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A Systematic Review of Telehealth in Palliative Care: Caregiver Outcomes

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Abstract

Objective: Telehealth interventions have proven efficacy in healthcare, but little is known about the results of such interventions in palliative care. We conducted a systematic review to evaluate caregiver outcomes related to palliative telehealth interventions. **Materials and Methods:** We searched multiple databases for articles published between January 2003 and January 2015 related to telehealth in palliative care. Two hundred twenty-one articles were considered; nine of these met study inclusion criteria. Data on study design, population, interventions, methods, outcomes, conclusions, and methodological quality were extracted and evaluated by three investigators. **Results:** Of the nine studies, five measured caregiver quality of life, three measured caregiver anxiety, and two measured caregiver burden. All the studies measuring caregiver quality of life showed no significant difference after telehealth interventions. The caregiver anxiety score decreased after the intervention in two studies, and one study reported significantly reduced caregiver burden. Although feasibility of or caregiver satisfaction with the telehealth intervention was not the focus of this review, most studies reported such findings. Of the nine studies, the majority were rated as having moderate quality using the Cochrane Collaboration's tool for assessing risk of bias. **Conclusions:** This systematic review suggests there is evidence of overall satisfaction in caregivers who undergo a telehealth intervention, but outcomes reported were often not substantial. Methodological flaws and small sample sizes negatively affected study quality. More rigorous research to test and evaluate such palliative interventions is needed.

Key words: telehealth, palliative care, hospice care, caregiver, intervention

Introduction

Telehealth interventions have become widely accepted as a means for assessment, education, and disease management in healthcare systems around the world. Such interventions overcome geographical challenges while providing convenient, immediate responses to patients and caregivers. Much has been published related to the value of telehealth interventions, and new journals have emerged devoted totally to telehealth and telemedicine. However, there are few studies evaluating palliative telehealth interventions for palliative care patients or their caregivers.

The vast majority of telehealth interventions have been directed toward chronic diseases such as diabetes,^{1,2} heart failure,^{3,4} and chronic obstructive pulmonary disease,⁵ and the telehealth strategy is most often focused on preventing, managing, or improving the condition. Although one might argue that managing a chronic condition is palliative care, palliation has not been the stated goal in most telehealth interventions. Therefore, little is known about the value of telehealth that is directed toward the provision of palliative care.

When the patient is seriously ill or dying, the caregiver assumes the responsibility for managing care, receiving information, and communicating with professional clinicians and support staff.^{6,7} Because the family caregiver is central to the patient's care and assumes major responsibility for the day-to-day management, it is recommended that supportive interventions be directed toward the caregiver when palliative care is the focus.⁸

In order to develop a comprehensive perspective on the impact of palliative telehealth interventions on caregivers, we conducted a systematic review of the literature.

Materials and Methods

SEARCH STRATEGY

The literature search was performed using the following electronic databases: Academic Search Premier, Ageline, CINAHL, Medline, Psychology and Behavioral Science Collection, Psych INFO, Sociological Collection, and TOPIC Search. Search terms used were telehealth and palliative care, telehealth and advanced cancer, telehealth and hospice, and telehealth and chronic illness. The term telemedicine was intentionally not used as this generally refers to telehealth education and

communication among healthcare providers; however, telehealth and telemedicine are used by some interchangeably, and 32 telemedicine articles were included in the search results.

INCLUSION CRITERIA

To be included in this review, an article had to meet the following criteria:

1. The intervention was focused on patients receiving palliative or end-of-life care for a serious condition (i.e., advanced disease, end-stage disease).
2. The study reported caregiver outcomes using either qualitative or quantitative measures.
3. The study was published in English between January 2003 and January 2015.

Reports that described an intervention or evaluated the feasibility of an intervention but did not report caregiver outcomes were excluded, as were single case studies. Studies focused on chronic conditions not considered to be advanced or end stage without a stated purpose of providing palliative or end-of-life care were also excluded.

STUDY QUALITY EVALUATION

The Cochrane Collaboration's tool for assessing risk of bias in randomized trials was used to evaluate study rigor and quality. This tool evaluates study performance on six domains of bias: selection bias, performance bias, detection bias, attrition bias, reporting bias, and other bias.⁹ Developed by the Cochrane Collaboration's methods groups in 2005, this tool is used to identify flaws in design, conduct, analysis, and reporting that can cause the effect of an intervention to be underestimated or overestimated.

All three authors reviewed each article to be included and participated in extracting descriptive information for *Table 1*. Each also evaluated risk of bias independently. The authors then consulted to develop consensus regarding *Table 1* and study quality evaluation. The PRISMA Statement for reporting systematic reviews¹⁰ was used to structure our analysis.

Results

STUDY INCLUSION

One hundred eighty-six articles were identified using the search criteria described above. Another 35 were identified through supplemental searches, including review of references cited in each relevant article. Of the 221 considered articles, 212 were excluded for various reasons (*Fig. 1*). Twenty-four articles and several of the systematic reviews included in the search results were directed toward chronic

disease management without a documented focus on advanced disease, palliative care, or end of life and were excluded from the final results. Fifty-six of the articles described interventions but did not report outcomes. *Table 1* displays the nine studies included and describes the design, population, intervention, outcome measurement, significant results of each, and study quality rating.

STUDY QUALITY/RIGOR

Using the Cochrane Collaboration's tool for assessing risk of bias, the nine studies were categorized into three quality/rigor levels: high, moderate, and low, with low risk of bias indicating high quality/rigor (*Fig. 2*). A study was considered high quality/rigor when it met at least five of the seven criteria for low risk of bias (>75%), a study was determined as moderate quality/rigor if it met between one and four of the seven criteria for low risk of bias (25–75%), and a study was determined to be a low quality/rigor study if it met none of the seven criteria for low risk of bias (<25%). Of the nine studies, the majority (77.8%) scored as moderate. Only two of the nine studies reported a randomized process of participant recruitment and allocation, and none reported using a process of blinding participants. However, all of them described the completeness of their outcome data reporting for main outcome measures.

PATIENT CHARACTERISTICS

Of the nine studies, four recruited patients from local hospice programs,^{11–14} whereas two recruited from palliative care programs.^{15,16} Patients in one study were from a pediatric palliative care program.¹⁷ One study recruited patients with heart failure from cardiac care programs,¹⁸ and one recruited patients from cancer centers.¹⁹

CAREGIVER CHARACTERISTICS

The caregiver samples ranged from 8¹⁵ to 217¹⁹ participants. All of the participants were adult caregivers over 18 years of age. Caregivers' relationships to the patient included spouses/partners, parents, children, and others (siblings, grandchildren, daughters-in-law) to the patients, although three studies did not report the type of relationship.^{12,13,15} The caregivers were from various locations, including both urban and rural areas. Five studies took place in the United States,^{11–14,19} two in Australia,^{15,17} one in Taiwan,¹⁸ and one in Canada.¹⁶

MEASUREMENTS AND DATA COLLECTION METHODS

Of the nine studies, five measured the caregiver quality of life using various scales, including Caregiver Quality of Life Index-Revised,^{11–13} Quality of Life in Life Threatening Illness-Family instrument,¹⁷ and the Medical Outcome 36-Item Short-Form

Table 1. Systematic Review Data Extraction Form

REFERENCE (YEAR)	STUDY DESIGN	POPULATION	INTERVENTION	OUTCOME: MEASUREMENT	SIGNIFICANT RESULTS/ CONCLUSIONS	STUDY QUALITY
Bradford et al. ¹⁷ (2012)	Prospective exploratory cohort study; control or intervention group assignment based on primary caregiver preference or access to Internet	14 primary caregivers of children (0–18 years old) diagnosed with a life-limiting condition, recruited from a pediatric palliative care program in Brisbane, Australia	Intervention group received usual care supplemented with home telehealth consultations; control group received usual care.	Caregiver OOL: 16-item OOLTLI-F	High attrition due to patient death. No difference in OOLTLI-F between intervention and control. Caregivers equally satisfied regardless of home telehealth program participation.	Moderate
Oliver et al. ¹¹ (2010)	Sequential mixed method two-phase design (Phase 1 serving as historical comparison for Phase 2), using repeated measures	75 caregivers, (predominantly female, white) caring for hospice patients from two rural hospice programs in the Midwest of the United States	Phase 1 participants received traditional hospice care. Videophones were used to connect the Phase 2 caregivers with the interdisciplinary team meeting, allowing them to have a visual image of the team as well as two-way conversation.	Perception of pain management: CPMQ Caregiver OOL: CQI-I-R Anxiety: CAI Hospice patient OOL: HQI Primary: CPMQ/HQI Secondary: CAI/CQI-I-R	The CPMQ subscale scores of "tolerance" and "stoicism" showed significant association with the phase of the study. No significant differences were found between baseline and last follow-up on HQI, CPMQ total scores, or CQI-I-R. Intervention was seen as a promising way to improve hospice care, especially pain management. HQI proved impractical for study use. Videophone technology was a feasible way to overcome traditional barriers preventing caregivers' participation in meetings.	Moderate
Chiang et al. ¹² (2012)	Two-group nonrandomized pretest–posttest design. The intervention group had to be able to pay for telehealth equipment and support.	30 patients with advanced heart failure and their primary caregivers, recruited from several medical institutions in Taiwan	Experimental group subjects were trained by the telenursing specialist to measure patients' physiological parameters at home and to upload the data to the telehealth center via the telehealth device. Caregivers also received 24-h telehealth support. The comparison group caregivers received traditional instruction.	Caregiver burden: Chinese version of CBI Caregiver stress: MSS Family functioning: Chinese version of FFFS	The intervention group experienced significantly reduced family caregiver burden, improved mastery of stress, and improved family function. Telehealth care can improve caregiver outcomes.	Moderate
Chih et al. ¹⁹ (2012)	Pooled analysis of two randomized trials	217 advanced-stage lung, breast, and prostate cancer patients and their adult caregivers were recruited at five outpatient oncology clinics in the United States.	Caregivers received access to CHESS. A second group (n=110) had access the CHESS plus CR, an online symptom-reporting system, notifying clinicians of symptom distress. Clinicians received e-mail alerts when symptom distress above a predetermined threshold was reported.	Caregiver preparedness: 4-item Caregiver Preparedness Scale, a subscale of the Family Care Inventory Caregiver physical burden: 4-item Caregiver Physical Burden Scale, a subscale from the CBI Caregiver negative mood: subset of negative mood items from SV-POMS	Caregivers in the CHESS + CR group reported less negative mood than those in the CHESS-only group. Groups were not significantly different on caregiver preparedness and physical burden at either time point. Caregivers may experience less emotional distress due to timely communication of caregiving needs.	Moderate
Phillips et al. ¹⁵ (2008)	Mixed-methods analysis of multiple data sources. No comparison group	8 caregivers from a rural palliative care program in Australia	An AHTSS was provided by generalist nurses.	Data sources included key informant consultations, review of case notes, interviews with stakeholders, meeting minutes, quality assurance activities, and audits of call sheets.	The average duration of the call was 12.35 min. The AHTSS is an efficient and effective strategy in alleviating distress of underserved rural caregivers and is highly valued by caregivers.	Low

continued →

Table 1. Systematic Review Data Extraction Form *continued*

REFERENCE (YEAR)	STUDY DESIGN	POPULATION	INTERVENTION	OUTCOME: MEASUREMENT	SIGNIFICANT RESULTS/ CONCLUSIONS	STUDY QUALITY
Demiris et al. ¹² (2007)	Pilot study. Feasibility testing. Pre-/postintervention survey design, with noncomparison group	12 caregivers recruited from two outpatient hospice programs: one in a rural area and one in an urban area of Missouri; 9 females and 3 males	A videophone was installed at each patient's home to communicate caregivers' issues and problems.	Anxiety: STAI QOL: CQUJ-R Caregiver perceptions were assessed through research assistants' observation journal, caregiver comments, and informal interviews with selected caregivers.	STAI score significantly decreased after the intervention. Differences in QOL were not statistically significant. Caregivers had an overall positive perception of the videophone tool, found it easy to use, and saw benefit in the visual communication with hospice staff.	Moderate
Stern ¹⁶ (2008)	Mixed-method case study; utilization data and qualitative analysis of interviews, observations, and nursing documentation	12 caregivers for palliative cancer patients in Canada	Specialist nurses available 24 h/day who communicated with patients and families using videophones	Utilization patterns (quantitative); thematic analysis of qualitative data.	Mean length of exposure to telehealth was 3.5 months. Remote monitoring was used in 9% of all contacts; 4% of all contacts required a visit by the tele nurse. Thematic analysis revealed three subthemes: ease of access to a healthcare professional; reassurance with visual access to care; and enhanced access to pain symptom management. Caregivers reported high levels of satisfaction with the intervention, finding the technology easy to use.	Moderate
Demiris et al. ¹³ (2012)	Randomized noninferiority trial with two groups	126 caregivers, recruited from two hospice programs in the United States: 77 were randomly assigned to the group receiving face-to-face PST and 49 to the group receiving PST via videophone.	A videophone that operates over regular telephone lines was installed at patients' homes. In total, three intervention video calls were made, each one lasting approximately 45 min.	QOL: CQUJ-R Anxiety: STAI Problem-Solving Inventory	The anxiety score decreased significantly after the intervention. Differences in QOL were not significant. PST delivered via videophone was not inferior to face-to-face delivery. The observed changes in scores were similar for each group. Under both conditions, caregiver QOL improved, and state anxiety decreased.	High
Kilbourn et al. ¹⁴ (2011)	A single-group feasibility study	23 caregivers recruited from seven participating hospice programs in the United States	A telephone cognitive-behavioral stress-management intervention including 10–12 weekly telephone counseling calls	Depression: CES-D Stress: PSS QOL: MOS SF-36 Social support: ESSI, BFS	Depression and perceived stress decreased. Social support and benefit finding increased. The intervention was feasible for informal hospice caregivers. Caregivers reported high levels of satisfaction. They also reported high levels of self-efficacy regarding their ability to implement the adaptive coping skills. There was a decrease in physical QOL across the three measurements.	Moderate

AHTSS, after-hours telephone support service; BFS, Benefit Finding Scale; CAI, Communication Anxiety Inventory; CES-D, Center for Epidemiological Studies Depression Scale; CHES, Comprehensive Health Enhancement Support; CPMQ, Caregiver Perception of Pain Medicine Questionnaire; CQUJ-R, Caregiver Quality of Life Index-Revised; CR, Clinician Report; ESSI, ENRICH Social Support Instrument; FFFS, Feetham Family Functioning Survey; HQLI, Hospice Quality of Life Index; MOS SF-36, Medical Outcome 36-Item Short-Form Health Survey; MSS, Mastery of Stress Scale; PSS, Perceived Stress Scale; PST, problem-solving therapy; QOL, quality of life; QOLLTI-F, Quality of Life in Life Threatening Illness-Family Instrument; STAI, State-Trait Anxiety Inventory; SV-POMS, Shortened Version of the Profiles of the Mood Status.

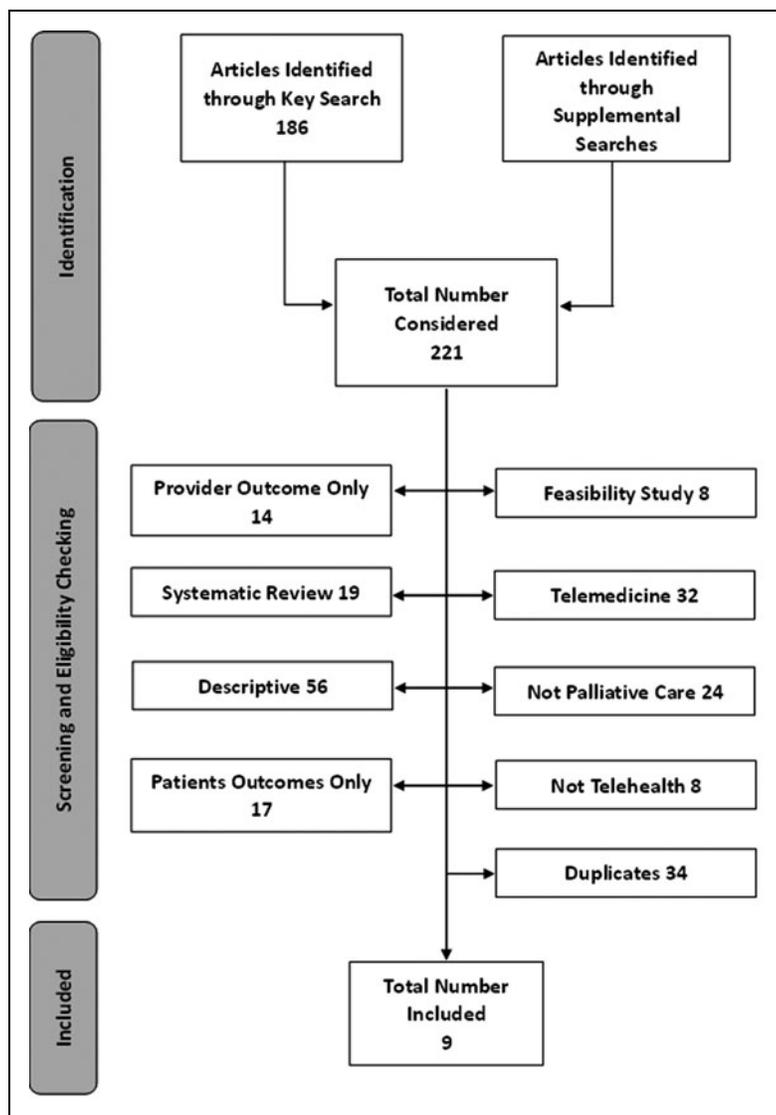


Fig. 1. Flowchart of literature search procedure for eligible studies.

Health Survey.¹⁴ Three measured caregiver anxiety: two of them using the State-Trait Anxiety Inventory and one using Communication Anxiety Inventory. Two measured caregiver burden using the Caregiver Burden Inventory, one used the Chinese translated version Caregiver Burden Inventory, and one used only a subscale of the Caregiver Burden Inventory. Other instruments used in the nine studies included the Caregiver Perception of Pain Medicine Questionnaire, Mastery of Stress Scale, the Feetham Family Functioning Survey, the Shortened Version of the Profiles of the Mood Status, the Center for Epidemiological Studies Depression Scale, the Perceived Stress Scale, the ENRICH Social Support Instrument, and the Benefit Finding Scale.

Seven out of the nine studies used quantitative measures and analysis. The other two studies^{15,16} used predominately qualitative methods (interviews and analysis of documentation) coupled with utilization data.

TELEHEALTH TECHNOLOGY

Of the nine studies, four used videophones to simulate face-to-face communication with medical professionals.^{11-13,16} Two used regular phones for the purpose of counseling.^{14,15} Two used Internet-based interventions.^{18,19} One study did not report the details of the telehealth device used in the intervention.¹⁷

FINDINGS

Telehealth and caregiver quality of life. All five of the studies measuring caregiver quality of life^{11-13,17} showed no significant difference between the experimental and control groups (or between pretest and posttest). Caregivers in the single-group feasibility study showed decreased physical quality of life over time.¹⁴

Telehealth and caregiver anxiety. The anxiety score significantly decreased after the intervention in two studies.^{12,13} One study did not show significant improvement in caregiver anxiety.¹¹

Telehealth and caregiver burden. Of the two studies testing caregiver burden, one reported that the intervention group experienced significantly reduced caregiver burden,¹⁸ and the other showed no significant difference on the caregiver burden measurement.¹⁹

Other measured outcomes. Besides the findings listed above, there were other outcome measures used in the nine studies. One study¹⁸ found that the intervention group experienced significantly improved family functioning by reporting patients' physical data through the telehealth device and accessing 24-h telehealth support. Chih et al.¹⁹ found an online symptom reporting system helped caregivers to reduce negative mood. Kilbourn et al.¹⁴ found caregivers who received the telehealth intervention showed decreased depression and perceived stress and increased social support and benefit finding over time. Another study¹¹ found no significant difference in anxiety between baseline and follow-up.

FEASIBILITY/SATISFACTION

Although feasibility of or satisfaction with the telehealth intervention was not a focus of this review, many studies reported such findings. Of the nine studies, four concluded that

Bradford 2012	⊖	⊖	⊖	⊖	⊕	⊕	⊖
Oliver 2010	⊖	⊖	⊖	⊖	⊖	⊕	⊖
Chiang 2012	⊖	⊖	⊖	⊕	⊕	⊕	⊖
Chih 2012	?	?	⊖	⊕	⊕	⊕	⊖
Phillips 2008	⊖	⊖	⊖	⊖	?	?	⊖
Demiris 2007	⊖	⊖	⊖	⊖	⊕	⊕	⊖
Stern 2008	⊖	⊖	?	?	⊕	⊕	⊖
Demiris 2012	⊕	⊕	⊖	⊕	⊕	⊕	?
Kilbourn 2011	⊖	⊖	⊖	⊕	⊕	⊕	⊖
	Random sequence generation	Allocation concealment	Blinding of participants and personnel	Blinding of outcome assessment	Incomplete outcome data	Selective reporting	Other sources of bias

Fig. 2. Risk of bias evaluation.^{11–19} Bias was evaluated as follows: low risk, ⊕; high risk, ⊖; and unknown risk of bias, ?.

the telehealth intervention was feasible.^{11,12,14,16} Five found overall caregivers' satisfaction with the intervention.^{12,14–17}

Discussion

This systematic review sought to assess the effectiveness of telehealth interventions for caregivers of patients in home-based palliative care across multiple studies. Overall, this systematic review suggests there is evidence of overall satisfaction in caregivers who undergo a telehealth intervention; studies reported that the interventions were well received, and few technological issues were reported.

Of the nine studies identified, the majority (66.7%) reported improvement of quality of life and decreased level of caregiver burden, anxiety, depression, and/or stress as a result of the telehealth intervention. There was little duplication of measures across the studies, making it difficult to assess the impact of telehealth interventions across studies, but there is at least weak evidence to support the use of telehealth as an efficient and effective strategy in improving a variety of quality of life indicators and alleviating psychological distress of caregivers for palliative care patients, especially for those living in underserved rural areas.

Based on the Cochrane Collaboration's tool for risk analysis, the quality of the studies was predominantly moderate. Methodological limitations in study designs and/or small sample sizes contributed to lower quality. As is common when conducting research in palliative and hospice populations, recruitment and attrition due to mortality challenged some of the researchers. Only two of the nine studies used an experimental design. More scientifically rigorous research is needed both in palliative care and in the evaluation of telehealth interventions.

This review has several strengths. It utilized an extensive, comprehensive, and reproducible search strategy. It utilized a rigorous and transparent study quality assessment and applied strict inclusion and exclusion criteria. The authors reviewed all procedures and developed consensus as to content of the extraction form and study quality evaluation.

Limitations of this review should be addressed as well. The number of studies in this systematic review was lower than might be expected. Chi and Demiris²⁰ found 52 experimental studies reporting telehealth tools and interventions to support family caregivers. However, there are few studies that specify a focus on palliative, hospice, or advanced disease patients only. Our findings include only English-speaking populations.

Telehealth interventions have the potential to improve the experience of caregiving for those who care for palliative patients, but more rigorous research to test and evaluate such interventions is needed to justify telehealth approaches in palliative care.

Disclosure Statement

No competing financial interests exist.

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