COMMENTARY

What Is the Rural Cultural Perspective?

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An article by Lally et al. (2018) in the current issue describes the process of collecting end-user feedback from a sample of rural Nebraskan women with breast cancer regarding a web-based, psychosocial distress management program, CaringGuidance™. The current article uses that study to inform discussion on future work in the realm of interventions for rural cancer survivors.

The primary aim of the study by Lally, Eisenhauer, Buckland, and Kupzyk (2018) was to better understand the needs of rural breast cancer survivors to tailor the existing CaringGuidance™ program, which was originally tested with an urban population. Feedback was collected via synchronous, online focus groups after participants had access to the program for an average of 12 days. A secondary aim of the study was to explore the feasibility of using synchronous online focus groups with rural cancer survivors.

A strength of the study is the intentional aim to understand the unique needs of rural cancer survivors and the recognition that web-based support programs can help address many barriers to cancer care in rural regions—specifically, challenges related to transportation and geography, availability of resources, and privacy. As the authors clearly articulate, the psychosocial needs of cancer survivors, particularly those who live in rural areas, remain a critical health services delivery gap. Additional key strengths of this study include the evidence-based approach to the original design of the CaringGuidance program, a strong conceptual model to guide the online focus groups, the comprehensive recruitment strategy, the 100% participant retention rate, and the rigorous approach and clear description of data analysis.

Within the focus groups, participants were asked to discuss the quality (time expenditure, relevance to them and newly diagnosed rural women, and trustworthiness) and usability (navigability and comfort) of the program. Participants made recommendations to the program in terms of information offered on treatment, rural issues, survivorship, diet, and using the program. Overall, this study supports the feasibility and acceptability of web-based psychosocial interventions in rural breast cancer survivors and the willingness of participants to take part in synchronous online focus groups.

These results offer important insights to inform future work and raise additional questions about designing optimally effective and tailored cancer interventions. The discussion in the current article is intended to generate constructive dialogue about how healthcare researchers and providers can ensure interventions are truly designed for rural cancer survivors and have as much reach and impact as possible. These concerns and questions are certainly not unique or limited to Lally et al.'s (2018) work, but rather are relevant for all research that seeks to design and test tailored Internet-based cancer interventions.

Participant Sample

One important consideration for the design of web-based tools is the participant sample. Breast cancer survivors are well known for being a particularly active and willing sample to engage in research and self-management interventions. Although the needs of this survivor group are important, future work could explore if programs similar to CaringGuidance are as well received and effective for other key groups of rural cancer survivors. For example, in rural southwest Virginia, there is a disproportionately high incidence of malignancies attributed to tobacco use and occupational exposures (Virginia Department of Health, n.d.; Yao, Alcalá, Anderson, & Balkrishnan, 2017). Would men with head and neck or lung cancer in this rural region be as willing to access tools like CaringGuidance? This question is also related

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to the issue of participant socioeconomic status. Patients who are rural and low-income (and arguably at highest risk for psychosocial distress) may lack reliable access to computers, mobile phones, or Internet service. As acknowledged by the authors, the sample for this study was skewed toward a college-educated, employed, Caucasian group of cancer survivors who had computers, mobile phones, and Internet experience and access. Future work in this area should seek to recruit cancer survivors of diverse socioeconomic status to ensure that web-based interventions are realistic and accessible for rural residents with more limited economic resources.

The CaringGuidance program was designed to address coping strategies in the initial months following a new cancer diagnosis, but the current study recruited participants one month to 10 years past the initial diagnosis of stages 0–IIIA breast cancer. Twenty-one of 23 participants were 1–6 years postdiagnosis. Survivorship needs at one month versus six years are different, as are the needs and psychosocial concerns of a patient facing a stage 0 (noninvasive in situ) versus a stage IIIA (lymph node involvement) diagnosis. This incongruence is revealed in the participant feedback that "lack of information for longer-term survivors was the principal disappointment expressed about the program" (Lally et al., 2018, p. E118). Future work should explore how to optimally tailor web-based interventions for the cultural, social, and economic context of rural participants, as well as offer flexible psychosocial support relevant for the specific stage of patient survivorship that can account for dynamic and changing needs and concerns over time.

Content and Evaluation of the Program

The CaringGuidance program focuses on coping with mental health–related distress, such as depression, anxiety, and post-traumatic stress, that commonly accompanies a cancer diagnosis. Addressing these psychosocial concerns must be a priority. However, distress for patients with cancer is a broad concept and can include economic, social, spiritual, and physical stressors (National Comprehensive Cancer Network, 2018; VanHoose et al., 2015). Consistent with this knowledge and in keeping with participant feedback in which additional information was requested regarding treatment, diet, and longer-term survivorship, web-based distress management tools should incorporate a holistic focus to more fully address sources of distress encountered by rural cancer survivors. Ideally, web-based and mobile interventions should strive to leverage advanced technology to identify specific and evolving sources of distress and deliver timely, tailored, and personalized support.

The average length of time of participant access to CaringGuidance was 12 days, but at least one participant received access only 24 hours prior to her assigned focus group. One suggestion for future work is to consider weighting design input based on participant engagement with the program and being clear about this in describing intervention design. For example, feedback from a participant who spent 10 minutes navigating a web-based intervention should likely be considered differently than that from a participant who spent five hours exploring the same program.

Scalability, Data Sharing, and Ethical Considerations

As with all Internet-based approaches to cancer care, considering issues of scalability, data sharing, and ethics is important. Although not the focus of Lally et al.'s (2018) article, it is worth considering whether CaringGuidance (and similar support programs) can and should be packaged as a downloadable mobile application. What are the advantages and disadvantages of this, particularly for rural populations? Should the support tools of CaringGuidance be available to family caregivers? If so, in what ways? Finally, researchers should question the optimal ways to share data among key stakeholders and what the ethical responsibilities of researchers and clinicians are once issues are identified. For example, should caregivers (informal and healthcare providers) be notified if patient use of the program suggests high levels of distress? If yes, what immediate resources are realistically available for a rural patient? These are questions without easy answers, but they are important to consider in the design and implementation of web-based support tools for cancer survivors.

The Rural Perspective

Critically important questions include asking in what ways the psychosocial needs of rural cancer survivors are unique, and what is potentially unique about the ways this group may or may not access and use web-based resources and support tools? These questions are at the crux of Lally et al.'s (2018) article, but, based on the reported findings, they feel inadequately addressed. Lally et al. (2018) state that "evaluation of quality was embedded within the survivors' rural cultural perspective" (p. E117). This is a crucial sentence, but the reader is left to wonder what the rural cultural perspective in Nebraska actually is. Is it different than the rural cultural perspective of central Appalachia

or the Mississippi Delta? If so, how? How is the rural cultural perspective shaped by other key factors, such as historical context, availability of social and family support, and economic influences? Lally et al. (2018) state that "nurses should not assume rural women lack Internet access" (p. E122). However, critical modifiers seem missing from this sentence, particularly given the study sample. Perhaps more accurately, one could say that nurses should not assume educated, employed, and Caucasian rural women lack Internet access. Participants also stated they appreciatedanaestheticallypleasing,convenient,easy-to-navigate, affirming, professional web-based interface with relevant content. The authors frame these comments as uniquely relevant to rural cancer survivors, but it seems these would be common and expected sentiments from breast cancer survivors (and potentially any cancer survivor) regardless of whether they live in a rural or urban area.

Conclusion

Lally et al. (2018) address a critical and timely issue in cancer care—how to leverage technology to deliver effective support to rural populations. However, it is unclear if the majority of issues and design feedback they identify and describe are actually specific to a rural population or if they are more reflective of breast cancer survivors in general. Digging deeper to truly understand the rural cultural perspective is critical to be able to design truly tailored interventions for cancer survivors.

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