the caregiver was stressed/overwhelmed (9) or became ill (2). Yet, because no formal exit interview with dyads who withdrew from the study was included in the study design, we do not have details about the reasons for withdrawal. However, informal data from weekly follow-up calls suggest that, in these dyads, caregivers perceived the study procedures as burdensome and reported that they were unable to provide massage on an ongoing basis. Some caregivers who completed the study reported that their full-time caregiving tasks were highly stressful and expressed their desire for receiving massage themselves. This raises the important issue of how to better support caregivers who are supporting their partners through cancer treatment.

All dyads who completed the 8 weeks of the study reported that it was easy to learn the massage techniques from the instructional materials. Compliance with providing massage in dyads that returned at least 4 weeks of data forms was excellent, reporting a mean number of massages of 5.7 per

week (median, 5.07; range, 0-14) and each massage session lasting an average of 21 minutes (median, 18 minutes; range, 2-120 minutes). We did not continue to follow up with the dyads beyond the study's exit interview. However, at the time of the interview (between 1-5 weeks after data collection), all dyads reported continuing the practice. These findings suggest that those dyads had integrated the massage within their daily routines even when they no longer needed to report to the study.

Although the sample size of this study was too small to provide conclusive results with regards to changes in symptom scores associated to the intervention, data collected show a significant reduction in symptom scores when comparing pre- and post-intervention scores. As shown by Table 6, this is particularly obvious for patients who had a pre-massage symptom score ≥ 3 . Results from our study indicate that symptom reduction was greater for pain and stress/anxiety, which showed a mean difference of 1.061 (range, 0.2-2.143) and 1.483 (range, 0.2-3) respectively (Table 5). A reduction in symptom scores has also been reported within a larger non-Veteran sample by Collinge et al.²⁰

This study had several limitations. The most important limitation of this study was its sample size. Another limitation of our study was the inability to recruit Veterans who did not have caregivers to participate in the study. A third limitation was the perceived burden of the data collection instruments, which resulted in a high attrition rate. Finally, a fourth limitation is that our data may not be representative of oncology and palliative care at other VA facilities across the country.

Conclusion

Feasibility for implementing this program was assessed according to partner availability, compliance with watching training materials as well as practicing massage regularly, perceived study burden, and clarity of instructional materials. This study shows that it is feasible to train caregivers of Veterans with cancer to provide massage for supportive care at home by using the Touch, Caring and Cancer program. An interesting finding of this study was that many Veterans wanted to participate in the study but did not have caregivers available. Therefore, future studies should examine the possibility of recruiting volunteers who could be trained to provide the massage.

Results from qualitative interviews in this study suggest that the program was well accepted and helpful to patients and caregivers alike. Of particular interest was the impact of the program on the participant couples' sense of closeness and connection, an issue that appeared as a theme in most of the dyads' exit interviews. Another theme was the ability gained by caregivers in providing comfort and symptom reduction at times in which the

caregiver would usually feel unable to help. These findings are in agreement with those published earlier in a non-Veteran population.²⁰ Further studies should identify appropriate outcome measures to assess the effect of the program on relationship quality.

Pre- and post-massage symptom scores showed significant decreases in this study, suggesting that this intervention may be suitable for comanaging cancer symptoms such as pain, anxiety, and fatigue. Similar results have been reported by Collinge et al.²⁰ Because the sample size of this study was very small, studies involving a larger Veteran population should confirm these findings. This study also showed that instruments that may be considered a low burden by researchers' standards may be burdensome for a population such as the one recruited in our study. Future studies should consider collecting data via phone interviews, which showed to be a widely accepted mean for communication with this particular Veteran population.

Lastly, a very important finding of this study is the unmet needs that caregivers of Veterans with cancer have in terms of psycho-social support and stress management, which have been reported extensively in the palliative care literature.²⁸ During exit interviews, caregivers consistently reported their wishes that they had received massage themselves during the study. Providing massage to caregivers either by engaging massage therapists or volunteers may be a way to increase social support and relaxation, both of which have been shown consistently to be associated with decreased stress and higher resilience.³⁴ In 2 cases, patients who were feeling well at times reciprocated offering massage back to their partners. However, our study population included mostly patients with advanced cancer and most patients were unable to reciprocate the massage with their partners because of their health status. It is possible that in populations of cancer patients who have a lesser disease burden, the patient could reciprocate and provide massage to their caregiver at least some of the time. Future studies may benefit from an intervention that includes providing massage to the caregiver in addition to the patient, which may increase the possibility of caregivers to provide support to their loved one. In this regard, our study led to writing a proposal to implement the program at various Veteran facilities with the goal of collecting data from the implementation process and dyad outcomes, including QOL and relationship outcomes. It is expected that these data will help us understand the particular needs of our Veteran oncology populations.

More research is needed to investigate how to help caregivers in their daily task of supporting a loved one with cancer. While caregivers are a great resource for comfort care and symptom management, more support needs to be of-

ferred to caregivers so they may be able to accomplish their tasks while providing for their own wellness needs.

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