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Integrating palliative care has not always extended to rural areas; however, some research is focusing on future progressive solutions.

Systematic Review of Palliative Care in the Rural Setting

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Background: Many of the world's population live in rural areas. However, access and dissemination of the advances taking place in the field of palliative care to patients living in rural areas have been limited.

Methods: We searched 2 large databases of the medical literature and found 248 relevant articles; we also identified another 59 articles through networking and a hand search of reference lists. Of those 307 articles, 39 met the inclusion criteria and were grouped into the following subcategories: intervention ($n = 4$), needs assessment ($n = 2$), program planning ($n = 3$), program evaluation ($n = 4$), education ($n = 7$), financial ($n = 8$), and comprehensive/systematic literature reviews ($n = 11$).

Results: We synthesized the current state of rural palliative care research and practice to identify important gaps for future research. Studies were conducted in the United States, Australia, Canada, Africa, Sweden, and India. Two randomized control trials were identified, both of which used telehealth approaches and had positive survival outcomes. One study demonstrated positive patient quality of life and depression outcomes.

Conclusions: Research to guide rural palliative care practice is sparse. Approaches to telehealth, community-academic partnerships, and training rural health care professionals show promise, but more research is needed to determine best practices for providing palliative care to patients living in rural settings.

Introduction

In 1990, the World Health Organization revised its comprehensive *Cancer Pain Relief and Palliative Care*

report to include palliative care.¹ Since then, strides have been made worldwide in providing patients with cancer access to palliative care, and professional medi-

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Submitted July 6, 2015; accepted October 12, 2015.

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Dr Bakitas receives support from R01NR011871-01 and the American Cancer Society Research Scholar Grant. Dr Dionne-Odom is a post-doctoral fellow supported by the University of Alabama at Birmingham Cancer Prevention and Control Training Program (5R25CA047888) and by a National Palliative Care Research Center Junior Faculty Career Development Award. Dr Elk receives support from NIH/NIA: 1R21AG046772-01A1. No significant relationships exist between the other authors and the companies/organizations whose products or services may be referenced in this article.

cal organizations have recommended early palliation for patients with advanced cancer.²⁻⁷ However, access and the dissemination of palliative care advances to the 40% to 60% of the global population who live in rural areas have been limited.⁸

Although persons with cancer are more likely than those with other, nononcological, progressive, and life-limiting illnesses to receive palliative care, those with cancer living in rural communities continue to be underserved.⁹ The limited focus on palliative care in the rural setting is evident in the lack of guidance by national organizations to address the unique challenges and barriers faced by these patients and health care professionals.¹⁰ Clinical guidelines on quality palliative care from the National Consensus Project do not contain the term *rural* nor do they address how these standards should be applied in rural settings.¹¹ Not only must performance indicators of palliative care need to be modified, but the reality is that many rural health care facilities do not have access to any type of special oncology or palliative care resources.¹⁰

Thus, the purpose of this paper is to synthesize empirical evidence, much of which has focused on persons with cancer, to describe the current practice and state of research relating to palliative care in the rural setting, and to identify important gaps for future research.

Methods

We conducted a systematic review of 2 large databases from January 1990 to February 2014. The search revealed 248 relevant articles and we identified an additional 59 articles through networking and a hand search of reference lists. We screened titles and abstracts of 307 articles and assessed the full text (focused on methodology sections to identify original research) of 225 articles. Thirty-nine articles met the inclusion criteria of being a research study or systematic review and had a rural focus. Papers meeting the inclusion criteria were included regardless of study quality so we could obtain the broadest possible representation of the state of research.

Articles were grouped into 7 categories and 1 or 2 authors reviewed and synthesized each category. Studies reports represented the United States (n = 13), Australia (n = 7), Canada (n = 4), Africa (n = 2), Sweden (n = 1), and India (n = 1). Category definitions and summaries of the studies are described in Tables 1 and 2.¹²⁻⁴⁹

Intervention Studies

Four papers representing 2 randomized controlled trials (RCTs) were identified.¹²⁻¹⁵ Both RCTs offered early palliative care approaches to patients with advanced cancer and their family caregivers using a telehealth/telephonic intervention. The settings, which were rural New Hampshire and Vermont outpatient cancer clinics that included a US Veterans Affairs Medical Center,

were the same for both studies.^{12,13} Each study generated separate papers focused on patient or caregiver outcomes.¹²⁻¹⁵ Positive patient quality of life (QOL), depression and survival and positive caregiver outcomes were reported.^{12,13,15}

Needs Assessment

Two US studies focused on needs assessments and the development of rural palliative care.^{16,17} Ceronsky et al¹⁷ focused on palliative care quality practices and utilized a learning collaborative methodology to assist communities to establish and strengthen palliative care capacity in rural Minnesota. A program-development evaluation survey assessed the benefits of the Minnesota Rural Palliative Care Initiative and satisfaction with participation.¹⁷ All the program components were rated well and an increase was seen in participant knowledge of pain management and goals of care discussions.¹⁷ Fink et al¹⁶ used an investigator-developed needs assessment instrument to determine awareness, knowledge, barriers, and access to resources of palliative care services in 236 Rocky Mountain-area rural hospitals. They found that 99% of health care professionals were familiar with the palliative care concept, 76% had a contract with a local hospice organization, 72% participated in a program to promote advance-care planning, 56% had access to palliative care resources, and 72% had palliative care education offered in the past year.¹⁶

Program Planning

Three studies addressed program planning for rural palliative care services and programs; 2 were conducted in Australia and 1 in Canada.¹⁸⁻²⁰ The Australian studies found that palliative care had moved from being marginalized to a key component of rural health care delivery.^{18,19} Blackford and Street¹⁸ developed and evaluated the effectiveness of a model to improve advance-care planning in the community setting. Their model consisted of 5 domains: service-level governance, advance-care planning education, advance-care planning documentation, community engagement, and quality processes.¹⁸ They found that an advance-care planning model is feasible in the rural community and should focus on advance-care planning conversations and involve families rather than just advance-care planning completion rates.¹⁸ Phillips et al¹⁹ evaluated the applicability of the Predisposing, Reinforcing, Enabling, Causes in, Educational Diagnosis and Evaluation (PRECEDE) and Policy, Regulatory, Organizational Constructs in Educational and Environmental Development (PROCEED) model in the development of targeted, nursing-led chronic illness interventions. They studied an aging population with rural, unmet palliative care needs and a disadvantaged urban community at high risk for cardiovascular dis-

Table 1. — Selected Studies of Palliative Care in Rural Settings

Study	Design/ Intervention	Sample	Setting	Measure	Outcome	Comment
Intervention						
Bakitas ¹²	Prospective RCT ENABLE phone-based coaching vs usual oncology care	322	NH/VT Outpatient cancer clinics and VAMC	FACIT-Pal CES-D Edmonton Symptom Assessment Scale Resource Use	Improved QOL and depression (both $P = .02$) Trend toward improved symptoms ($P = .06$)	One of the first studies to describe benefits of early palliative care
O'Hara ¹⁴	Prospective RCT Patient-directed ENABLE phone-based coaching vs usual oncology care	222	NH/VT Outpatient cancer clinics and VAMC	Caregiver burden MBCBS After-death interview Complicated grief	No differences in caregiver burden Higher caregiver objective and stress burden related to lower patient QOL	No specific intervention offered to these caregivers, but they were allowed to participate in patient intervention
Bakitas ¹³	Prospective, wait-control RCT ENABLE phone-based coaching at diagnosis vs 3-mo delayed	207	NH/VT Outpatient cancer clinics and VAMC	CES-D FACIT-Pal QUAL-E Survival Resource use	Immediate group had improved survival (15%, $P = .38$) compared with delayed group at 1 y	Failure to achieve recruitment target may have impacted ability to demonstrate differences between groups
Dionne-Odom ¹⁵	Prospective, wait-control RCT ENABLE phone-based coaching at diagnosis vs 3-mo delayed	122	NH/VT Outpatient cancer clinics and VAMC	QOL-CG CES-D MBCBS	Immediate group had improved depression at 3 mo ($P = .02$); decedent caregivers had improved depression and subjective burden (both $P = .01$)	—
Needs Assessment						
Ceronsky ¹⁷	Quality improvement/learning collaborative to assist communities to establish/strengthen palliative care in rural Minnesota using theory and NQF preferred practices	10	Rural Minnesota MRPCI	Program development Evaluation survey to assess benefit of MRPCI and satisfaction with participation	Teams grew from 1 to 6 All components of program rated well Increased knowledge of pain management by 73% and goals of care discussion by 81%	10 teams represented 64 organizations; used community capacity development theory
Fink ¹⁶	Descriptive, determine awareness, knowledge, barriers, and resources of palliative care services in rural hospitals	374	236 Rocky Mountain rural hospitals (< 100 beds) in Montana, Wyoming, Utah, New Mexico, Colorado, Kansas, and Nebraska	Investigator-developed qualitative/quantitative 7-section needs assessment instrument covering current palliative care services, professional education programs, desired learning methods, satisfaction with and barriers to palliative care, community resources, and populations needing assistance	99% familiar with palliative care concept 76% had a contract with hospice 72% participated in advance-care planning program 56% had access to palliative care resources 9% had board certified physicians in hospice and palliative medicine 72% offered palliative care education in past year Ethical issues and psychosocial support least satisfied Barriers: Patients avoiding discussions of dying and inadequate policies and education	36 surveys did not list location 40% response rate

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Table 1. — Selected Studies of Palliative Care in Rural Settings (continued)

Study	Design/ Intervention	Sample	Setting	Measure	Outcome	Comment
Program Planning						
Blackford ¹⁸	Multisite, action research to design and evaluate the feasibility of an advance-care planning program	3 community sites n = 611 (urban) n = 460 (urban) n = 186 (regional)	3 community palliative care services: 1 regional and 2 metropolitan, urban in Victoria, Australia	Client and service management audits (pre- and post-implementation of the program/model) Key informant interviews (n = 9) Development and evaluation of efficacy of a model to improve advance care planning in the community setting	Model to implement advance care planning in the community is feasible Documentation of advance care planning discussions with clients and families is a more useful outcome than completing advance-care planning Community palliative care services needs to engage with local communities Leadership essential ingredient to change the process	—
Phillips ¹⁹	Reflective case study approach to demonstrate the applicability of model to the development of nursing-led chronic illness interventions	2 case studies/ populations	Regional coastal Australian aging population with rural, unmet palliative care needs Urban area in Sydney, Australia: Disadvantaged urban community at high risk for cardiovascular disease	PRECEDE-PROCEED model used Needs assessment conducted (social, epidemiological, behavioral, environmental, educational, and ecological)	Data shaped development of a multifaceted intervention focusing on increasing aged care personnel's palliative care capacity, access to resources, development of evidence-based guidelines, and evaluation	—
Watanabe ²⁰	Assess feasibility of pilot study and explore symptom, cost, and satisfaction outcomes	44 initial consultations and 28 follow-up visits	Canada	Videoconferencing to provide specialist palliative care and radiotherapy consultation to those with cancer living in rural settings and explore symptoms, cost, and satisfaction outcomes	Videoconferencing is feasible, may improve symptoms, results in cost savings, and satisfactory to patients and HCPs	—
Program Evaluation						
Hatton ²¹	2-y pilot project delivering palliative care services	1 case study	Rural and remote Griffith, Australia	Evaluation of Griffith Area Palliative Care Service model Key elements included: • 24-h access • Governance and staffing • Case management review • Enhanced primary care • Information management • Outcomes and evaluation • Weekly multidisciplinary team meeting	Coordinated integrated application of existing resource Investment of new resources Formal evaluation	Plans for future dissemination identified

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Table 1. — Selected Studies of Palliative Care in Rural Settings (continued)

Study	Design/ Intervention	Sample	Setting	Measure	Outcome	Comment
Program Evaluation (continued)						
Wilkes ²²	Descriptive evaluation of a pilot project of a palliative care telephone call service	48 HCPs 21 after-hours telephone support nurses	New South Wales, Australia	Telephone logbook (12 calls), text analysis of reflective journals, questionnaire, interviews	Major themes: <ul style="list-style-type: none"> • Program preparation and introduction • After-hours telephone support service for families and HCPs • Nurse experiences (personal impact and support) 	Lack of HCP knowledge about service
Bensink ²³	Evaluation of the acceptability of videotelephony/webcam	17	Tertiary pediatric oncology service in Brisbane, Australia	Interview (face to face or telephone) Cost analysis	92% participation rate Families receiving videotelephone calls found them to be more useful than a telephone call	2 RCTs previously attempted and abandoned following difficulty with family recruitment Evaluation of videotelephony was conducted
Logie ²⁴	Program evaluation	8 5 hospices 3 home-based care organizations	Zambia	Multiple methods rapid field evaluation: <ul style="list-style-type: none"> • Desk surveys • Facility interviews • Data from 2 field visits (practice observation, trainee feedback, interviews with key personnel and funders) 	Program enhancement with modest funding included: <ul style="list-style-type: none"> • Training program (rural and urban) • Improved access to morphine and other drugs • Increased government lobbying to support palliative care and hospice and to improve standards 	For palliative care to thrive in a resource poor country, public health system integration is crucial and long-term funding needed
Education						
Smith ³¹	Qualitative program evaluation of providing specialists in 2 rural community hospitals	6,958 audited patient charts pre-RCOP and 7,572 post-RCOP	RCOP of the Massey Cancer Center Medical College of Virginia	No formal measurement; anecdotal observations include ability to keep patients with cancer in their local communities	Rural practitioners able to safely administer cancer therapy	Focused on outcomes for local clinicians
Thulesius ²⁵	Comparison of learner-centered education program and control group	460	Rural areas in Sweden Intervention and control groups separated by 20-mile-wide rural district Matched in terms of demography and home care structure	20-item attitude questionnaire HADS administered to staff	Postintervention: Significant differences on 17 of 20 items between 2 groups Preintervention: Significantly higher in education group Postintervention: Significantly lower in education group Improved attitude about care and improved mental health well-being of staff	Education program was evidence-based, mixing small group work with lectures, seminars, and discussion Objective was to produce local guidelines for end-of-life care Only study reviewed with control group

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Table 1. — Selected Studies of Palliative Care in Rural Settings (continued)

Study	Design/ Intervention	Sample	Setting	Measure	Outcome	Comment
Education (continued)						
Kelley ²⁶	Retrospective analysis of the Ontario Ministry of Health educational palliative care program delivered in last 8 y	353	Ontario	Questionnaires (26 questions)	83% said training very significant compared with other sources of learning 87% reported practice of palliative care changed 91% shared palliative care knowledge with others 68% reported palliative care delivery in their community much better than prior to training 70% now had palliative care team (compared with 9% prior to training)	—
Reymond ²⁷	Pre- and post-design 14 workshops for general practitioners tailored to specific patient symptoms	149	Remote areas in Australia	Cost of training Evaluation of education and clinical objectives	Goal to evaluate intervention aimed at increasing knowledge and capacity of palliative care 95% general practitioner satisfaction with workshop in teaching palliative care skills (91% for nurses and other HCPs) Confidence in managing palliative care cases increased from 2.9 to 3.9 (5-point scale) HCPs reported improvement in confidence at 3 mo	—
Kaufman ²⁸	Prospective design study of educational presentations to HCPs (nurses = half-day conference; physicians = grand rounds)	27	New Mexico	Change in hospice utilization pattern: • Subsequent referral to hospice • Patient referral pattern • Length of stay • Diagnosis at admission • Nursing home referral pattern	Significant increase in hospice utilization (33 to 61) 113/254 eligible for hospice were referred (65%) Increase in referrals by community nursing homes (but not other sources) • Not significant in time in days in hospice • Not significant in terms of diagnosis • Significant increase in frequency of referral from 2 nursing homes	Goal to increase hospice utilization in rural community Effective for changes in referral by nursing homes alone (no change in physician referrals) Training conducted by local HCPs at very low cost
Easom ²⁹	Pre- and post-design study of educational presentations to rural nurses and licensed practical nurses in assisted-living and nursing home environments	9	Assisted living facility in southeastern United States	End-of-life attitudes survey End-of-life knowledge assessment Open-ended questions	Post-test results significantly higher than pre-test knowledge on end-of-life care Most knowledge growth on response to pain medication, administration of opioid analgesics for pain, and interventions to relieve nausea Significant difference in attitudes	—

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Table 1. — Selected Studies of Palliative Care in Rural Settings (continued)

Study	Design/ Intervention	Sample	Setting	Measure	Outcome	Comment
Education (continued)						
Kortes-Miller ³⁰	Determine staff needs for palliative care education, then develop 15-h interprofessional curriculum Program piloted in 3 facilities	128	Ontario (remote, rural, and long-term care facilities)	Identify 3 most important learning needs and preferred format	Highest ranking topics: stress management for staff (73%), for individual and family (71%), understanding emotional needs of dying person (67%) Majority preferred education in face-to-face format, liked interdisciplinary focus, team-building, felt empowered by program	Approach can serve as a model for palliative care education in other rural areas
Financial						
Smith ³¹	Pre- and post-financial analysis of RCOP	1 site	3 rural clinics serving 3–5 counties in Virginia	Chart audits after 3 y of operation (post-RCOP) compared with 2-y results (pre-RCOP)	Profitable for rural hospitals Revenue-neutral for academic centers Cost saving for society	Successful enough to be a required part of all comprehensive cancer center programs
Desch ³²	Pre- and post-financial data analysis of RCOP	1 site	Low-income areas in rural Virginia	Main outcome measures: <ul style="list-style-type: none"> • Costs (estimated reimbursement from all sources) • Revenues • Contribution margins • Profit (or loss) 	Rural hospitals generated > \$500,000 USD/y after RCOP Total cost per patient in network decreased from \$10,233 USD to \$4,392 USD (57% decrease)	Programmatic part of all National Cancer Institute centers
Uys ³³	3-mo, multisite home-based care project providing palliative care for patients with AIDS	7 sites rural = 2 peri-urban = 2 urban = 3	Underserved in South Africa	Evaluation of costs: <ul style="list-style-type: none"> • Setup (training, equipment, and planning) • Cost per site • Site operating cost (total and average per patient) • Average hospital inpatient • Hospital outpatient • Primary care clinic costs per participating patient 	Palliative home-based care increased in rural areas where a vehicle is required for staff transport	Impossible to know whether home-based care adds services or can cost-effectively substitute for hospital services
Cassel ³⁴	Analysis of Rappahannock Rural Palliative Care Program	1 site	Northern Virginia, located in a 5-county rural farming area Seacoast area on Chesapeake Bay	Collected data from consults, physician billing, and receipts to calculate hospital charges for patients treated with concurrent palliative care	Cost per day decreased to \$400 USD/y (25% of total) Generated \$80,000–100,000 USD in savings in reduced hospital charges and cost per year	—
Emanuel ³⁸	Single site pilot survey of patient-caregiver dyads	11	Trivandrum, Kerala, India Southwest coast of India	Pilot study of economic impact and openness to training	100% reported decreased family earnings Families surveyed averaged \$1,082 USD of debt 8 of 11 caregivers open to training	—

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Table 1. — Selected Studies of Palliative Care in Rural Settings (continued)

Study	Design/ Intervention	Sample	Setting	Measure	Outcome	Comment
Education (continued)						
Klinger ³⁵	Analyze resource utilization and costs of Niagara West End-of-Life Care Project over a 15-mo period	3 small towns	Public health system of Ontario, Canada	Economic evaluation to establish evaluations in monetary units and Expenditure Panel Survey	Total costs for all patient-related were \$1,625,658.07 CAN (\$17,112.19 CAN/patient and \$117.95 CAN/patient/d) Costs within parameters of Medicare hospice benefits	Project has expanded Did not take into account cost avoidance or hospitalization cost avoided Medicare hospice benefits: cost equivalent to US Medicare hospice benefits and lower than average alternate level of care and hospital costs within Ontario, Canada
Simon ³⁷	Pilot survey of working-age adults with a family member with a serious/long-term illness	81 working-age US adults	Web-based US adults	Cost of illness-related health care Changes in economic behaviors Changes in employment or education behaviors	Mean reported cost of medical bills paid by respondents (\$17,108 USD) 29.4% of respondents sold possessions as a result of family illness 42.4% reduced work hours as a result of family illness	
Bradford ³⁶	Cost minimization analysis comparing actual costs of HTP consultations with estimated potential costs associated with face-to-face consultations occurring by either hospital-based consultations in outpatient department or home visits from pediatric palliative care specialists	95 home video consultations	Royal Children's Hospital (Brisbane, Australia)	Data from 95 home video consultations occurring over 2 y Included costs associated with projected: clinician time and travel, costs reimbursed to families for travel through the Patients Travel Subsidy scheme, hospital outpatient clinic costs, project coordination, and equipment and infrastructure costs Mean costs per consultation calculated for each approach	Air travel (n = 24) significantly affected results Mean cost of HTP intervention was \$294 USD and required no travel Estimated mean cost per consultation in the hospital outpatient department was \$748 USD Mean cost of home visits per consultation was \$1,214 USD	Face-to-face consultations are gold standard of care, but families located at a distance from the hospital may find video consultation in the home to be an effective and cost efficient method to attend a consultation Video consultation in the home ensures equity of access to services and minimum disruption to hospital-based palliative care teams

$P \leq .05$ is considered statistically significant.

CAN = Canadian dollar, CES-D = Center for Epidemiological Studies Depression Scale, ENABLE = Educate, Nurture, Advise Before Life Ends, FACIT-Pal = Functional Assessment of Chronic Illness Therapy-Palliative, HADS = Hospital Anxiety and Depression Scale, HCP = health care professional, HTP = Home Telehealth Program, ICHC = integrated community home-based care, MBCBS = Montgomery Borgatta Caregiver Burden Scale, MRPIC = Minnesota Rural Palliative Care Initiative, NH/VT = New Hampshire/Vermont, NQF = National Quality Forum, PRECEDE = Predisposing, Reinforcing, Enabling Constructs in Education, Diagnosis, and Evaluation, PROCEED = Policy, Regulatory, Organizational Constructs in Educational and Environmental Development, QOL = quality of life, QOL-CG = Quality of Life Caregiver Scale, QUAL-E = Quality of Life at the End of Life Scale, RCOP = Rural Cancer Outreach Program, RCT = randomized controlled trial, USD = US dollar, VAMC = US Veterans Affairs Medical Center.

ease.¹⁹ They suggested the PRECEDE-PROCEED model could be used to guide nursing-led interventions in existing health care environments.¹⁹ Watanabe et al²⁰ evaluated the feasibility of videoconferencing to provide specialist palliative care, radiotherapy consultations, and to explore symptoms in rural Canadian persons with cancer. They found videoconferencing to be feasible, suggested that its use may improve symptoms and result in cost savings, as well as in-

crease satisfaction for patients, families, and health care professionals.²⁰

Program Evaluation

Three Australian studies and 1 Zambian study evaluated various, rural, palliative care delivery approaches.²¹⁻²⁴ Hatton et al²¹ evaluated a pilot collaborative project among multiple agencies in Australia to meet the challenges of providing palliative care services in rural and

Table 2. — Selected Systematic Reviews of Rural Palliative Care in Rural Settings

Study	Purpose	Findings
Evans ³⁹	Conduct systematic literature review of studies examining organization of rural palliative care and views of professionals in rural areas	<p>No case-control, cohort, randomized controlled trials, or meta-analyses were found</p> <p>Majority of studies based out of Australia (n = 16)</p> <p>Role of primary care discussed in 12 studies</p> <p>Problems reported in the provision of symptom control for patients</p> <p>Issues with education, training, and emotional support for professionals providing palliative care in rural settings</p> <p>Accessing specialist services was reportedly difficult for professionals</p> <p>Professionals and rural families described difficulties in accessing information</p> <p>Developments in information technology were mentioned in a few studies as possible solutions</p> <p>Need perspectives from rural primary care professionals about the optimal organization of palliative care in the rural setting</p>
Hughes ⁴⁰	Identify needs of rural-dwelling patients with cancer and their caregivers in delivery of palliative care	<p>All studies from developed countries</p> <p>No studies specifically about ethnic minorities</p> <p>Noted difficulty of comparing studies due to differing methodologies and contexts</p> <p>Rural caregivers may have additional care demands placed on them</p> <p>Information needs may be higher in rural vs urban patients</p> <p>Geographical distance a major variable in care</p>
Jennett ⁴¹	Review of readiness models for rural telehealth	<p>Four distinct models identified for readiness assessment</p> <p>Each model discussed various themes essential for telehealth readiness</p> <p>Three themes common to each discussions: appreciation of practice context, strong leadership, perceived need to improve practice</p> <p>Combining e-health and telehealth with health informatics</p> <p>Theories of change, diffusion of innovations, components of telehealth readiness tools (eg, patient, public, health care professional, organization, system) could be reviewed and refined for application to e-health</p>
Wilson ⁴²	Assess challenges and other important issues/ circumstances involving planning and providing EOL care in rural areas	<p>Most research was single site, small sample, and exploratory</p> <p>Identified and described differences between EOL care in urban and rural settings, assessed EOL needs and wishes of terminally ill or dying persons, their family members, and health care professionals in rural areas, explored EOL education for rural EOL specialists</p> <p>EOL care as an essential service in rural communities</p> <p>Integration of EOL care into rural health care settings</p> <p>Family caregivers must be provided with more information and support (eg, home-based nursing care)</p> <p>Improved linkages to specialized palliative care necessary for continuing education</p> <p>Prepare and support rural health care professionals while delivering EOL care</p>
Steers ⁴³	Determine role played by UK community hospitals in provision of palliative care	<p>Many UK community hospitals have resources to counter inequalities in access to general palliative care</p> <p>More prospective research using qualitative methods involving patients, caregivers and nurses required to understand complexities of providing palliative care</p>
Cox ⁴⁴	Literature review of quality of care in rural areas	<p>Rural communities more different than alike</p> <p>Rural issues differ from those in urban settings</p> <p>Research in rural health facilities to determine best practices for patient safety and outcomes</p> <p>Must determine best practices for mental health and effective smoking cessation programs and technological interventions</p> <p>Identification of mental health programs and services providing cost-effective quality care</p>
Robinson ⁴⁵	Identify, evaluate, and synthesize literature on rural palliative care	<p>Grouped into patient and caregiver perspectives, professional attitudes, knowledge, and practice issues, and health care services</p> <p>Body of research is small and eclectic</p> <p>Little evidence to inform palliative policy and service development in rural settings</p> <p>Coordinated programs required to develop adequate body of knowledge to support effective service and policy development</p>

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Table 2. — Selected Systematic Reviews of Rural Palliative Care in Rural Settings (continued)

Study	Purpose	Findings
Downing ⁴⁶	Explore global developments in palliative care provision in rural settings since 2010, highlighting models, including challenges faced in establishing services	<ul style="list-style-type: none"> Provision of care based on premise that individuals wish to die at home Communication is a key concept to palliative care Community volunteers and networks intrinsic to palliative care models of rural Sub-Saharan Africa Challenges to recruitment and sustainability of main clinical team Lack of rural generalist providers having access to specialist support Major challenge is the cost and time of travel to access care Care services need to be individually tailored to specific rural communities Use of community volunteers in care delivery may be effective Practical issues related to access and traversing geographical distances remain challenging
Phillips ⁴⁷	Review published studies evaluating impact of continuing professional development programs on ability of rural nurses to provide palliative care; inform the development of targeted learning activities for this population	<ul style="list-style-type: none"> Evaluated programs involving rural nurses and focused on increasing care capabilities Evidence limited by the absence of randomized controlled trials Valuable insights into barriers and facilitators to engaging rural nurses in learning opportunities Continuing education to positively impact patient and family outcomes Optimize opportunities for web-based technologies by developing and maintaining computer competencies Investigation needed of impact of specialist clinical placements capabilities to provide palliative care among nurses
Jang ⁴⁸	Examine opioid availability, caregiver burden, and use of health care resources at patient EOL by setting to determine optimal setting for palliation in Africa	<ul style="list-style-type: none"> Recognizing and treating symptoms occurring at the EOL Research in Africa sparse; most from South Africa and Uganda Use of health care resources for palliative care at EOL More research on nurse prescribing training program, which is part of Uganda's public morphine program
O'Brien ⁴⁹	Discuss palliative care and EOL models of care for Aboriginal people in New South Wales, Australia	<ul style="list-style-type: none"> Resistance to the idea of inpatient care due to Aboriginal Australians from their homeland and community Ceremonies that assist the spirit to leave the physical body and return to its sacred place common among Aboriginal people Lack of understanding of Aboriginal belief systems and their links to the land lead to a disconnect for health care professionals Aboriginal people must have culturally appropriate and locally accessible palliative care services because they have a sense of isolation and are disconnected culturally from accessing mainstream services Clarification of the social, emotional, spiritual, and cultural factors that influence decision making about accessing palliative care among Aboriginals

EOL = end of life.

remote areas of Australia. Key elements of the model included enhanced primary care, 24-hour palliative care access, weekly multidisciplinary team meetings, case management review, and a formal outcomes evaluation of existing resources.²¹ Barriers comprised inequity in community palliative care support and access to ambulatory and home services for patients with cancer compared with those without cancer, but with no formal system for after-hours home nursing support, and lack of dedicated palliative care beds.²¹ Two studies evaluated technological support for palliative care in rural areas.^{22,23} Wilkes et al²² evaluated an after-hours, nurse-driven telephone support service and found that its availability reduced isolation for families caring for rural palliative care patients at home. Physicians and nurses were satisfied with its accessibility because they believed it decreased rehospitalization rates for seriously ill patients.²²

Bensink et al²³ researched the acceptability of video telephone services to pediatric patients in regional and remote areas. This study team attempted 2 RCTs with this patient population; however, due to ethical constraints (eg, family reluctance to participate, patients too sick to participate) and technological issues (eg, blurred video, internet connection problems) the RCTs were not fully carried out.²³ They suggested future research might include integration of a videotelephony model at the time of diagnosis with a life-threatening illness, rather than at the time of palliative care.²³

One study evaluated a synergistic, multipronged palliative care initiative in Zambia, a country with a high HIV prevalence rate and poor access to care.²⁴ Eight hospices and palliative care organizations in poor and rural areas were partially funded for 2 years, and an extensive training program of staff was ini-

tiated.²⁴ A mixed-method analysis of outcome was conducted and determined that the palliative care environment in Zambia was strengthened with this approach.²⁴ Funding enabled agencies to expand their services, more reliably offer morphine, provide gas for transportation, and support patient caregivers.²⁴ Training enhanced staff confidence in caring for very ill and dying patients and their families, and raised competence and confidence rates were sustained 2 years later.²⁴ However, once funding ended, services had to be curtailed, which led to the determination that the need for sustainable, long-term funding is essential to maintain success.²⁴

Education

Six studies evaluated palliative care services and education in rural patient settings.²⁵⁻³⁰ One study used a retrospective design and a control group.²⁵ The studies used various education methods (didactic or experiential) and time allocation (half-day to multiple days).²⁵⁻³⁰ One study developed training methods by assessing the needs of staff and another tailored the training to specific patient symptoms (eg, pain, constipation, dyspnea, delirium).^{27,30} Training resulted in enhanced knowledge, and changes to the palliative program, including initiation of a palliative care team, increased hospice utilization, improved staff attitudes, and improved confidence in providing care.²⁵⁻²⁸ Most educational programs were low cost but yielded significant changes in study outcomes.

Financial

Eight studies analyzed financial data from rural-area palliative care programs: 4 were conducted in the United States, and 1 each in Canada, South Africa, Australia, and India.³¹⁻³⁸ Smith et al³¹ conducted pre- and post-financial analyses of the Rural Cancer Outreach Program (RCOP) in 3 clinics that served 3 to 5 counties in Virginia. Chart audits were performed after 3 years of operation (post-RCOP) and results were compared with the 2 years preceding the study (pre-RCOP).³¹ Outcome measures included costs (estimated reimbursement from all sources), revenues, contribution margins, and profit (or loss) of the program.³¹ RCOP generated at least \$1 million in profit for the rural hospital, even while expanding cancer and palliative services, and reduced the net cost per patient by about 40% due to better coordination.³¹ RCOP was deemed profitable for the rural hospitals, revenue-neutral for the academic centers (a marked increase in referrals, including 9% in nononcological cases, from the rural areas was offset by the poor payer mix, which included uninsured and underinsured patients), and cost saving for society; it has also continued for 25 years.³¹

Cassel et al³⁴ performed an analysis of the Rap-

pahannock Rural Palliative Care Program located in a 5-county rural farming and seacoast area in northern Virginia. This study collected data from consultations, physician billing, and receipts, and the researchers calculated hospital charges for patients treated with concurrent palliative care.³⁴

Klinger et al³⁵ analyzed resource utilization and costs of the Niagara West End-of-Life Care Project during a 15-month period in rural Ontario, Canada. The project was a success because hospital costs decreased by more than \$400 per day when palliative care was involved, the in-hospital death rate decreased, and hospice discharges increased.³⁵ The net effect was a sustainable program with \$80,000 to \$130,000 savings per year (although this number does not include avoided rehospitalizations).³⁵

Uys et al³³ conducted a 3-month, multisite, home-based care project providing palliative care for South African patients with AIDS living in underserved areas. Evaluation of costs included setup (training, equipment and planning), cost per home-based care site, home-based care operating cost (total and average per patient), and average hospital inpatient, hospital outpatient, and primary care clinic costs per participating patient.³³ It was not clear whether home-based care added services or was a cost-effective substitute for hospital services.³³

Bradford et al³⁶ conducted a cost-minimization analysis to determine the cost of a home telehealth consultation for pediatric palliative care patients compared with costs of either a face-to-face consultation at a hospital or a home visit from a palliative care service. The cost for the home telehealth consultation was cheaper than the other 2 options because the telehealth option required no travel (which substantially increased costs).³⁶ For families living in rural areas who must sometimes travel long distances to get to a hospital, video consultation can help ensure equity in access to quality palliative care.³⁶

Two studies from the same team — one focusing on India and the other in the United States — focused on the economic impact of a terminal illness and the feasibility of training caregivers as a means of stemming illness-related poverty.^{37,38} The pilot study conducted in India found that patients were forced to give up work as a result of their illness and, in the majority of families, caregivers had to change their work habits and many had to sell assets.³⁸ Most families indicated that a trained caregiver would have reduced or prevented some of the household's illness-related change, and most caregivers said they would be interested in becoming a trained caregiver.³⁸ The second paper proposed a strategy that would simultaneously mitigate household financial pressure as a result of illness as well as train caregivers to provide care that would in turn address the workforce talent shortage.³⁷

Systematic Reviews

Eleven papers were systematic reviews (see Table 2).³⁹⁻⁴⁹ Six of the reviews directly assessed palliative care in rural settings, and 5 assessed some aspect of rural palliative care, though this was not specifically part of the study purposes.³⁹⁻⁴⁹ Robinson et al⁵⁰ identified and evaluated 79 studies to ascertain the strength of evidence available to inform public policy and guidelines and identify direction for future research. Identified studies were grouped into 3 categories: patient and caregiver perspectives (n = 24), professional attitudes, knowledge, and practice issues (n = 28), and health care services (n = 27).⁵⁰ Our review of these studies concluded that little is known about experiences of rural patients and their caregivers because only 6 of the 24 studies directly assessed these perspectives. In addition, a need exists to better operationalize how palliative care specialists should integrate with rural primary care physicians. We also concluded that the medical literature is eclectic and lacks focused and sustained programs of research that specifically focus on developing and testing models of palliative care delivery in the rural setting.⁵⁰

Discussion

When death is imminent, no second chance exists to improve the quality of care for the patient and family.⁵¹ Nationally, a significant increase has been seen in palliative care programs attempting to “get it right the first time”; however, rural areas still have limited palliative services, thus resulting in an important disparity for seriously ill patients with cancer and those without cancer.⁹ Nevertheless, as is evident from this review, through community support, academic support and partnerships, telehealth, community advisers, and other creative strategies, providing expert care to seriously ill patients may be feasible, even in the most remote locations. Such success occurs not by bringing the patient to the urban experts, but by bringing palliative care expertise to the patient and/or ensuring that palliative care support becomes imbedded into the fabric of the rural community.^{17,18,21,24} Tailoring studies and methods to the unique aspects of a rural community likely resulted in most studies using a quality-improvement design because the primary goal of the initiative was to improve care in a particular area or system rather than for the purpose of creating generalizable knowledge.

We acknowledge that publication bias is a limitation in our review, and we are aware of many unpublished examples of the successful integration of palliative care into rural communities. For example, 10 years ago, the Center to Advance Palliative Care, the National Hospice and Palliative Care Organization, and the National Rural Health Association partnered to compile *Providing Hospice and Palliative Care in Rural and Frontier Areas*, a comprehensive

toolkit with exemplars of rural palliative care programs.⁵² Key informants from 31 programs were interviewed, representing 5 rural regions across the United States.⁵² Yet, our literature search yielded few added information about their programs since that monograph was published.⁵² Nonetheless, the body of published work that we reviewed has yielded a number of important pearls and lessons.

The first of the 2 RCTs, which used a telehealth/telephonic approach in patients newly diagnosed with advanced cancer, was also the first RCT to demonstrate the benefits of palliative care in any locale compared with usual cancer care.¹² Despite the positive rates of patient QOL, mood, and survival outcomes in the first RCT and positive care giver outcomes in the subsequent RCT, the results are difficult to generalize due to the racial/ethnic homogeneity of the study participants.¹⁵

Quality-improvement efforts have also demonstrated positive results in rural settings. In the Minnesota Rural Palliative Care Initiative, a needs assessment was combined with an active quality improvement project.¹⁷ These rural communities identified diverse community resources and a strong commitment to developing palliative care programs.¹⁷ Although palliative specialists were commonly not available, hospice programs were identified as a primary resource for enhancing clinical knowledge.¹⁷ Improving processes of care was an identified need and teams worked across settings to meet quality guidelines.¹⁷

One finding in this review is that the community is pivotal to any future plans for developing primary palliative care services in the rural area. This includes enhancing education within the community so that primary care clinicians may have the knowledge to integrate 24-hour palliative care access in the rural area to all patients with life-threatening illness, not only patients with cancer. Educational offerings for rural practitioners may be web-based or onsite intensives. Partnering with local hospices to assist with palliative care education for clinicians may be helpful because the ability of rural health care professionals to travel to conferences can be a barrier due to lack of time and insufficient workload relief.⁹ Cancer Care Manitoba maintains a website (www.cancercare.mb.ca) describing its long-standing Community Cancer Program Network. According to its website, the Community Cancer Program Network, in partnership with regional health authorities, has helped rural patients outside of Winnipeg, Canada, receive oncology care close to home in 1 of 15 community cancer programs.

A primary palliative care model geared toward the rural setting might include the provision of palliative care through an existing home nursing-care agency, interdisciplinary team involvement as needed, difficult case review with access to tertiary palliative care ser-

vices through videoconferencing, a formal assessment of existing resources, and subsequent outcomes evaluation. Of interest, in the rural Virginia Cancer/Palliative Outreach Program, educating rural health care professionals was a compelling reason for the retention of health staff.⁵³ In addition, strategic alliances between rural health care professionals and academic centers made access to up-to-date consultations, telehealth, and experts easier.³²

Limited studies, many of which have focused on rural cancer programs, have documented the cost savings/avoidance of employing palliative care services in rural areas.^{54,55} This body of work suggests that the impact of palliative care on health care costs and services is similar for both rural and urban populations.^{54,55} For example, the \$400/day savings observed in the rural Virginia study is very similar to the \$279 to \$374/day savings observed in contemporary, urban hospital studies.⁵⁴ Furthermore, the increased use of home hospice always follows palliative care consultations⁵⁵; the only concern may be that reduced occupancy may stress rural hospitals, especially if they cannot maintain a census of adequately insured patients. Palliative care may also positively impact household economics in rural and urban settings by keeping the patient and family caregivers economically productive, requiring less need for travel and time off from work.^{54,55}

The 11 systematic reviews addressed some component of rural palliative care (either alone or combined with urban studies), but the purposes, quality, and methodological rigor considerably varied among them. Thus, any direct comparison, compilation, and formal ratings of evidence strength among the reviews were problematic. Nevertheless, a few common themes were noted:

- Small and insufficient literature base to guide palliative care policy development in rural areas
- Geographical distance and lack of access to palliative care specialists limit the integration of quality palliative and end-of-life care in rural health care settings
- Stakeholder perspectives and “on-the-ground” involvement are essential to incorporating palliative care services to rural settings that are more dissimilar than homogeneous
- Policy and delivery models of rural palliative care have yet to be fully developed and tested
- Although promising, emerging telehealth and e-health methods need further testing, with emphases on improving health technology, connectivity, and competencies of rural health care professionals

Notable gaps in these reviews included assessments of symptom management practices in rural settings and palliative care for specific illness subtypes.

Use of telehealth strategies was prominent as a way to bring palliative support to patients. This tech-

nology is ushering in a new era of medicine in which health care will move toward becoming a commodity among others that people can access from their home or mobile devices.⁵⁶ It is powerful and will entail rethinking the core of medicine, namely the doctor-patient relationship. Its decentralized and electronically mediated nature and the likelihood of scaling up due to its convenience (thus driving greater use) is likely to make quality control and transparent accountability both more challenging and easier.⁵⁷ The types of medical errors that can occur while using mobile health technologies will morph, and methods for reducing medical errors must be revised to keep up. The roles of family caregivers and local unskilled, semi-skilled, and professional providers and distance providers will all change, entailing adjustments to credentialing and maintenance of professional certification.⁵⁸ The economics of care delivery and the form of reimbursement will likely change, requiring revised models for billing and insurance. Emerging new issues that can scarcely be predicted will require assessment of concomitant regulatory issues.⁵⁹ Policymakers will need to keep a close eye on telehealth to keep pace with its rapid development. Given the ability of integrated care-delivery networks to increase access to high-quality, person-centered care, the time is now to develop and evaluate comprehensive models of telemedicine that include standardized telephone support, use of peripherals to assess vital signs and oxygenation status, and video care to assess and interact with patients who are in a place of crisis.^{56,60} These models warrant rigorous testing and attention to the unique challenges and needs faced by patients in rural areas.^{56,60}

Other successful initiatives to expand palliative care expertise in low-resource and rural areas have included community partnerships and training local community clinicians, community health advisers, community health workers, and communication, behavioral health, and palliative care specialists.^{10,61} These initiatives can be time intensive due to the time and need for developing relationships with the cultural leaders and within the norms of the community.^{10,61} However, attempting to skip this critical step could result in efforts not relevant to or not embraced by community members. Regardless of the strategies employed, expanding palliative care into rural areas will take explicit planning and multicomponent, unique strategies.

Conclusions

Research has informed the development of professional guidelines and integration of the principles of palliation into oncology care, from the time of diagnosis to end of life among patients with curable cancers, high-symptom burden, and metastatic disease alike. However, the rural setting has created a barrier for these

advances to reach patients not located near specialty centers. This global issue has been recognized and efforts are being initiated to discover novel strategies to ensure that high-quality palliative and end-of-life care can reach those living in rural communities.

Telehealth, community health workers, specialists trained in various health care fields, and other volunteers trained in the approaches of palliative care have shown promise in bringing complex comfort strategies to many remote regions of the world. In addition, the ability to educate all of the health care professionals working in rural settings presents challenges that are surmountable. Organized efforts do exist for bringing palliative care skills to rural health clinicians and care settings. Shortages of palliative care specialists are a reality, even in urban areas. Hence, every clinician should have a basic set of primary palliative care skills of communication, advance care planning, and symptom control to ensure high-quality care for all persons with cancer and their families.

Acknowledgments: *The authors wish to thank Karen Herman for coordinating the search and Kristen Allen and Claire Bourgeois for assistance with manuscript preparation.*

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