

Touch, Caring, and Cancer: randomized controlled trial of a multimedia caregiver education program

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Abstract

Purpose A randomized controlled trial was conducted to evaluate outcomes of a multimedia instructional program for family caregivers in simple touch-based techniques to provide comfort to cancer patients at home.

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Methods A multilingual 78-min DVD and 66-page manual were produced for homebased instruction. Content addresses attitudes and communication about touch in cancer, psychological preparation for giving and receiving touch, safety precautions, massage techniques for comfort and relaxation, acupressure for specific cancer-related symptoms, and practice in the home setting. Materials were produced in English, Spanish, and Chinese versions. A community-based multiethnic sample of 97 adult patient/caregiver dyads was randomized to experimental (massage) or attention control (reading) groups for 4 weeks. Massage dyads received the program and instructions to practice at least three times per week, while control caregivers read to their patients for the same frequency. Self-report instruments assessed change in symptom severity, quality of life, perceived stress, and caregiver attitudes.

Results Significant reductions in all symptoms occurred for patients after both activities: 12–28 % reductions after reading vs. 29–44 % after massage. Massage caregivers showed significant gains in confidence, comfort, and self-efficacy using touch and massage as forms of caregiving.

Conclusions Multimedia instruction in touch and massage methods may offer family members a viable means of enhancing self-efficacy and satisfaction in caregiving while decreasing patient pain, depression, and other symptoms. Family members may be able to learn and apply safe and simple methods that increase patient comfort and reduce distress.

Keywords Caregiver education · Oncology massage · Palliative care · Psychosocial oncology · Family caregivers

Introduction

Touch in the form of massage and other gentle, noninvasive methods is one of the most popular forms of palliative care for relief of pain and other symptoms in cancer. Numerous studies

of massage with cancer patients have demonstrated significant effects on perceived stress [1, 2], quality of life [3–6], and common symptoms such as pain, nausea, anxiety, mood disturbance, fatigue, and disturbed sleep [7–17]. Impact can be both immediate and clinically significant; in a study of 380 adults with advanced cancer, both massage and simple touch were found to bring immediate improvement in pain and mood [18], and a large study of 1,290 patients found a single massage to reduce symptom levels by 21–52 % [19].

Touch-based methods of comfort are offered in many cancer treatment centers, hospice programs, and other palliative care settings [20, 21]. However, there are significant obstacles to wide use and consistent delivery to patients over time, often resulting in such therapy being a novel or special event outside routine care. For many, the cost of such services and lack of insurance coverage makes regular use unaffordable. For those with the means, treatment settings often lack sufficient availability of personnel who are trained or have time to deliver this form of care. For home-based patients, to visit a provider requires travel from home and the scheduling of appointment times into the future—both of which can be problematic for patients carrying high burdens of distress.

The integration of touch as routine supportive care may be achievable through tapping an underutilized resource in the patient's natural social environment: family members and friends who have the need and desire to contribute to relief of suffering in their loved one. Numerous studies have found that care partners, often due to perceived helplessness or low self-efficacy in contributing to the well-being of the patient, can experience as much or even more distress than cancer patients [22–28]. There is also evidence that care partners benefit from doing active, hands-on caregiving [29, 30]. One study found that family caregivers receiving instruction in reflexology can reduce pain and anxiety in cancer patients [31]. Caregiver education for partners is needed to help build their sense of self-efficacy and empower them with the ability to have an impact on patient well-being. Such programs hold the potential to benefit the patient, the partner, and the quality of their relationship [32].

Preliminary to the present study, a phase I feasibility study was conducted using focus groups and experiential workshops to explore attitudes and receptivity toward use of touch in cancer caregiving, and to identify content that could be easily taught and received by lay care partners. That study found inhibitions about touch in cancer lead to unnecessary physical and emotional distancing at a time when patients need touch the most, and that brief instruction could increase caregiver efficacy, patient satisfaction, quality of life, and quality of the relationship [33]. Based upon those findings, a multimedia instructional program was produced to offer psychoeducational content on use of touch and teach

simple techniques for comfort and relaxation in cancer caregiving. Multimedia instruction for caregivers (in this study also referred to as “care partners”) was seen as a strategy to overcome barriers of cost and access to professionals for touch-based comfort care. This article reports findings of a randomized controlled study that aimed to (1) determine impact of caregiver-administered massages on patient symptoms and side effects, (2) evaluate the effects of the instruction on caregiver attitudes toward use of touch-based methods of supportive care, and (3) assess impact of the intervention on quality of life in patients and stress levels in both patients and caregivers.

Methods

Instructional materials

Two 6-h workshops were filmed to obtain video footage for an instructional DVD. The workshops were led by WC (principal investigator/clinical social worker), JK and TW (oncology massage practitioners/researchers), and filmed by a professional production company [34]. Eleven adult patient/caregiver dyads consented for filming, including three white, three African American, three Asian American, and two Hispanic/Latino dyads. Relationship diversity included eight spousal couples, one father/daughter, one mother/son, and one sibling pair. The dyads were filmed receiving the instruction, practicing the techniques, and discussing their observations as a group. Spanish and Chinese interpreters assisted. Instructional content included safety precautions related to touch with cancer patients, communication, intention and frame of mind, centering, positioning on home furniture, manual techniques for comfort and relaxation (head, neck, shoulders, back, feet, and hands), and acupressure for pain, anxiety, and nausea.

A 78-min DVD was produced to deliver the instruction outlined above. Expert commentary by an oncologist (David S. Rosenthal, MD) and an oncology nurse researcher (SB) was incorporated in final editing. A language menu offers user-selectable voice tracks in English, Spanish, Cantonese, and Mandarin, each with the option of captioning for the hearing impaired. The chapter menu offers user-selectable chapters on the content areas listed above. A 66-page illustrated manual mirrors the DVD content and was produced in English, Spanish, and Chinese versions. The manual includes a “Precautions Checklist” which the user is instructed to review with the patient's physician to identify precautions relevant to the patient's specific medical condition (e.g., pressure restrictions, locations of lymphedema, etc.).

The DVD and manual are bound together and titled *Touch, Caring and Cancer: Simple Instruction for Family and Friends*. Usability testing on all components was

conducted during production with a convenience sample of 18 patients and caregivers to obtain recommendations for design and ease of use.

Settings and subjects

Flyers announcing the opportunity to participate in the project were given by supportive care staff to adult patients and their caregivers at nine cancer treatment centers and support and advocacy organizations in Boston, Massachusetts, Portland, Maine, and Portland, Oregon. Eligibility criteria included age 18 or above; ability to speak, and read and write in English, Spanish, or Chinese; the patient currently experiencing the effects of any type or stage of cancer or its treatments; both patient and caregiver willing to participate; and caregivers with no prior instruction in massage or touch therapy techniques. The application materials included a medical information form and the Precautions Checklist to be completed by the patient's medical provider. The Greater Boston Chinese Golden Age Center and the Latino Health Institute (Boston) assisted with minority recruitment as well as translation and interpreter services. All subjects were consented in person or by phone interview. IRB oversight was provided by the New England Institutional Review Board, Newton, Massachusetts.

Study design

Subjects were randomized to treatment or control conditions for 4 weeks, after which controls were allowed to join the intervention and all subjects were followed for an additional 16 weeks. (Data on the combined sample's longitudinal use of the intervention will be reported in a separate paper.)

Randomization Block randomization of each dyad was applied based on ethnicity of the patient to achieve equivalent ethnic diversity in treatment and control groups (using <http://www.randomization.com>). In cases of an odd number of dyads for an ethnicity, a coin flip determined the final dyad's assignment.

Experimental condition Dyads in the experimental condition attended an orientation meeting with other subjects where they viewed the DVD together and were then given a packet containing their own copy of the program plus the data collection materials. No direct instruction or practice took place at the meeting. They were instructed to view the materials (both DVD and manual) as often as they wished and practice techniques of their choice at least three times per week. Suggested duration of sessions was 20 min, but they were told that as little as 5 min could be beneficial, and they could decide how long each session would last.

Control condition Caregivers assigned to the attention control condition were instructed by phone and written instructions to read to the patient at least three times per week. Suggested duration of sessions was 20 min, but they were told that as little as 5 min could be beneficial, and they could decide how long each session would last. Reading material could be any literature of the patient's choice, such as poetry, fiction, nonfiction, religious, etc.

Data collection All data except medical information, documented by the physician or nurse, were collected via self-report instruments and submitted through postal mail. Patients and caregivers were asked not to share the answers to the self-report instruments to avoid interference with the data. All data collection and instructional materials were produced in English, Spanish, and Chinese language versions.

To assess the effects of practice sessions, both groups were instructed to designate one session per week of their assigned activity to use as a "weekly reporting session." This was to be a 20-min session in which patients rated their symptom levels on a two-sided 5 × 8-in. card before the session and again 15 min after. Patients used a 1 to 10 scale to rate how "bothersome" a symptom was, 1="not at all" and 10="extremely." Symptoms assessed included pain, stress/anxiety, depression, fatigue, nausea, and a patient-defined "other" (miscellaneous) symptom. The patient-defined "other" symptom assessment was used to capture less common symptoms yet those that were significant to patients. This approach and the use of session cards was successfully used in a prior study of massage session effects by Cassileth and Vickers [19]. At the same weekly reporting session the care partner completed a card reporting the duration of the reporting session, total number of sessions conducted during the past week, average duration, and, for experimental dyads, viewings of the instructional materials.

In addition to the weekly reports, a survey package was completed at baseline and 4-week follow-up. Caregivers completed seven investigator-generated questions on attitudes toward caregiving (Table 5), all rated from 1, "lowest" to 10, "highest." They also completed the seven-item caregiver esteem subscale of the Caregiver Reaction Assessment [35], one of seven subscales derived using confirmatory factor analysis on an independent sample ($N=377$) and tested for factorial invariance across spouse and nonspouse caregivers of persons with cancer or Alzheimer's disease. Responses range from 1, "strongly disagree" to 5, "strongly agree."

Both caregiver and patient completed the Perceived Stress Scale (PSS-10), a 10-item Likert-scaled instrument with responses ranging from 0, "never" to 4, "very often," to determine perceived stress levels over a one-month recall

period. The PSS is a validated and widely used scale for community samples with at least a junior high school education [36].

Patients also completed the Functional Assessment of Cancer Therapy-General (FACT-G, version 4) [37]. This is a validated, widely used instrument with 27 Likert-scaled items (0–4) yielding a total score and subscale scores for physical, functional, social/family, and emotional adjustment. The scale has been shown to discriminate patients based on stage of disease, performance status, and hospitalization status.

Safety monitoring For dyads using massage, one home visit was conducted at the beginning of the intervention period by an oncology massage therapist. The purpose was to observe for proper implementation of safety precautions specific to the patient as identified on the precautions checklist completed by the patient’s medical practitioner. Assessment for adverse events was conducted by phone query by the research assistant bi-weekly.

Statistical methods

Categorical demographic data were compared using either Chi-square tests or Fisher’s exact p . Continuous data were compared using t tests.

To determine effects of massage and reading sessions on symptoms, mean pre- and postsession ratings were calculated for each symptom for each of the four weekly reporting sessions. Next, weighted group means across the four reporting sessions were calculated to determine mean “difference scores” and percent change for each symptom.

Group-by-time repeated measures analysis of variance (ANOVA) was used to assess group differences in changes over time. This method was applied both to session effects on symptoms, and to the survey data collected at baseline and 4-week follow-up.

Finally, hierarchically optimal classification tree analysis (CTA) [38] was conducted to search for predictors of individual responses to the follow-up survey

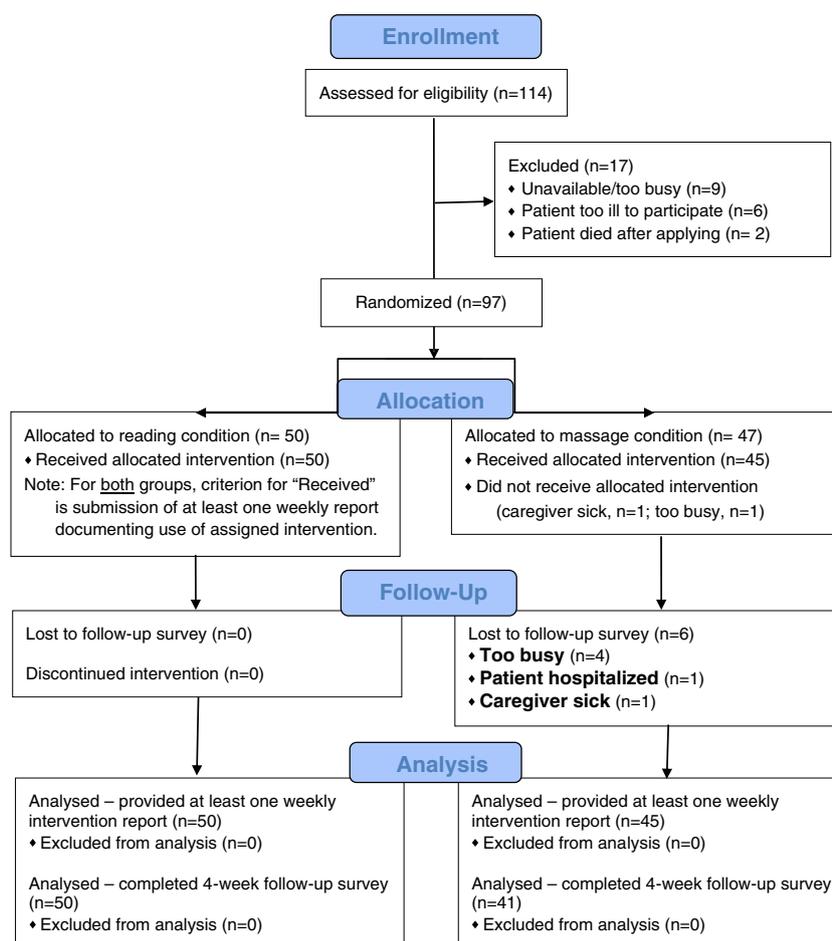


Fig. 1 CONSORT flow diagram

Table 1 Sample

Demographics	Patients	Caregivers
Sex (% (<i>n</i>))		
Male	23.7 (23)	44.3 (43)
Female	76.3 (74)	55.7 (54)
Age (years)		
Mean (SD)	54.7 (11.6)	51.5 (13.6)
Median	56.0	53.0
Range	24–78	18–82
Ethnicity (% (<i>n</i>) White)	65.0 (63)	66.0 (64)
African American	13.4 (13)	13.4 (13)
Asian	12.4 (12)	10.3 (10)
Hispanic	8.2 (8)	8.2 (8)
Native American	1.0 (1)	2.1 (2)
Education (% (<i>n</i>))		
No high school	1.0 (1)	2.1 (2)
Some high school	0.0 (0)	2.1 (2)
High school graduate	14.4 (14)	17.5 (17)
Some college	5.2 (5)	17.5 (17)
College graduate	59.8 (58)	40.2 (39)
Graduate degree	18.6 (18)	18.6 (18)
Unknown	1.0 (1)	2.1 (2)
Caregiver relationship to patient (% (<i>n</i>))		
Spouse or life partner	64 (62)	
Adult child	17.5 (17)	
Parent	4.2 (4)	
Friend	10.3 (11)	
Other relative	3 (3)	
Share household (77 (75))		
Duration of relationship ((years) mean (SD))	25.5 (14.8)	
Median (range)	24.3 (1–62)	
Patient cancer history at enrollment ^a		
Months since diagnosis (mean (SD))	29.7 (40.2)	
Median (range)	12 (1 to 258)	
Stage (% (<i>n</i>))		
I	9.3 (9)	
II	24.7 (24)	
III	16.5 (16)	
IV	36.1 (35)	
Remission	5.2 (5)	
Unknown	8.2 (8)	
Metastasis	41.2 (40)	
Treatment (% (<i>n</i>))		
Chemotherapy	66.0 (64)	
Radiation	48.4 (47)	
Surgery	79.4 (77)	

^a Information provided by physician or nurse

outcomes. All demographic variables and utilization variables (i.e., frequency and duration of the use of the

interventions) were entered as potential predictors of survey outcomes.

Results

Sample

A total of 114 dyads applied to participate in the study. Seventeen were excluded because of being unavailable, the patient too ill, or the patient died during the enrollment process, and 97 were randomized (see Fig. 1). Demographic variables and patient diagnostic and treatment status are shown in Table 1. The majority of dyads were in a spouse or partner relationship sharing the same household. We used Fisher's exact tests to compare the two groups on demographic, stage, and treatment variables and found no significant differences between groups.

Languages Eight dyads were Spanish speaking, with the four experimental dyads using the Spanish language program. Ten dyads were Chinese speaking, with the five experimental dyads using the Chinese language program. All others used the English language program.

Diagnoses Types of cancer represented were breast ($n=44$), lung ($n=10$), gastrointestinal ($n=10$), blood ($n=9$), gynecological ($n=8$), brain ($n=4$), prostate ($n=3$), thyroid ($n=3$), kidney ($n=2$), and one each of melanoma, peritoneal, testicular, and tongue. Over half of patients were stage III or IV at enrollment, and all had received conventional treatment (Table 1).

Attrition

As seen in Fig. 1, all attrition was from the experimental condition. Two dyads dropped out before starting intervention, two dropped during the intervention period, and two completed intervention (with four weekly reports) but not the follow-up survey (see Fig. 1 for reasons).

Table 2 Reported activity over 4 weeks

Group	Mean (SD)
Massage ($N=45$ dyads)	
Times viewed DVD weekly	1.35 (2.03)
Times viewed manual weekly	1.64 (1.36)
Number of massages weekly	3.60 (4.05)
Duration each massage (minutes)	17.80 (11.86)
Reading ($N=50$ dyads)	
Number of reading sessions weekly	3.79 (3.39)
Duration each reading (minutes)	22.50 (13.63)

Caregiver outcomes

Utilization Caregiver compliance with weekly assigned activities was high in both groups with no significant differences in average frequency or duration of sessions. Massage caregivers reported accessing the instructional materials about three times per week (Table 2).

Caregiver attitudes Both groups of caregivers had significant increases over the 4 weeks in satisfaction with their ability to help the patient feel better and reduced concern about causing distress with touch (Table 3). In addition there were significant time by group effects, with massage caregivers becoming more comfortable using touch and massage, and increasing perceived self-efficacy in providing massage (comfort providing massage and confident can provide massage effectively).

Stress and caregiver esteem There were no significant within- or between-group differences for caregivers on the PSS-10 or the Caregiver Esteem Scale.

Patient outcomes

Session effects on symptoms Both groups reported significantly reduced postsession scores for all symptoms ($p<0.001$ for all proportions of change for both conditions) (Table 4). Reductions for reading patients averaged 12 % (for nausea) to 28 % (for stress/anxiety) while massage patients averaged 29 % (for nausea) to 44 % (for stress/anxiety).

The average proportion of decreased symptomatology reported from pre- to postsessions over the 4 weeks was significantly greater for patients in the massage condition for three of the symptoms: pain (34 vs. 18 %, $p=0.04$), nausea (29 vs. 12 %, $p=0.02$), and other self-reported symptoms (42 vs. 17 %, $p=0.02$) (Table 4).

Comparison of session effects for the two groups across time (Table 5) found reductions in symptom ratings to be significantly greater for massage than reading, as follows: for stress/anxiety in weeks 2, 3, and 4; for pain in weeks 3 and 4; and for fatigue in weeks 1 and 4. ANOVA results showed significant group effects for stress/anxiety ($F_{(1, 78)}=8.82$, $p=0.004$), pain ($F_{(1, 79)}=4.41$, $p=0.04$), and fatigue ($F_{(1, 78)}=6.26$, $p=0.01$), with no significant effects for time or group by time.

Stress and quality of life There were no significant within- or between-group differences for patients on the PSS-10 or the FACT-G. However, CTA, which was applied to all patient survey outcomes, found a statistically significant model associating patients' diagnostic and massage variables with their PSS-10 score at follow-up (Fig. 2). In the model, 81.2 % of patients diagnosed with stage I-III cancer improved their PSS-10 score regardless of any other

Table 3 Change in caregiver attitudes from baseline to 4-week follow-up

Question	Baseline mean (SD)		Follow-up mean (SD)		Time	<i>p</i>	Time by group	<i>p</i>	Group difference	<i>p</i>
	Massage	Reading	Massage	Reading						
1. In general, how satisfied are you today with your ability to help your partner feel better?	7.36 (2.22)	7.31 (2.07)	7.93 (1.98)	7.67 (1.83)	$F_{(1, 85)}=5.536$	0.02	$F_{(1, 85)}=0.300$	0.58	$F_{(1, 85)}=0.158$	0.69
2. How comfortable are you today with using touch as a form of support for your partner?	8.12 (2.43)	8.49 (2.16)	8.64 (1.94)	8.04 (2.41)	$F_{(1, 85)}=0.029$	0.87	$F_{(1, 85)}=4.268$	0.04	$F_{(1, 85)}=0.073$	0.78
3. How concerned are you today about causing pain or discomfort by touching your partner?	4.74 (3.13)	5.13 (3.08)	3.31 (2.77)	4.84 (3.10)	$F_{(1, 85)}=7.345$	0.008	$F_{(1, 85)}=3.324$	0.08	$F_{(1, 85)}=2.897$	0.09
4. How concerned are you today about touch making your partner's medical condition worse?	3.29 (3.18)	3.73 (3.32)	2.29 (2.40)	3.71 (3.03)	$F_{(1, 85)}=3.276$	0.07	$F_{(1, 85)}=2.997$	0.09	$F_{(1, 85)}=2.598$	0.11
5. How comfortable are you today in talking with your partner about touch?	8.40 (2.61)	8.67 (1.71)	9.00 (1.59)	8.33 (2.28)	$F_{(1, 85)}=0.274$	0.60	$F_{(1, 85)}=3.445$	0.07	$F_{(1, 85)}=0.297$	0.59
6. How comfortable are you today with providing any form of massage to your partner?	8.10 (2.55)	8.80 (1.50)	8.55 (1.93)	8.11 (2.43)	$F_{(1, 85)}=0.279$	0.60	$F_{(1, 85)}=6.499$	0.01	$F_{(1, 85)}=0.112$	0.74
7. How confident are you today that you can provide massage effectively as a form of support to your partner?	7.38 (2.82)	8.00 (2.11)	8.29 (2.27)	7.71 (2.35)	$F_{(1, 85)}=1.206$	0.28	$F_{(1, 85)}=4.529$	0.04	$F_{(1, 85)}=0.003$	0.96

variables, including group assignment ($p=0.045$). For stage IV patients, however, improvement on the PSS-10 was predicted by their reported mean duration of massage sessions received: only 15.4 % of patients reporting a mean of <13.75 min/session improved, while 78.3 % of those with a mean of ≥ 13.75 min improved ($p=0.0001$). This model had an effect strength for sensitivity of 45.6, a moderate effect

[39]. No other classification trees were produced by the data.

Adverse events

There were no reports of adverse events related to participation during the study period.

Table 4 Session effects: weighted means (SD) of 4 weeks of symptom ratings pre- and postsession

Symptom	Group	Pre	Post	% change ^a	Test of difference in % change between groups
Stress/anxiety	Reading	4.75 (2.63)	3.43 (2.21)	28	0.06
	Massage	4.86 (2.52)	2.72 (1.59)	44	
Pain	Reading	4.23 (2.66)	3.46 (2.46)	18	0.04
	Massage	3.97 (2.66)	2.62 (1.92)	34	
Fatigue	Reading	5.46 (2.39)	4.37 (2.26)	20	0.10
	Massage	5.44 (2.00)	3.70 (2.15)	32	
Depression	Reading	3.24 (2.18)	2.52 (1.85)	22	0.17
	Massage	3.13 (2.38)	2.17 (1.62)	31	
Nausea	Reading	2.08 (2.12)	1.83 (1.83)	12	0.02
	Massage	2.01 (2.08)	1.42 (1.42)	29	
Other	Reading	4.37 (3.01)	3.62 (2.74)	17	0.02
	Massage	2.53 (2.96)	1.47 (2.48)	42	

Weighted group means and standard deviations across four weekly "reporting sessions" per group

^a Test of proportion, >0 %;

$p < 0.001$ for all proportions in both conditions

Table 5 Pre- to postsession change in symptom ratings over the four weekly reporting sessions: repeated measures ANOVA results

	Mean (SD) reduction in symptom ratings by week group							
	Week 1		Week 2		Week 3		Week 4	
	Massage	Reading	Massage	Reading	Massage	Reading	Massage	Reading
Stress/anxiety	2.03 (1.84) <i>t</i> (78)=1.47	1.46 (1.57)	2.13 (1.87) <i>t</i> (78)=2.90**	0.93 (1.84)	2.15 (2.07) <i>t</i> (58.61)=2.285*	1.29 (1.15)	2.08 (1.80) <i>t</i> (78)=2.34*	1.22 (1.48)
Pain	1.25 (1.53) <i>t</i> (79)=0.91	0.95 (1.41)	1.20 (1.34) <i>t</i> (79)=1.03	0.85 (1.67)	1.425 (1.62) <i>t</i> (79)=2.01*	0.78 (1.26)	1.375 (1.44) <i>t</i> (79)=2.70**	0.59 (1.18)
Fatigue	1.90 (1.53) <i>t</i> (78)=2.51**	1.075 (1.40)	1.875 (1.51) <i>t</i> (78)=1.60	1.30 (1.70)	1.40 (1.57) <i>t</i> (78)=0.82	1.125 (1.44)	1.80 (1.88) <i>t</i> (78)=2.49*	0.85 (1.51)
Depression	0.92 (1.17) <i>t</i> (76)=1.09	0.65 (1.03)	1.13 (1.80) <i>t</i> (76)=1.63	0.45 (1.89)	0.82 (1.11) <i>t</i> (76)=0.15	0.775 (1.33)	1.00 (1.51) <i>t</i> (76)=0.93	0.725 (1.09)
Nausea	0.51 (0.82) <i>t</i> (74.80)=0.58	0.39 (1.07)	0.74 (1.50) <i>t</i> (78)=1.43	0.32 (1.15)	0.44 (0.94) <i>t</i> (68.87)=1.475	0.17 (0.63)	0.62 (0.94) <i>t</i> (78)=1.41	0.32 (0.96)
Other	1.07 (1.74) <i>t</i> (74.80)=0.58	1.00 (1.35)	1.37 (2.06) <i>t</i> (78)=-1.43	2.08 (5.38)	0.53 (1.38) <i>t</i> (68.87)=-1.48	0.75 (1.06)	1.33 (2.22) <i>t</i> (78)=1.41	0.58 (1.16)

* $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

Discussion

An interesting comparison can be made between the massage effects obtained by the care partners in this study and those of professional massage therapists documented in other studies. For example, while there was slight difference in symptom scales between this and the Cassileth and Vickers study [19] (10 vs. 11 scale points), the magnitude of symptom reductions reported in this study (29–44 %) approached that of professionals (21–52 %)—equaling them for depression (31 %) and surpassing them for nausea (29 vs. 21 %).

An obvious consideration is the nature of the relationship between provider and recipient. Clearly the relationship dynamics with a care partner at home are very different from those with a professional. Use of massage in the context of an established and ongoing intimate relationship introduces the possibility of additional psychosocial

variables that may affect outcomes. This may help explain, for example, the observed reductions in depression and nausea that compare favorably with those of professionals. Future research could elucidate what qualities of the caregiving relationship may enhance or impede the impact of this form of support on symptoms, and may point to new relationship interventions for enhancing outcomes.

We note that all attrition (six dyads) was in the massage group. We attempted to match subject burden between the two groups in terms of time demanded by the study. The fact that two of these six dyads completed all 4 weeks of intervention but missed only the follow-up survey suggests the nature of the intervention was not an obstacle for them. For the other four dyads, illness in the caregiver or patient was reported by two while “too busy” was reported by the other two. We cannot rule out the nature of the intervention as a contributing factor for these four. It seems plausible that use of massage may be perceived as more taxing than the reading activity for caregivers who may already be feeling burdened. This may point to the value of offering added support or encouragement to users of the massage instructional as opposed to presenting it as the completely autonomous and self-directed approach used in this study.

The fact that the reading companionship led to significant reductions in symptoms, though not to the extent of massage, underscores the impact of attention as a potent force that needs to be controlled for in future studies of caregiver intervention. It also suggests that very simple practices such as reading or other structured attention activities might be worthy of further clinical investigation as deliberate interventions in themselves.

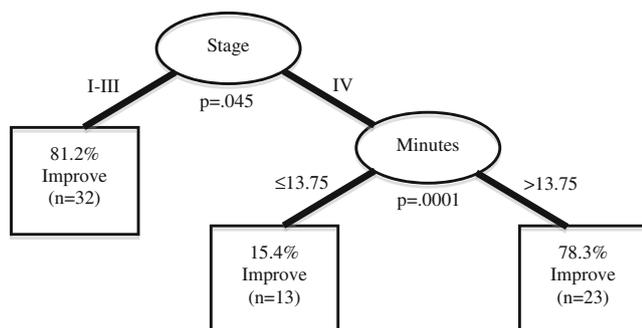


Fig. 2 CTA model: cancer stage and reported duration of massage sessions predict improvement in PSS-10 at follow-up

The reasons for lack of significant changes on the PSS-10, as well as the FACT-G for patients, are unclear. It may be that the intervention was not sufficiently powerful to impact those measures, that the measures were not sensitive enough, that there were ceiling effects, or that more time is needed for effects to arise. We aim to learn more from a later analysis of longitudinal (16 weeks post-RCT) data from the combined sample.

The CTA model for stage IV patients, indicating a dose–response relationship between duration of massage sessions and stress scores at follow-up, is intriguing. It may be that a longer session allows more opportunity for relaxation effects as well as a deepened sense of connection and intimacy with the giver. These factors separately or combined may contribute to declining background stress over time. A formal dose–response study with a larger sample of stage IV dyads may potentially yield new guidelines for enhanced caregiving with these patients.

As for caregiver esteem, in examining the caregiver attitude scores it is clear that caregivers came into the study with a relatively high degree of confidence in their abilities to provide care, which may have influenced their choice to enroll. Thus a ceiling effect may account for the lack of significant increase in caregiver esteem.

The safety monitoring in home visits appeared to confirm that multimedia instruction regarding safety precautions was effective, and that a focus on the broad concept of “comfort and relaxation” rather than “treatment” or “massage therapy” per se enables users to apply the instruction without undue inhibition. This is important because a common concern around use of massage and touch methods by family members in cancer is the possibility of adverse effects.

During the course of the study we received many anecdotal reports in the form of freehand comments on subjects’ weekly report cards, verbal statements to the research assistant during phone communications, and comments made to the oncology massage therapists during observation visits. We did not conduct a systematic approach to collection or analysis of qualitative data. We can only report informally that many positive comments were made about the impact of both the massage and reading activities on the quality of the relationship, particularly in reference to the theme of spending “quality time” together. Future research on this form of intervention should build in a structured approach to collection and analysis of qualitative data pertaining to quality of relationship.

Since professionals’ effects were found to last up to 48 h in the Cassileth and Vickers study, this raises an intriguing question: could patients receiving multiple sessions per week from a care partner at home experience sustained symptom reduction, and therefore improved quality of life, on-going with this form of support?

To answer this question would require study of the short- and longer-term duration of effects by care partners. If found to be the case, this could have important implications for

caregiver education initiatives—especially for low-income and underserved populations who are less likely to have access to supportive and palliative care resources. For example, educational initiatives could disseminate this form of instruction via workshops, support groups, community presentations, in-house video networks, or orientation materials given to families entering a cancer care environment.

An important limitation of this study is the heterogeneity of the sample. Randomization was based solely on ethnicity, with no matching by type or stage of cancer, relationship type, or other subject variables, as the focus of the research was on the broader themes of caregiving and patients’ acute responses to practice sessions. Hence, while analysis of demographic data found no differences between groups, clinical equivalence of the groups was not assured.

In summary, this study suggests that multimedia instruction in simple massage and touch-based methods of supportive care at home may offer family members a viable means of enhancing self-efficacy and satisfaction in caregiving. Family members can learn and safely apply uncomplicated methods that increase patient comfort and reduce distress. Currently, the program is being used in cancer centers, hospices, and other palliative care settings in the USA, Canada, UK, Ireland, Australia, and Vietnam, with the language options facilitating outreach to underserved populations. Further research is needed to explore effects in more narrowly conscribed samples and diverse methods of dissemination including internet download.

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