Palliative and supportive interventions to improve patient-reported outcomes in rural residents with cancer

Stephanie Gilbertson-White, PhD, APRN-BC, Seyedehtanaz Saeidzadeh, MSN, Chi W Yeung, MA, Hannah Tykol, BSN, and Praveen Vikas, MD

University of Iowa ‘College of Nursing, ‘College of Education, and ‘Holden Comprehensive Cancer Center, Iowa City

Palliative care and supportive oncology are designed to increase the quality of life (QoL) and other important patient-reported outcomes (PROs) for people with advanced cancer. People living in rural areas have limited access to these supportive services and the impact of palliative care and supportive oncology on this population is not well studied. The objective of this systematic review is to identify publications that evaluated effects of palliative care and supportive oncology interventions on various PROs in people with advanced cancer in rural areas. Systematic search was conducted in Psych INFO, CINHAL, PubMed and Scopus. The databases were searched up to December 2016. Eight studies were included in this systematic review. The studies identified consisted primarily of small sample sizes, single-group designs, and were not powered to detect impact on PROs. However, these studies did provide preliminary evidence that palliative care and supportive oncology interventions may have a positive effect on physical and emotional symptoms as well as overall QoL in this population. In addition, these interventions were positively viewed by participants and have the potential to positively impact financial outcomes for the individuals and the society. Funding This work was supported by a Junior Faculty Career Development Award from the National Palliative Care Research Center.

Background
Typically, the primary goals of treatment for individuals with advanced cancer are to control the spread of the disease; maintain important patient-reported outcomes (PROs) such as physical, mental, and psychosocial function; and optimize quality of life (QoL). Health-related QoL (ie, the physical and mental health perceptions) are increasingly being used to assess effectiveness of cancer treatment. Palliative care and supportive oncology focus on managing physical, social, psychological, and spiritual needs of patients and have been recommended by the American Society of Clinical Oncology to be integrated into standard oncology care.

People living in rural areas are less likely to get their care within a single health system. Often, their care is divided across multiple facilities and providers, which increases the chances of miscommunication between providers and can lead to inferior clinical outcomes and decreased patient QoL. There is a growing body of research describing the impact of palliative care on people with advanced cancer. Specifically, palliative care has been shown to reduce symptoms, improve QoL, and increase survival. Differences have been observed in the palli-
ative care needs between people with cancer living in urban and suburban areas. It is likely that palliative care needs as well as the impact of palliative care services for people with advanced cancer in rural areas differs from those of their urban and suburban counterparts. Despite the known differences in access to care and impact of cancer between rural and nonrural residents, the impact of palliative care on people with advanced cancer living in rural areas has not been well described in the literature.

The purpose of this systematic review is to examine effect of palliative care and supportive oncology interventions on QoL in people with advanced cancer living in rural areas.

Methods
This systematic review was developed using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Eligibility criteria
To achieve the objective of a systemic review of studies describing supportive oncology and palliative care interventions in rural communities articles had to meet 4 inclusion criteria:

- Rural residents were all, or part, of the sample;
- A palliative care or supportive oncology intervention was described;
- Patients with advanced cancer were all, or part, of the sample; and
- Outcome variables (eg, QoL, cost saving, increased access) were described.

All research methods were eligible, including mixed-methods and program evaluations, as long as the article met the 4 inclusion criteria. Review articles were ineligible for inclusion as only original research was considered.

Search process
Search terms were developed by the research team with consultation from a medical librarian. Four main search terms were developed and included: palliative care, supportive oncology, rural, and cancer. Synonyms and terms closely related to the main terms were included in the search using the OR command. Examples of closely related search terms include: Palliative care: palliative, Rural: remote; Cancer: neoplasms (Table).

We systematically searched PsychINFO, PubMed, CINHAL, and Scopus for articles that had been published during 1991-2016 and written in English. Databases were chosen to reflect the different subfields that encompass palliative care and supportive oncology: PsychINFO to capture the psychological perspective, CINHAL to capture the nursing perspective, and PubMed to capture the medical perspective. Finally, Scopus was searched to ensure that articles not indexed by the other databases would be included. The search was limited to the past 25 years to capture the most up-to-date literature.

Selection process
In accordance with PRISMA guidelines, articles underwent an initial screening and an eligibility screening for inclusion in the final review. After duplicates were removed, 2 research team members reviewed all abstracts to screen for initial eligibility. Articles that successfully passed the screening process were reviewed in full by 4 research team members. Each member made an independent inclusion decision based on the stated inclusion criteria. Disagreements across team members were resolved through discussion and consensus.

Analysis
The articles that met the inclusion criteria were heterogeneous in design and analytic approach. The set of manuscripts identified, therefore, did not meet the statistical assumptions for meta-analytic data analysis. The analytic plan for this review consisted of sorting the results described in the identified articles into meaningful categories, identifying cross cutting themes, and presenting the results of these themes in narrative forms.

Results
Study selection
The search strategy resulted in 886 articles across the 4 databases. The breakdown for each database is as follows: PsychINFO (n = 286), PubMed (n = 194), CINHAL (n = 334), Scopus (n = 72). After duplicates were removed, 864 articles were left and were initially screened resulting in 844 articles being excluded. The remaining 20 articles were reviewed and 12 articles failed to meet the inclusion criteria. Reasons for exclusion included: the population was not rural; no advanced cancer in sample; intervention was not specifically palliative care or supportive oncology. Nine articles representing 8 projects (one project published 2 manuscripts included in this review) were included in the final review (Figure).

After reviewing the articles, 2 clear themes arose: PROs, and overall impact of rural palliative care for people and society. The PRO theme included articles that provided information on how an intervention or program improved the personal lives experience of rural cancer patients. PROs, such as decreased symptomology, were often reported. The “overall impact of rural palliative care for people and society” theme included articles that provided information on how an intervention or program improved the lives of rural people and society as a larger group. An example would include results indicating how a program increased access to supportive oncology care in a rural area.

Study characteristics
Nine publications, describing 8 projects were included in this review (Table). These projects were conducted...
in Canada (n = 3)\textsuperscript{14-16} Australia (n = 1)\textsuperscript{17} and the United States (n = 5).\textsuperscript{18-22} All of the the projects used a quantitative approach for the analysis, except 1 that used mixed-methods.\textsuperscript{16} The studies designs were: 4 feasibilities/pilot studies, 1 randomized control trials (RCT), and 3 program evaluations.

A total of 807 patients participated across the 9 articles. Participants’ age ranged from 20 to 88 years. The average ages for participants ranged from 50.4 to 70.7 years. Overall, there were slightly more men (55%) than women (45%) when all the demographic data were combined across the 9 articles; however, 2 articles exclusively had women as part of the sample.\textsuperscript{17,20} The cancer types that participants had included: gastrointestinal, genitourinary, breast, lung, brain, kidney, and hematological. Finally, the articles had inconsistent reporting of race/ethnicity data with only 4 studies reporting this information; of the 4 studies, 91% of participants self-identified as white.

The projects targeted multiple PROs, including physical symptoms and psychosocial issues (ie, stress management, grief, mood, emotional distress, coping, self-efficacy, dignity, joy, affection) domains. Publications dates ranged from 1996 to 2013. The sample sizes ranged from 8 to 322; 11.7%-100% of the study population had advanced cancer, and 20%-100% were living in rural area. The duration of the clinical intervention described was 30-120 minutes. The modes of delivery for the palliative intervention were videoconference/ videophone (n = 3), telephone/teleconference (n = 3), and in person (n = 2). The interventions were delivered by nurses, psychiatrists, and social workers. In 5 of these studies, participants received palliative care on an individual basis and 2 studies delivered their intervention through groups. The individual basis studies focused on physical aspects of care and the group studies focused on emotional aspects of care.

**Patient-reported outcomes**
Cancer and its treatments are often associated with physical and emotional sequelae that can have a significant impact on patients and therefore PROs. The interventions reviewed in this article often reported data on the reduction of the physical and/or emotional symptom burden of cancer as well as overall QoL.

**Reduction in physical symptoms.** Three articles included physical symptoms as an outcome measure. Of those, 2 were pilot or feasibility studies, and 1 was a randomized control trial. Common physical symptoms included: shortness of breath, pain, fatigue, nausea, and appetite change. Across the articles, the Edmonton Symptom Assessment Scale (ESAS), a 10-item inventory of common cancer symptoms, was frequently used to measure symptom scores in these interventions.\textsuperscript{14,15,19} The ESAS is an empirically validated measure that is used in palliative care research and clinical practice. Individuals are asked to rank 10 common symptoms on an ascending scale from 0 to 10 (0, the symptom is absent; 10, worst possible severity).\textsuperscript{23}

The findings from these 3 research studies were encouraging. In a large randomized control trial of a supportive education program, researchers reported decreased physical symptom intensity after the intervention, however the change did not reach statistical significance.\textsuperscript{18} Similar findings were reported in a videoconferencing and a home health program to improve access of palliative and supportive oncology health care.\textsuperscript{14,15} Physical symptoms that had decreasing trends were pain, tiredness, and appetite change. However, trends for shortness of breath found increasing severity.\textsuperscript{14,15} Although these trends were observed, it is important to note that scores on the ESAS did not reach statistical
<table>
<thead>
<tr>
<th>Author (country)</th>
<th>Study aim/objective</th>
<th>Design</th>
<th>Sample and settings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bakitas18,19 (US)</td>
<td>To determine whether a palliative care intervention for a newly diagnosed advanced stage cancer, could influence QoL, symptom intensity, mood, and resource use; also to examine caregiver outcomes (eg, caregiver burden, perceptions of EoL care, grief).</td>
<td>Randomized controlled trial</td>
<td>322 adult patients with advanced cancer; an identified caregiver; living in a rural area during 2003-2008.</td>
</tr>
</tbody>
</table>

**Description of the intervention**

Palliative care nurse educator delivered the intervention through 4 weekly sessions and 1 monthly follow-up to death. The intervention was based on problem solving, communication, social support, symptom management, advanced care planning, and unfinished business.

**Results on QOL measures**

- The intervention group reported: higher mean QoL on the FACT-G (4.6 [SE, 2]; P = .02).
- A toward lower symptom intensity on the total symptom score on the ESAE that did not reach statistical significance (−27.8 [SE, 15]; P = .06).
- Lower depressed mood scores on the CES-D (−1.8 [SE, 0.81]; P = .02)

**Results on impact measures**

There was no difference in terms of hospital and ICU stay duration and Emergency department visits between the two groups.

| Collie20 (US) | To assess the feasibility and acceptability of providing support groups to women with breast cancer in a large rural area using videoconferencing; and to assess the intervention’s potential to reduce distress and increase emotional expression and self-efficacy for coping with cancer. | Pilot study | 27 rural women with any stage breast cancer. |

**Description of the intervention**

The supportive-expressive videoconferencing intervention consisted of support group sessions for 8 weekly sessions led by a licensed clinical social worker.

**Results on QOL measures**

- A decrease in depression symptoms (t = 2.44, P < .02, 2-tailed)
- PTSD symptoms between pre- and post-intervention assessments were found at posttest and in PTSD symptoms (t = 4.24, P < .05, 2-tailed).
- The effect sizes of depression (d = 0.71) and PTSD symptoms (d = 0.59).
- No difference found for self-efficacy for coping with breast cancer or emotional expression.

**Results on impact measures**

Participants were satisfied with videoconferencing modality for the support group.

| Howell15 (Canada) | To assess the effect of a shared-care pilot program on symptom severity and emotional distress of patients and their family; and to match patient’s preferences and place of death. | Pilot study | 95 patients with advanced life-threatening disease including, but not exclusively, cancer; less than 6-mo life expectancy and living in a rural area. |

**Description of the intervention**

A shared-care health care program in consisting of a family physician, palliative medicine physician, APN nurse, psychosocial-spiritual counselors who collaborate to deliver palliative home care in a rural area.

**Results on QOL measures**

- Reduced anxiety severity measured by ESAS that did not reach statistical significance (P = .08; coefficient estimate = −0.49) and higher shortness of breath (P = .07; coefficient estimate = 0.46).
- No change in emotional distress as measures by the DT between baseline and day 14.

**Results on impact measures**

More people preferred to die at home. There was no statistically significant difference between the stated preference for location of death and where death occurred.

---

Continued on following page
### O’Brien17 (Australia)

**Study aim/objective**
To determine the effectiveness of the supportive-expressive group therapy intervention, on mood dimensions, and stress symptoms.

**Design**
- Evaluation of a clinical practice change
- Program evaluation

**Sample and settings**
34 women with metastatic breast cancer during 2001-2005.

**Description of the intervention**
This was a weekly supportive-expressive group that was delivered by group therapists including psychiatrists and social worker. Therapists encouraged women to describe their experience about the disease and help them to make supportive relationships with others to overcome isolation.

**Results on QOL measures**
- Participants showed significant gains on standardized measures of well-being as measured by ABS.

**Results on impact measures**
- There was a reduction in negative affect and an increase in positive affect.
- A reduction in intrusive and avoidant stress symptoms was also observed and it was measured by IES, however, this difference was not significant.

### Passik21 (US)

**Study aim/objective**
To determine the feasibility of using telemedicine to deliver dignity psychotherapy to patients dying at home.

**Design**
Feasibility

**Sample and settings**
8 people with cancer living in rural area with life expectancy of <6 mo.

**Description of the intervention**
The dignity psychotherapy was delivered by a videophone.

**Results on QOL measures**
- Measures of depression, boredom, and hopelessness were collected to show feasibility. No statistically significant analyses were reported.

**Results on impact measures**
- The majority of participants felt that dignity psychotherapy was somewhat helpful (mean = 3.29, SD = 1.38) and believed it would help their family and loved ones (mean = 3.86, SD = 0.89). Participants were comfortable with the videophone technology (mean = 4.43, SD = 0.79) and did not have a preference for a face-to-face format (mean = 2.43, SD = 0.79).

### Smith22 (US)

**Study aim/objective**
To compare the result of the Rural Cancer Outreach Program with care prior to enacting project.

**Design**
- Program evaluation
- Pre-post design

**Sample and settings**
Patient care pre- and post-program implementation were reviewed at a rural site for 3 important clinical indicators: breast cancer treatment, clinical trial accrual for adjuvant therapy, and pain management.

**Description of the intervention**
The program was a collaboration between Massey Cancer Center-Medical College of Virginia Hospital, an academic center with tertiary oncology services, and rural hospitals. Nurses and physicians travelled every 2 weeks to the rural hospitals for training the rural hospital staff.

The program consisted of training rural nurses for administering chemotherapy and delivering intermediate care through the support received from nurses in the hospital, offering consultation through telephone for rural hospital for cancer staging and outpatient oncologist consultation through the biweekly visits.

**Results on QOL measures**
- Breast conservation increased from 20% to 70%.

**Results on impact measures**
- In the years before the program, there were no in-hospital prescriptions written for oral or intravenous morphine. In the subsequent 5 y, there has been a 500%-700% increase in oral and intravenous morphine use, from none to adequate levels.
- A 45% decrease in patient visits from rural areas in urban hospitals.
- When comparing the cost of urban hospitalizations to rural hospitalization there was a 62% reduction in average per patient admission charge.
- Increasing revenue for rural hospitals by admitting 100 new patients annually.

---

Continued on following page
Continued from previous page

<table>
<thead>
<tr>
<th>Author</th>
<th>Study aim/objective</th>
<th>Design</th>
<th>Sample and settings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stern (Canada)</td>
<td>To explore family caregivers and palliative cancer patients’ patterns of use, perceptions of, and experiences with home telehealth.</td>
<td>Mixed method design, report focused on qualitative results. Data were obtained from interviews (caregivers, patients and telenurses), direct observations (families engaged in video-based communication with telenurses), and computerized nursing documentation.</td>
<td>5 patient/caregiver dyads and N = 7 bereaved family members who had experienced home telehealth.</td>
</tr>
</tbody>
</table>

### Description of the intervention

Nurses with expertise in palliative care communicated with patients and family caregivers by telephone or videophone with the capability of remote monitoring of blood pressure, blood oxygen levels, and heart, lung, and abdominal sounds.

### Results on QOL measures

None reported

### Results on impact measures

The views of patients and caregivers about remote monitoring varied. Sub-themes include:

- Ease of access to a health care professional,
- Reassurance with visual access to care,
- Enhanced access to pain and symptom management, and
- Ease of access to a health care professional.

| Watanabe (Canada) | To assess the feasibility of using videoconferencing to provide specialist multidisciplinary palliative care and palliative radiotherapy consultation to cancer patients in rural areas and to explore symptom, cost, and satisfaction outcomes. | Evaluation of Implementation Pre-post design | 44 adult patients with cancer; self-report of inadequately controlled cancer-related symptoms; living in rural area during 2008-2011. |

### Description of the intervention

Patients were referred to the virtual clinic and received 90 min of videoconferencing consultation plus follow-up 30-min visits. A total of 72 clinical visits (44 initial consultations, 28 follow-up visits) were completed.

### Results on QOL measures

Mean ESAS scores (range, 0-10; 0 = No symptom, 10 = Worst possible symptom). Anxiety and appetite were statistically significantly improved at first follow-up.

### Results on impact measures

Savings for patients and their families in terms of distance, time, and expenses were reduced by 471.13 km, 7.96 h, and $192.71, respectively, per visit. Patients and families reported a high degree of satisfaction with the intervention.

---

ABS, Derogatis Affects Balance Scale; APN, advanced practice nurse; CES-D, Center for Epidemiological Studies-Depression; DT, distress thermometer; EoL, end of life; ESAS, Edmonton Symptom Assessment Scale; FACT-G, Functional Assessment of Cancer Therapy-General; IES, Impact of Event Scale; LoS, length of stay; PTSD, posttraumatic stress disorder; QoL, quality of life; SE, standard error

significance for physical symptoms in any of these studies.

**Reduction in emotional symptom reduction.** In addition to reducing physical symptoms, researchers also sought to understand the impact of programs on the emotional symptoms of cancer including: anxiety, depression, negative affect, and posttraumatic stress disorder (PTSD). Five articles included emotional symptoms as an outcome measure. Four were pilot or feasibility studies, and 1 was a randomized control trial.

Results across studies indicated an observable decrease in the severity of anxiety and depression for those exposed to an intervention program.\(^{14,15,17,18}\) Again, although trends were found, the results were not statistically significant. Only Watanabe and colleagues\(^{14}\) reported a statistically significant decrease in anxiety in participants after the implementation of a rural palliative care videoconference consultation program. One report indicated that data on depression severity was collected but was not analyzed because of a small sample size.\(^{21}\)

O’Brien and colleagues\(^{17}\) also collected data on negative affect and found that participants who participated in a supportive-expressive therapy group had a reduction in the negative affect as measured by the Derogatis Affects Balance Scale (ABS). Other researchers found no change in emotional distress.\(^{15}\)

Finally, Collie and colleagues\(^{20}\) also measured the impact of a videoconference support group of PTSD symptomology for people with breast cancer in rural areas. Their results indicated a statistically significant decrease on the
PTSD Checklist-Specific after intervention. Analysis of the data also found a medium effect size. Participants in the intervention group spoke about how participation in the support group allowed them to be generative and share information about breast cancer as well as build an emotional bond with other women with cancer.

**Overall quality of life and well-being.** Researchers have also looked into impact of intervention on overall QoL. Two articles included QoL or Well-being as an outcome measure. One was a pilot study and 1 was a randomized control trial.

Bakitas and colleagues \(^{15,17}\) found that those enrolled in the intervention arm of their study had higher QoL scores on the Functional Assessment of Cancer Therapy-General (FACT-G) compared with those in the control arm. These results were also found in an analysis of data from participants who subsequently died during the intervention. Improvements in overall well-being were also found by O’Brien and colleagues \(^{15}\) using ABS. They reported that a post hoc comparison of participants’ total positive affect score was significantly higher at the 12-month follow-up. In addition, the authors also noted qualitative improvements in well-being, including increased effort to be at the support group and the low attrition rates.

**Overall impact of rural palliative care on individuals and society.** In addition to reducing physical and emotional symptoms in patients, several of the articles also addressed other measures of the overall impact of the intervention or program on society as a whole. The authors evaluated patient satisfaction and quality of life, access to health care services, and financial impact on individuals and society at large.

**Satisfaction with intervention.** In 2 of the articles, individuals or their family members reported to be satisfied with the intervention\(^ {14,20}\) and said they would recommend it to others as well.\(^ {20}\) Both of those studies used teleconferencing to provide access to the intervention to people in rural communities.

**Increasing access to the health care services and quality of care.** Four of the articles evaluated the impact of intervention on patient’s access to the health care services.\(^ {14,16,20,22}\) Specifically, after the interventions individuals had increased access to palliative care information in rural areas where it had previously been unavailable\(^ {20}\) as well as actual delivery of clinical care in their home community, thus eliminating the need to travel to urban areas.\(^ {14,20,22}\) This increase of access to health care services in rural area had significant effect on time and distance spent traveling. In 1 study, the amount of saving in terms of distance was 471.13 km and time in, 7.96 hours, for each visit.\(^ {14}\)

In addition, the quality of overall cancer care in rural area was increased. In an early clinical program, to increase access of palliative care in rural communities, the authors reported an increase in the breast conservation from 20% at the start of the program to 70% 2 years after the program was implemented.\(^ {22}\) Breast conservation is not a typical outcome for palliative care studies, but the authors highlighted this practice change because of the improved QoL that is associated with the use of breast conservation therapies. In the same study, the authors reported an increased use of curative therapies for other cancers such as lymphoma as well as an increase use of pain management medication.

**Financial impact.** Two articles described the financial impact of cancer care costs on the patient and society.\(^ {14,22}\) In a study by Watanabe and colleagues in Canada,\(^ {14}\) the amount of savings after the intervention in terms of travel expenses was C$192.71 for each visit because patients had previously had to travel from their rural communities to urban tertiary hospitals to receive palliative care. For some patients in that study, the amount of saving for expenses was as high as C$500 a visit. In addition, some individuals were not able to travel and would not have received anything if the intervention had not been available remotely.\(^ {14}\) In a study by Smith and colleagues in the United States, there was a 62% decrease in the cost to society for each patient, from US$10,233 to US$3,862.\(^ {22}\) The factors contributing to that reduction included increasing outpatient services, engaging nurses and primary care providers instead of specialists, and the lower costs of living in rural areas. In addition, the rural hospitals saw an increase in revenue and profits because of higher admission rates ($500,00 for each hospital annually).\(^ {22}\)

**Discussion**

The articles identified in this review provide some evidence of the potential impact that palliative and supportive oncology interventions could have on PROs for rural residents with advanced cancer. Noteworthy results were seen for impact on reducing physical and emotional symptoms, increasing overall QoL and well-being, increasing satisfaction and access to palliative care, and reducing the overall cost of palliative care for individuals and society.\(^ {14,18,20,22}\)

Although statistical significance was not observed for most of the symptom assessment, trends toward improved symptom reports were observed. A likely explanation for this finding, is the small sample size or inadequate design to evaluate symptoms as an outcome measure. Three studies were pilot or feasibility projects\(^ {15,20,21}\) that were not powered to detect the impact of the intervention on symptoms. In contrast, QoL stands out as an outcome that was positively affected by palliative care interventions. Further research is needed to determine if there are important mediating and
moderating factors that contribute to improve QoL that are specific to rural residents. Significant outcomes were also reported for participant satisfaction with the interventions, the increase in access to services, and the decrease in costs.

Although there were not enough studies to determine the efficacy of these interventions, these results suggest that palliative and supportive interventions can have an impact on important patient-reported outcomes, such as symptoms and quality of life, and on health care system outcomes, such as cost. Evidence supporting the extent of the effectiveness of palliative care on various PROs in rural people is limited. None of the studies in this review evaluated the different aspects of palliative care specifically in rural residents.

It is interesting to note that all but one of the interventions used a telehealth approach to deliver the intervention. Telehealth interventions seem to be feasible, acceptable to people in rural areas, and show preliminary evidence that they can have an impact on PROs.

Limitations of this review include only inclusion of publications in English. In addition, some studies in this review include populations that were not exclusively rural residents, which makes it difficult for generalization.

**Conclusion**

Palliative and supportive interventions may improve various PROs in people with advanced cancer living in rural areas. Technologies that support remote access to people in rural areas, such as teleconferencing and videoconferencing, seem particularly promising delivery modalities with their potential to increase access to palliative and supportive interventions in underserved communities. Large-scale studies that are powered to test the impact of palliative care and support oncology interventions on PROs and other aspects of quality care among rural residents with advanced cancer are needed.

**Acknowledgment**

The authors thank Jennifer DeBerg, Health Science Librarian at the University of Iowa for her assistance in developing the literature search strategies.

**References**


