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The Landscape of Connected Cancer Symptom Management in Rural America: A Narrative Review of Opportunities for Launching Connected Health Interventions

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The Landscape of Connected Cancer Symptom Management in Rural America: A Narrative Review of Opportunities for Launching Connected Health Interventions

Abstract

Background: The 2016 President's Cancer Panel called for projects focusing on improving cancer symptom management using connected health technologies (broadband and telecommunications). However, rural communities, like those in Appalachia, may experience a "double burden" of high cancer rates and lower rates of broadband access and adoption necessary for connected health solutions.

Purpose: To better understand the current landscape of connected health in the management of cancer symptoms in rural America.

Methods: A literature search was conducted using four academic databases (PubMed, CINAHL, MEDLINE, and PsycINFO) to locate articles published from 2010 to 2019 relevant to connected cancer symptom management in rural America. Text screening was conducted to identify relevant publications.

Results: Among 17 reviewed studies, four were conducted using a randomized controlled trial; the remainder were formative in design or small pilot projects. Five studies engaged stakeholders from rural communities in designing solutions. Most commonly studied symptoms were psychological/emotional symptoms, followed by physical symptoms, particularly pain. Technologies used were primarily telephone-based; few were Internet-enabled video conferencing or web-based. Advanced mobile and Internet-based approaches were generally in the development phase. Overall, both rural patients and healthcare providers reported high acceptance, usage, and satisfaction of connected health technologies. Ten of the 17 studies reported improved symptom management outcomes. Methodological challenges that limited the interpretation of the findings were summarized.

Implications: The review identified a need to engage rural stakeholders to develop and test connected cancer symptom management solutions that are based on advanced mobile and broadband Internet technologies.

Keywords

Appalachia, cancer, symptom management, broadband, Internet, telehealth, connected health, mobile health

Cover Page Footnote

This narrative review was prepared by the L.A.U.N.C.H. (Linking & Amplifying User-Centered Networks through Connected Health), a public-private collaborative between the National Cancer Institute (NCI), the Federal Communications Commission (FCC), Amgen, the University of California San Diego Design Lab, and the University of Kentucky Markey Cancer Center. Direct funding support was provided by Westat and Amgen. The authors greatly appreciate the review support provided by Grant Patterson from Amgen, and Michele Ellison, Ben Bartolome, Brayden Parker, and Karen Onyeije from the FCC. The Research Communications Office at the University of Kentucky's Markey Cancer Center assisted with preparation of this manuscript. This research was also supported by the Biostatistics and Bioinformatics Shared Resource Facilities of the University of Kentucky Markey Cancer Center (P30CA177558). Disclaimer: The opinions expressed by the authors are their own, and this material should not be interpreted as

representing the official viewpoint of the Federal Communications Commission, the U.S. Department of Health and Human Services, the National Institutes of Health or the National Cancer Institute. No competing financial or editorial interests were reported by the authors of this paper.

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INTRODUCTION

Cancer symptom management is an important area of research highlighted by the President's Cancer Panel's 2016 report on *"Improving Cancer-Related Outcomes with Connected Health"* and the Cancer Moonshot℠ Blue Ribbon Panel's 2016 report.[1,2] The National Cancer Institute (NCI) defines "symptom management" as "care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of symptom management is to prevent or treat, as early as possible, the symptoms of disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment."[3] Early and routine management of cancer symptoms and associated stressors can lead to improved treatment adherence, lower healthcare utilization, and reduced patient anxiety and depression.[4] The Blue Ribbon Panel identified the need to accelerate development of evidence-based guidelines for "routine monitoring and management of patient-reported symptoms in all care settings and in all populations, throughout the cancer continuum."[2] To address this need, the President's Cancer Panel proposed the use of connected health technologies to effectively manage cancer symptoms as part of routine cancer care.[1]

Connected health-enabled cancer symptom management refers to "use of broadband and telecommunications technologies to evaluate, diagnose, and monitor patients beyond the clinic"[5] and encompasses a wide range of telecommunications approaches from traditional telephone-based support to advanced broadband Internet-enabled, web-based eHealth, and wireless Internet and mobile technologies.[5,6] Connected health-enabled cancer symptom management can improve patient outcomes, including lower symptom burden, better quality of life, and longer survival.[7–9] Connected health allows cancer patients to communicate their symptoms and receive care from their care teams without traveling to a traditional healthcare setting. Therefore, these approaches could especially benefit patients experiencing difficulty in accessing care because of their geographical location, such as those from the 13-state region of Appalachia.[10,11]

People living in rural communities, including Appalachia, experience health disparities, such as higher rates of cancer incidence and mortality, particularly in lung, prostate, and colorectal cancers.[12,13] A similar trend was found related to the prevalence of cancer symptom burden,[14] including physical, psychosocial, and financial distress.[15,16] People living in rural areas also experience lower

access to adequate broadband Internet, which enables connected health solutions.[17,18] The realization that Appalachian communities have a "double burden" of high cancer rates and lower rates of broadband access and Internet adoption prompted the establishment of a public–private partnership called the L.A.U.N.C.H. (Linking and Amplifying User-Centered Network For Connected Health) Collaborative in 2017.[5] This began a 3-year demonstration project focused on solving the issue of double burden faced by people living in rural Appalachian Kentucky.[5]

Purpose

To inform the work in the L.A.U.N.C.H. Collaborative and future research in this area, an assessment of literature was conducted about the use of connected health technologies in symptom management among rural cancer patients in America over the past 10 years. A narrative review was then conducted to summarize a collection of original scientific studies from which narrative syntheses may be drawn to better understand the current field of research.[19] Research questions that guided the selection of studies and evaluation of scientific content are: (1) What symptoms are the focus of connected health technologies developed for cancer symptom management in rural America?; (2) How and what connected health technologies for symptom management have been studied in this context over the last decade?; and (3) What evidence supports the feasibility and efficacy of using such an approach?

METHODS

Conceptual Model for Literature Search

To guide the literature search, the focus was on finding studies in the intersecting domains in the subject of interest: Internet/connected technology, rural populations, and symptom management in the context of cancer. A set of detailed search terms was developed for each conceptual domain (Appendix 1; see Additional Files). The terms "rural" and "Appalachia" were used to search literature focused on rural America. During the article screening, studies conducted in other countries were excluded to keep the focus on rural America. Symptom management search terms, such as "distress" and "side effects" focused the literature review on physical and psychosocial distress symptoms that patients experience as a result of their disease and treatments.[20] Included were terms like "patient-reported outcomes" and "patient generated health data" to capture ways in which patients may report their symptoms and health-related data (e.g., heart rate) and could be useful for managing symptoms at home.[20,21] Connected technologies such as "Internet" and "smartphone" were included in

the search terms for Internet/connected technology. Specific terms about connected health technology, such as “telehealth,” “telemonitoring,” and “patient portal,” were used in the literature search as well.[22] In this model, the literature falls under the interaction among all three domains in the context of cancer as the subject of interest in this review.

Literature Review Process

The literature search was conducted in Spring 2020 to inventory current research on the topic of connected health technologies to support cancer symptom management in rural America over the last 10 years (2010–2019). General search terms were developed and used to derive specific subject headings in four academic literature databases: PubMed, CINAHL, MEDLINE, and APA PsycInfo (Appendix 1; see Additional Files). The general search terms and specific subject headings in each of the four domains were joined with the “OR” Boolean operator to capture all relevant articles in each domain. The search results in each domain were then joined with those from the other domains by using the “AND” Boolean operator to retrieve articles with relevancy in all domains.

Figure 1 shows the flowchart of the search and screening; 1020 articles were searched, and 23 full text articles were ultimately reviewed. The initial search was limited to English language publications between January 2010 and December 2019. Exclusion criteria included: abstracts, commentaries, reviews, international studies, and studies not focused on the rural cancer patient population, symptom management, or Internet/connected health technology. Three colleagues (MC, GP, AM) divided the screening tasks. At least two colleagues performed every screening task. Discrepancies were discussed and resolved to ensure the screening quality. The final articles to be reviewed were selected, and key information was retrieved through consensus. To answer the research questions outlined above, the following key information was retrieved:

1. Basic study information: the last name of the first author, journal title, publication year, study design, and rural cancer population
2. Cancer symptoms: psychosocial or physical symptoms and other needs/problems
3. Summary of rural cancer symptom management technology: type of Internet, information technology, symptom management program, and community ecosystem
4. Feasibility findings: acceptability, feasibility, usage, user satisfaction and challenges

5. Impact: patient outcomes, family/community outcomes, and healthcare/provider outcomes.

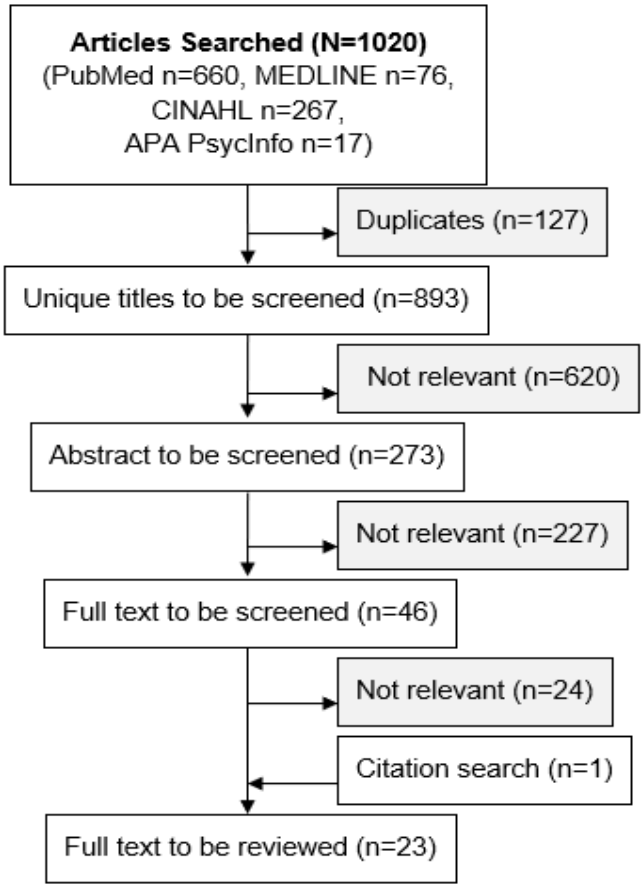

Figure 1. Flowchart of search and screening

RESULTS

The original screening yielded 22 selected articles. One paper[23] reported the engagement outcomes of a study whose main outcomes were reported elsewhere,[24] and the decision was to include it as well. Therefore, a total of 23 papers[23–45] representing 17 unique studies were included in this review (Appendix 2; see Additional Files). Appendix 2 contains the summarized details of each of the 17 unique studies in these categories: study design, cancer population, symptoms, connected cancer symptom management system,

feasibility, and key study impact. A synthesized summary of these results based on these 17 studies is provided below.

Study Populations, Rural Settings, and Designs

All studies focused on evaluation of connected cancer symptom management among rural patients solely or as part of the overall study population. The studies represented a mix of tumor types and various rural areas across America. Two studies[30,37] were conducted in Appalachia, with participants residing in West Virginia, Ohio, and Pennsylvania. Most connected symptom management programs were intended to be used in a patient's home; however, Doorenbos (2010 and 2011)[27,28] and Zhou (2016)[36] developed telehealth and videoconferencing approaches that were partially deployed in rural clinics. Various study designs were employed, including five formative evaluation studies[28,31,38,39,42]; one cross-sectional survey[27]; four one-arm feasibility studies[36,40,41,43]; one two-arm, nonrandomized feasibility study[30]; two small pilot randomization controlled trials[29,37]; and four standard randomization controlled trials.[24,25,32,33] Five studies[28,31,38,39,42] used participatory design approaches to solicit input from stakeholders to involve them in the design of connected health solutions that were more culturally informed.

Cancer Symptoms, Side Effects, and Needs Managed by Connected Health in Rural America

The most common cancer symptoms targeted by connected health interventions were psychological/emotional symptoms, fatigue, loss of physical function/restricted abilities, and pain (Table 1). These are not dissimilar to symptoms experienced by patients living outside of rural communities; however, limited access to care suggests that the symptom burden experienced by rural patients may be unique. Other symptoms that are the focus of current connected health solutions developed for symptom management include dyspnea and coughing, loss of appetite, nausea, and vomiting (Table 1). Along with these disease specific symptoms, management interventions also focused on financial and spiritual needs and medication adherence.

Table 1. Cancer Symptoms/Needs Reported by Rural Patients and Managed via Connected Health

Symptoms/Needs	Studies reported in	Cancer type studied
Psychological/emotional: depression and/or anxiety	10 [24,25,27,30–32,36,37,39,40]	Mixed
Pain	7 [25,27,28, 30,32,37,42]	Mixed
Loss of normal physical function	5 [24,29,30,37,41]	Mixed
Dyspnea, coughing	2 [30,37]	Lung cancer
Fatigue	7 [24,29,30,32,37, 40,42]	Mixed
Loss of appetite	4 [30,37,41,42]	Mixed
Nausea and vomiting	3 [30,37,41]	Mixed
Insomnia	2 [40,42]	Mixed
Lymphedema	1 [32]	Breast cancer
Difficulty standing and/or walking	2 [30,37]	Lung cancer
Weight gain	2 [34,43]	Breast cancer
Financial/spiritual needs	2 [31,32]	Breast cancer
Medication adherence	1 [25]	Mixed
Vital signs	2 [30,37]	Lung cancer

Connected Cancer Symptom Management in Rural America

Most reviewed symptom management approaches offered both remote symptom assessment and symptom management capabilities. Researchers reported using different data sources to assess symptoms that were separate from how other health data were captured. The primary source reported for remote cancer symptom data was patients' self-report collected via communications technologies, such as interactive voice-response systems,[25] telemonitors,[30,37] videoconferences,[27,28,40] e-mails,[33] web-based systems,[39,41,42] and smartphone apps.[38] Another data source was direct clinician assessment via providers' telephone calls to patients[24,29,32,33,43] and video conferencing.[27,28,40] The telemonitoring systems tested in Petitte (2014) and Chen (2016) also collected objective health data from peripheral sensors (e.g., blood pressure monitor).[30,37] Researchers used the collected symptom data to guide the symptom management programs delivered to patients. Either clinician-delivered or web-based systems provided these symptom management programs. Thirteen clinician-delivered remote symptom management programs were conducted at a

set schedule via telephone calls[24,25,29,30,32,37] or video conferencing.[27,28,33,36,40,42,43] Six web-based symptom management systems were made available at any time via Internet-enabled computers and mobile devices.[24,31,38,39,41,42] All six web-based symptom management systems offered patient education information on cancer symptoms, coping techniques, or self-management skills. In addition, one[24] of them provided an online forum for social support. The clinician-delivered programs provided not only tailored patient education (similar to web-based systems but at a set schedule and not available at any time), but also care services, such as care management and problem solving,[25,29,40] that can only be done through interaction with clinicians. Overall, more recent intervention programs adopted advanced information and communications technologies, such as mobile apps, to deliver symptom management support to rural cancer patients over the Internet. However, among the studies[24,31,38] that mentioned the development of advanced mobile apps to be used on tablets and smartphones, only one[24] developed and tested an actual system. Only one study mentioned the use of pedometers to track steps,[33–35] but the pedometer used in this study was unlikely to be a wireless connected wearable (e.g., Fitbit), because researchers asked the participants to report their steps manually.

Testing Feasibility of Symptom Management Approaches

Most researchers sought to understand the feasibility of operating a technology-focused intervention for symptom management with a rural cancer population. All but one study[31] conducted or reported some form of feasibility of the respective cancer symptom management systems. The feasibility measures reported in these studies included recruitment,[24,29,30,33,40] retention,[25,29] satisfaction,[27,29,36,37,38] ease of use,[42] usefulness,[27,38,42] willingness to use,[30,39] technology availability and acceptance,[40,42] study completion,[29,30,34,36,39–41,43] system usage,[24,29,32,33,37,39,41,42,43] and costs.[26,33,37] Most studies either required the participants to have their own access to the Internet and/or needed devices,[24,25,29,32,34,38–42] or provided the participants with access to these technologies directly[30,36,37] or via community clinics.[27,28] However, two studies reported that having no Internet access caused problems in recruitment.[24,30] Three studies[36,37,42] reported the access to and quality of the Internet connectivity in rural areas is often challenging based on the participants' feedback.

Impact and Key Findings

Ten studies reported improved patient health outcomes (e.g., improved symptoms, functional status, healthy behaviors and quality of life) among those with access to a cancer symptom management system.[24,25,29,30,33,36,37,40,41,43] However, the interpretation of these findings needs to consider the variations in study design (e.g., feasibility[30,36,40,41,43,29,37] vs. efficacy focused[24,25,33]). Researchers in one study did not find the significant improvement in stress reduction among those receiving their online video conferencing group education program.[36] They attributed this finding to the insufficient intervention doses (i.e., four shortened online sessions as compared to 10 in-person therapy sessions) and the challenges of using this novel technology (e.g., distraction during a videoconference and hardware/software/unstable connection issues).[36] Three studies reported that the connected symptom management may likely improve healthcare delivery, including reduced utilization of physical therapy services,[29] increased access to care,[28] and increased completion rates and adherence to planned cancer therapies.[41] Only two studies[26,33] reported incremental cost-effectiveness ratios and concluded that their connected cancer symptom management systems were cost effective.

IMPLICATIONS

A narrative review of 17 studies (23 papers) was synthesized; this focused on connected cancer symptom management in rural America. Several key implications can be derived from the results to inform future research. Based on the reviewed studies, cancer patients and survivors in rural America have a positive assessment of how connected health can improve access to care and self-management. These studies assessed some element of patient, survivor, or caregiver receptivity and usage of connected health. In these assessments, a majority of stakeholders showed positive receptivity to connected health, meaning these studies suggest rural cancer patients, survivors, and caregivers are open to use of technology as an element of their care when it enables remote support. Overall, successful recruitment and study completion indicate that connected health-enabled cancer symptom management in rural settings are achievable. The improved patient and healthcare delivery outcomes warrant further research. However, current evidence regarding the impact of connected cancer symptom management is weak due to the fact that most reviewed studies in this area are early phase feasibility evaluations. The larger randomized controlled trials often included nonrural patients and did not separate analyses

results by rural status. There is a real need for rigorous experimental studies in this field.

In the last decade, mobile and broadband Internet have become part of many Americans' daily life.[46,47] However, people living in rural areas with insufficient access to primary care may also not have adequate access to the broadband Internet that enables telehealth visits.[17] Some of the reviewed studies reported similar concerns of inadequate access to the Internet. Moreover, in this review, most studies focused on traditional telehealth approaches using telephone-based connectivity. A few studies aimed at using advanced mobile and broadband Internet technology were mostly in the development phase. The Society of Behavioral Medicine has recently urged nationwide efforts to expand the "access to high-speed, high-definition internet and increasing broadband width for rural communities in the USA to increase telehealth opportunities for populations facing geographic barriers to accessing quality healthcare."[18 (p489)] Projects aimed to develop and test connected symptom management approaches based on advanced mobile and broadband Internet technology will offer the lessons learned and evidence needed to strengthen our efforts as a nation to improve the access and adoption of broadband Internet and provide connected health for rural America.

The symptom burden of cancer patients living in rural communities, and the requirements for connected health systems to manage symptoms in these settings, differ from urban populations. One example is the logistical challenge of living far away from the cancer center as described by Zhou (2016).[36] Lack of access to healthcare providers in rural areas can lead to difficulty in getting adequate care. Such restrictions to access can have a profound impact on symptom burden for patients living in rural settings, which can adversely affect medical outcomes. The interventions reviewed in these studies were aimed at remotely alleviating symptoms and side effects that rural patients experience, in an attempt to lessen the double burden that rural patients carry.

As with any setting, there were specific cultural and communication differences evident in rural settings that presented unique challenges and opportunities in the research of connected cancer symptom management systems.[28,30] Also, we recognize that the cost of broadband services and technologies is a barrier to adoption of connected cancer symptom management systems. One potential resource is the Federal Communications Commission's (FCC) Lifeline program, which provides low income consumers with access to broadband at a low cost.[48] Partnering with those who will eventually use an intervention can ensure its

success and longevity. This review indicates that the research team and the symptom management approaches it is developing need to be trusted and fit in the unique social environment, especially in the rural areas.[39] To achieve this, future researchers need to understand the pace of life, priorities, assets, communication styles, and local conventions to truly partner with people in rural communities.[28,49]

Tarver and Haggstrom (2019) recently published a systematic review on the use of cancer-specific, emerging Internet technologies among underserved populations.[22] Their review included 71 articles, among which 14 focused on rural populations and published in earlier years (1995–2016). Moreover, they included the systems designed for cancer screening (e.g., telegenetics counseling), which was not the focus of this review. Likely due to these differences in the scope and inclusion criteria, we were able to locate and review a different set of articles with only two articles overlapping with theirs.[25,27] This review retrieved more detailed information about symptom management approaches and described the impact and key findings from the feasibility of the approaches. Despite these differences, both reviews have found that connected health technologies are generally feasible and acceptable among rural and underserved populations.

Two strengths of this review are worth mentioning. First, relevant studies of the last 10 years that focused on a very specific topic, namely cancer symptom management in rural America using connected health technologies, were searched and summarized. Useful information was retrieved, including most commonly experienced cancer symptoms, which connected symptom management approaches have been tested, and their related feasibility and impact. This provides an overview of the current landscape and identifies gaps to inform future research.

There are also limitations. This is not a systematic review; it is a narrative review that can be viewed as formative research. The results from this narrative review may not be comprehensive and generalizable. There was no attempt to evaluate or rate the methodological quality of each study; consequently, the results may be limited by the variation in experimental control and rigor used across the studies reviewed. Second, because of the search keywords and coding categories, it is likely that relevant articles or information in the review articles may have been missed. We have discussed the results among authors and updated the search and coding methods in several iterations to ensure the completeness of the review.

Several known challenges include the aforementioned cultural sensitivity, the scarcity of research testing advanced Internet and mobile technologies, and the initial investment costs.[26,33,37] These challenges call for innovative solutions to support symptom management among cancer patients living in rural settings. Appalachia is an example of such a setting where many patients may live further from clinics. Connected health solutions that necessitate access to advanced Internet or broadband and mobile technologies may have the potential to significantly improve symptom management in cancer patients, resulting in improved outcomes. As new opportunities arise for telehealth reimbursements,[50] future research is needed on how connected cancer symptom management can become an integral part of rural cancer care. In its demonstration project, the L.A.U.N.C.H. Collaborative is adopting a community-based approach[48,51] to co-design broadband Internet-enabled cancer symptom management solutions with the Appalachian community that we hope will improve the lives of those experiencing cancer.

SUMMARY BOX

What is already known on this topic? Early and routine management of cancer symptoms and associated stressors can lead to improved treatment adherence, lower healthcare utilization, and reduced patient distress. Appalachian communities may experience a "double burden" of high cancer rates and lower rates of broadband access and adoption necessary for connected health-enabled cancer symptom management.

What is added by this report? Rural cancer patients are receptive and accepting towards connected health technology, which could bridge the gap between symptom management and associated challenges in rural areas. However, few studies showed efficacy outcomes, and few tested advanced Internet and mobile communication technologies.

What are the implications for future research? This review highlights the need for more rigorous studies involving rural communities in the development and testing of broadband-enabled connected systems to support cancer symptom management.

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