

Rural Resilience in Cancer Survivors: Conceptual Analysis of a Global Phenomenon

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Abstract

Aim: The aims of this analysis are to (1) identify the concept of rural resiliency in cancer survivors in the nursing literature and (2) propose a conceptual framework that may help nurses leverage rural resilience to improve survivorship care.

Background: Rural cancer survivors demonstrate rural resiliency by utilizing aspects of rural culture to improve their psychosocial distress. However, resiliency in rural cancer survivors is poorly understood.

Design: We used Walker & Avants' concept analysis approach to direct article selection, review, and analysis.

Review methods: We identified a definition, antecedents, consequences, attributes, empirical referents, and related terms, and provide model, contrary, and borderline case examples.

Results: We identified 29 articles that met inclusion criteria. We propose a conceptual model of rural resiliency that is grounded in three domains of rural culture: spirituality, cultural norms, and social capital. Attributes of rural culture within these domains impact a cancer survivor's psychosocial health, leading to either negative or positive psychosocial outcomes.

Conclusion: A better understanding of how rural resiliency impacts cancer survivors can help clinicians and researchers provide culturally-targeted post-treatment interventions. Our proposed conceptual framework may guide nurse researchers to develop measurement tools that evaluate rural resilience and its impact on health outcomes.

Keywords: rural, cancer survivor, resilience, concept analysis, conceptual framework

Rural Resilience in Cancer Survivors: Conceptual Analysis of a Global Phenomenon

There are over 43.8 million cancer survivors worldwide (American Cancer Society, n.d.), and approximately 3.4 billion people living in rural communities (World Bank, n.d.). Globally, rural cancer survivors may experience greater psychosocial distress (distress due to physical, emotional, or mental pressures that can decrease quality of life in cancer survivors; (National Cancer Institute, n.d.) compared to urban cancer survivors (Butow et al., 2012). In countries such as Australia, the US, Ireland, and the UK, rural cancer survivors face barriers to psychosocial care such as provider shortages, local hospital closures, and greater travel times to health care facilities (Butow et al., 2012; Rogers-Clark, 2002). Additional barriers include low socioeconomic status, lack of health insurance, and mistrust in healthcare providers (Rogers-Clark, 2002; Zahnd, Jenkins, et al., 2018). Further complicating access to psychosocial care, rural cancer survivors may prefer to seek psychosocial support from informal sources such as family, friends, and community members instead of healthcare providers (Pascal et al., 2015). The global body of literature has identified negative outcomes that rural cancer survivors experience, such as decreased quality of

life (National Cancer Institute, n.d.), but little is known about how rural cancer survivors make positive adaptations to improve health outcomes (Katz et al., 2010). This concept analysis will help introduce the novel phenomenon of rural resilience in cancer survivors by describing how rural survivors adapt their available community resources to obtain psychosocial care and improve their health outcomes (Cosco et al., 2017).

Resiliency in cancer survivorship is poorly understood due to multiple definitions and contexts (Molina et al., 2014). The concept of *rural resilience* is scarce in nursing literature, and in cancer survivorship literature. At this point, resilience is ill-understood in rural communities, likely because of a strong focus on the negative outcomes that cancer survivors experience (Rogers-Clark, 2002). Concepts are dependent on their context (Rodgers, 1993) and resiliency in cancer survivors needs to be analyzed from the rural cultural perspective. Currently, rural resilience is a developmental concept in ecological literature (Heijman et al., 2019) but this concept may not depict how rural cancer survivors make positive adaptations despite poor healthcare access. Likewise, resilience has been analyzed as a concept in nursing literature for patients across the age continuum (Earvolino-Ramirez, 2007) but that model may not capture how rural culture influences resiliency, or how nursing research may utilize resiliency to improve health outcomes for rural cancer survivors. Resilience in adult cancer survivors has been conceptualized in a model that explains the continuum of distress-resilience and incorporated individual characteristics (Deshields et al., 2016) but does not explain the role of culture. Rural culture influences the health behaviors and beliefs of cancer patients, and its role needs to be understood to develop interventions that improve health outcomes (Carriere et al., 2018; Rogers et al., 2019). Developing a conceptual framework of rural resiliency is the first step towards future intervention development.

By understanding the attributes and outcomes of rural resiliency in cancer survivors, clinical nurses and researchers working in a variety of rural settings will be able to better identify how to engage their communities in survivorship care to improve health outcomes. The purpose of this concept analysis is to 1) establish rural resilience in cancer survivors as a global phenomenon of nursing interest, and 2) propose a conceptual framework to guide the development of interventions that promote rural resilience in cancer survivors. The concept of rural resilience in cancer survivors will be analyzed using the Walker and Avant (2005) method while discussing the challenges of measuring rural resilience, and recommending focus areas for future research (Schiller, 2018).

Methods

A clear and rigorous concept analysis is fundamental for future nursing theory and clinical practice changes (Schiller 2018). To accomplish this, we selected the Walker and Avant's method due to its prevalence in nursing concept literature and clear methodological steps (Walker & Avant, 2005).

The selection of rural resilience in cancer survivors was chosen based on our clinical experiences observing this population's successful adaptations to meet their post-treatment needs through informal community resources. The literature defines adaptation in the face of adversity as resiliency (Cosco et al., 2017). In this analysis, rural resilience is defined as 1) rural cancer survivors facing adversity, and 2) making an adaptation, specifically the use of informal community resources to meet post-treatment care needs and overcome structural, social, physical, and cultural barriers to accessing healthcare.

The purpose of this concept analysis is to identify the phenomenon of rural resiliency in the cancer survivorship literature. Language used to describe resiliency in the literature guided the search in two phrases. The first search phrase used (resilience OR self-efficacy OR coping OR

resiliency OR self-reliance OR spirit OR strength OR "positive adaptation") AND rural AND cancer AND survivor. The second phrase used community AND rural AND cancer AND survivor. Databases searched were: PubMed, GoogleScholar, Proquest Social Sciences, and Web of Science. One Hundred Sixty-Five (165) studies were retrieved. All studies retrieved by the search phrases were exported to citation manager for title and abstract review. Studies that were relevant to the conceptual analysis based on title and abstract review were fully read, and concept uses, antecedents, consequences, and empirical referents were coded and extracted by a single reviewer. 29 studies meet inclusion criteria for this conceptual analysis.

Analysis

Concept Uses

The literature reflects a continuum of positive and negative aspects of rural resilience as it relates to psychosocial outcomes. Negative aspects that increased psychosocial distress included: describing inaccurate beliefs about cancer (Livaudais et al., 2010); explaining how rurality caused poor health outcomes (Katz et al, 2010); describing how rural cancer survivors ended up isolated from their communities (Rogers-Clark, 2002); and describing a lack of care-seeking behaviors (Gunn et al.,2019). Positive aspects of the concept included: strong coping strategies (Cahir et al., 2017); inner strength (Gunn et al.,2019); informal community support systems (Allicock et al., 2017); changing negatives into positives (Gisiger-Camata et al., 2016); improved health outcomes (Rogers et al., 2019); buffers to emotional distress (Reid-Arndt & Cox, 2010); reduced distress (Angell et al., 2003); maintaining social standing during survivorship (López et al., 2005); improved self-efficacy (Olson et al, 2014); returning to normalcy (Torres et al., 2016) a positive survivorship narrative (Allen & Roberto, 2014).

Antecedents

Several antecedents were consistently found during the phenomenon of rural resilience in cancer survivors. These included barriers to health care access and health outcome disparities, unmet needs for caregivers, fear, having a goal of returning to normal, and a lack of survivorship information (DeGuzman et al., 2017). The dearth of healthcare access caused a cascade of issues such as unmet survivor needs, fear of cancer-related outcomes, and lack of available survivorship information. Facing these challenges, rural survivors needed to find survivorship care through the community resources available to them.

Attributes

Rural resilience is guided by cultural beliefs and values. Resiliency exists on a dynamic continuum of resilience-psychosocial distress (Deshields et al., 2016), and culture impacts resilience through subjective norms and health behaviors (Carriere et al., 2018). We found the rural cultural domains of spirituality, social capital, and cultural norms have aspects that can positively or negatively impact health along the resilience-psychosocial distress continuum. The attributes are presented here as a dichotomy between those positive aspects (such as seeking support from the community), and related negative aspects (such as mistrust in healthcare).

Spirituality: Faith vs Fatalism

Rural cancer survivors face challenges obtaining information about the survivorship period, including what to expect. Rural survivors use faith as a source of cancer knowledge and support, using spiritual explanations such as “God’s will” (Livaudais et al., 2010). Faith, prayer, and God are linked to strong social networks via local community churches, and this spiritual support can enable rural cancer survivors to remain positive during the survivorship transition (Torres et al., 2016). Through faith and spiritual knowledge, which supports inner-strength, rural survivors maintain their independence (Walker et al., 2015). Faith is utilized as a channel for rural cancer

survivors to return to their community; rural cancer survivors determined they were successfully transitioning back to their normal lives by spending time at church instead of in the hospital (Walker et al., 2015).

The negative aspect of spirituality was fatalism. With the spiritual knowledge of “God’s will”, rural survivors may accept their pre-determined fate and decide not to seek health care (; Torres et al., 2016). Through fatalism, spiritual knowledge of cancer is the result of poorly resourced communities and cultural oddities (Allen et al., 2014). Providers’ own perceptions of spiritual beliefs may result in culturally inappropriate care.

Social Capital: Strong Community Networks vs Cultural Differences

The attribute of strong social networks was frequently used to describe rural communities in research literature. Terms used to describe social networks include “support networks”, “community”, and “social support” (Olson et al., 2014; Rogers et al., 2019; Torres et al., 2016). Rural cancer survivors utilize their strong social networks as both informal community support systems and caregivers. Social networks keep community members closely connected, and therefore survivors’ cancer journeys are often public knowledge, which survivors view both positively and negatively (McNulty & Nail, 2015). Despite a loss of privacy, communities support rural cancer survivors to make healthy choices (Rogers et al., 2019), and make healthcare related decisions (Allen et al., 2014).

The presence and role of strong social networks in rural communities positively impact survivors’ health, but cultural differences may transmit false thinking and beliefs about cancer. The term “cultural differences” was used to encompass any cancer-related belief, activity, or value that was not congruent with mainstream medical practice. Cultural differences were used to

explain rural survivors' inaccurate beliefs about cancer, unhealthy patterns of behavior, and reasons for worse mental health outcomes (Andrykowski & Burris, 2010; Livaudais et al., 2010).

Cultural Norms: Seeking community support vs mistrust in healthcare providers

Rural cancer survivors often prefer to seek support from informal community sources instead of formal health providers (Pascal et al., 2015). Rural cancer survivors seek the opportunity to connect with community peers, and obtain community support (Allicock et al., 2017). Rural cancer survivors indicate they trust their community and community leaders and feel a strong desire to reconnect with their community as they transition to back to their normal lives (Gunn et al., 2019; McNulty & Nail, 2015).

However, seeking community care may also be due to culturally grounded mistrust in healthcare providers, particularly for rural ethnic and minority groups. Rural cancer survivors are sometimes unwilling to seek care from providers (Rogers-Clark, 2002). A negative outcome of seeking survivorship care and information from informal community sources, is that rural cancer survivors learn inaccurate beliefs about cancer (Livaudais et al., 2010). Minority survivors may face similar challenges to seeking care from providers, although the origins are different (Zahnd, Murphy, et al, 2021). Researchers have shown that inherent bias and racism in the health care system has left many patients from minority cultures mistrustful of the healthcare system (López et al., 2005; McNulty & Nail, 2015). There are differences specific to rural minority cultures. For example, rural Hispanic communities may not receive the same information as non-Hispanic white cancer survivors because of the inherent bias of providers (Livaudais et al, 2010).

Consequences

Consequences of rural resilience for cancer survivors is associated positive and negative outcomes along the resilience-psychosocial distress continuum. Resilient rural cancer survivors

can leverage self-and community-reliance to their benefit, but limited healthcare facility resources can lead to unmet post-treatment needs.

Rural cancer survivors who adapted their existing community systems to support their needs experienced positive consequences such as improved quality of life (McNulty & Nail, 2015), improved physical health (Rogers et al., 2019), decreased psychological distress (Angell et al., 2003), strong coping skills (Torres et al., 2016), improved self-efficacy (Olson et al., 2014), less emotional distress (Reid-Arndt & Cox, 2016), and post-traumatic growth (Andrykowski & Burris, 2010). Despite the lack of available health care providers and information, rural cancer survivors were able to utilize their informal community resources to improve their health outcomes.

When aspects of rural culture impacted health behaviors in a way that decreased rural resiliency and increased psychosocial distress, cancer survivors experienced chronic health crisis (Rogers-Clark, 2002), lower functionality (Reid-Arndt & Cox, 2010), unmet survivorship needs (Katz et al., 2010), worse coping skills (Schlegel et al., 2009), and poorer psychosocial health (Andrykowski & Burris, 2010). In context of these negative attributes, although rural cancer survivors adapt their strong informal community support systems to obtain survivorship care, they experience poorer health outcomes because they lack clinical support (Pascal et al., 2015).

Model, Borderline, and Contrary Cases

In a model case of rural resiliency, cancer survivors with poor access to providers obtain survivorship care efficiently using informal community resources. For example, Jackie, a 57-year old breast cancer survivor, is six months post treatment. She received her cancer treatment from a NCI-designated cancer center that is two hours away from her home. Her local hospital does not have an oncologist or social worker, and her primary care physician is not comfortable providing survivorship care. Jackie is experiencing high levels of anxiety about her physical and functional

changes post treatment. She seeks information and support from peers at her church group. Using her social network and spiritual knowledge, Jackie views her new changes as “God’s will” and experiences reduced levels anxiety. She does not seek clinical support or treatment. At her follow up visit with her oncologist, Jackie admits to having anxiety, but declines her oncologist’s offer for a social work referral.

A borderline case of rural resiliency would be if a cancer survivor sought information or support from informal community resources, but is unable to efficiently obtain help. Using the same situation as described above, a borderline case of resiliency would be if Jackie seeks knowledge and support from her local church group, but the church group is difficult for her to connect with. It takes Jackie several attempts before she is able to speak with the church group, but once she does, they give her information and support.

In a contrary case, consider James, a 70-year old thyroid cancer survivor who has been denied help from an informal community network. James received treatment from an oncologist and surgeon at the nearest Cancer Center-over 2.5 hours away from his home. He needs to make a follow-up appointment with an endocrinologist, but there is only one provider in his community, and the provider doesn’t have any appointments available for the next three months. James will need to travel back to the Cancer Center in a week to see the Endocrinologist there, but he is unable to drive because of the pain medications he is taking. James needs help with transportation to his appointment. He reaches out to his local community, friends and neighbors, and they tell him they cannot help him. James has to reschedule his appointment.

Empirical Referents

Although the phenomenon of rural resilience is present in the literature, the conceptual term is not. Likewise, there are currently no consistently used empirical referents of rural resilience.

While there are various resiliency measures, the Connor-Davidson Resilience Scale and Resilience Scale for Adults were found most frequently in our literature review, and both have higher psychometric ratings when compared to other resilience measures (Wells, 2009). The Resilience Scale has been used to assess resilience in rural cancer survivors, and found that the scale may not show how self-reliance in rural communities is possible due to the presence of strong social networks (Wells, 2009). The Resilience Scale for Adults measures resilience through the domains of personal competence, social competence, family coherence, social support and personal structure (Wells, 2009). When compared to the domains we found to impact rural resiliency, this scale measured social capital thoroughly. However, it may not measure the rural resilience domains of spirituality and cultural norms.

The Connor-Davidson Resilience Scale, a reliable and validated scale used to measure resiliency in cancer patients across the care continuum (Connor & Davison, 2003) has been used to assess resiliency in aging rural populations (McKibbin et al., 2016). This scale measures resilience through the domains of personal competence, trust, acceptance of change and secure relationships, control, and spiritual influence (Wells, 2009). When compared to our findings regarding rural resilience, this scale may address the domain of spirituality, and may address social capital through relationship, personal competence and secure relationships. However, the Connor-Davidson Resilience Scale does not factor in the impact of cultural norms, which we found to be a significant domain of rural resiliency.

Neither the Connor-Davidson Resilience Scale or the Resilience Scale of Adults comprehensively measure the domains of rural resilience found in our literature review. Furthermore, it is unknown if these scales are culturally appropriate for rural cancer survivors (Wells, 2009). Resilience may be understood differently within various cultures (Wells, 2009) and

we have established that rural culture is the foundation of rural resilience for cancer survivors through our analysis. Future qualitative research can determine the applicability of current resilience measures, and provide direction for how to improve those measures to be culturally tailored (Wells, 2009).

Discussion

We have identified rural resiliency within the literature by discovering how rural cancer survivors achieve health in a limited-resource environment. We found rural survivors experience more cancer-related fears, unmet needs, and higher levels of emotional distress than urban ones (Gunn et al., 2019). Due to cultural beliefs, personal preference, or lack of resources, rural survivors actively seek survivorship care through informal community systems (Pascal et al., 2015). While rural survivors demonstrate resiliency, the unique cultural context makes it challenging to define or measure rural resiliency. Rural cancer survivor needs are different from urban ones, and require different interventions (Katz et al., 2010).

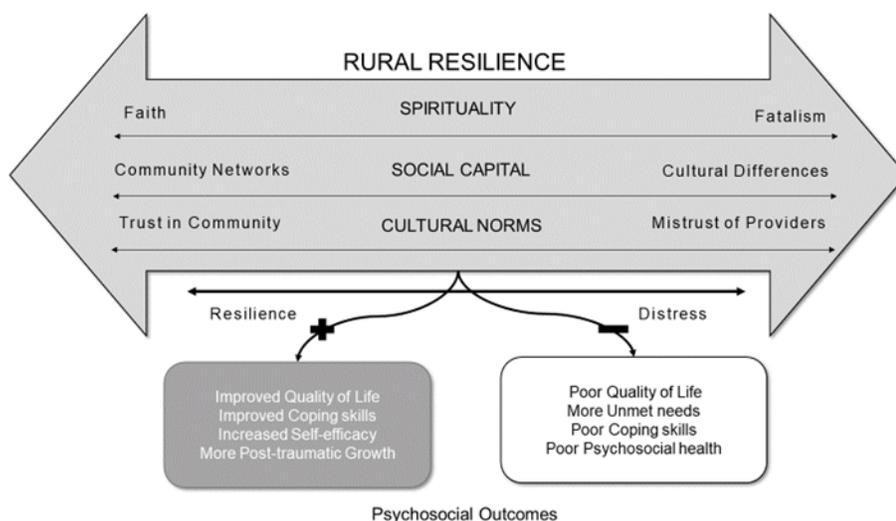
We propose a conceptual framework to aid in understanding the role of rural resiliency when addressing the unique needs of rural cancer survivors. Figure 1 depicts a conceptual framework of rural resilience based on the current analysis. This framework depicts attributes of rural resiliency found within the literature, which are represented as three cultural domains on the resilience- psychosocial distress continuum (Deshields et al., 2016). The domains of spirituality, social capital, and cultural norms can impact resilience in rural cancer survivors. We found that within the domain of spirituality, faith may be used to increase inner-strength (Allen & Roberto, 2014), while fatalism can hinder coping (Schlegel et al., 2009). In the domain of social networks, strong community networks provide an acceptable source of support (Allicock et al., 2017), which may help strengthen self-efficacy (Olson et al., 2014). However, cultural differences may be contributed to

the decision not to seek care (Gunn et al., 2019), particularly for ethnic and minority cancer survivors (Livaudais et al., 2010; López et al., 2005; Torres et al., 2016). In the domain of cultural norms, the rural cancer survivors often choose to seek information through trusted community knowledge and resources (Allicock et al., 2017), rather than from formal healthcare workers due to mistrust of providers (Rogers-Clark, 2002).

The attributes of each domain impact rural resiliency along the resiliency-psychosocial distress continuum (Deshields et al., 2016). Increased resilience leads to improved psychosocial outcomes, such as quality of life, coping, self-efficacy and posttraumatic growth. Less resilience leads to increased psychosocial distress and worse psychosocial outcomes, including poor quality of life, more unmet needs, and poor coping skills.

Figure 1

Conceptual Framework for Rural Resilience in Cancer Survivors



By investigating both positive and negative impacts of rural culture on cancer survivor resilience, nurse scientists can broaden the understanding of how rurality can positively impact health. Targeted interventions to strengthen resiliency has led to improved health outcomes for cancer survivors (Molina et al., 2014). Researchers have already successfully utilized community-

based interventions to improve survivorship care (Angell et al., 2003). Nurses are ideally positioned to improve psychosocial distress in rural cancer survivors by promoting rural resiliency. Rural communities highly value nursing care, and that nurse-driven interventions improve outcomes for rural cancer survivors (Schoenberger et al., 2016; American Cancer Society, n.d.). In fact, some rural cancer survivors have claimed that the ability to speak with their nurse is the most valuable aspect of survivorship care (Schoenberger et al., 2016).

Moving forward, our conceptual framework may be used to help clinicians and researchers support rural cancer survivors by identifying domains that are supporting or detracting from patients' health and directing patients to community resources that will support health. Nurse researchers can use the conceptual framework to develop targeted interventions within the domain areas to support rural cancer survivors, and use the framework to identify measurable variables. Nurse researchers can also use the conceptual model to guide future qualitative research that can evaluate the cultural appropriateness of current resilience measures, and to develop and evaluate a comprehensive measure of rural resilience (Wells, 2009).

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