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## Social Work's Dynamic Role in Oncology: Providing Leadership for Environmental Responsiveness

J. Sky Niesen

*University of St. Thomas, Minnesota*

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Social Work's Dynamic Role in Oncology:  
Providing Leadership for Environmental Responsiveness

by

J. Sky Niesen

A Banded Dissertation in Partial Fulfillment  
Of the Requirements for the Degree  
Doctor of Social Work

Saint Catherine University | University of Saint Thomas  
School of Social Work

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### Abstract

Social work has a long standing relationship with healthcare. Beginning in the settlement house movement, social workers have provided a dynamic micro, mezzo, and macro role in medical settings. Social work's ecological systems perspective allows for the inclusion of environmental and social justice factors in healthcare delivery. Ecological theory, epistemologically rooted in social work, is used as a conceptual framework throughout the three products, as the contextual environment is viewed as integral in understanding cancer patient experiences.

The first product of this Banded Dissertation is a conceptual article detailing the need for culturally responsive practice methods in oncology care with rural Indigenous people. Oncology systems have increasingly invested in psychosocial care, yet disparities exist in psychosocial oncology care in the context of diverse rural settings. Social workers must become leaders in the healthcare arena in order to advocate and provide essential psychosocial, culturally responsive services to marginalized and underserved people.

The second product includes qualitative research methodology with participants who are rural cancer patients in Illinois. The purpose of the second product was to explore psychosocial experiences of cancer patients who reside in a rural community in Illinois. The study used a rural cancer wellness center, Home of Hope, to recruit and interview 18 participants. The interviews were transcribed and organized into recurrent themes, highlighting the unique psychosocial experiences of the rural context.

The third product is a commentary calling for an increased presence of the social work profession in the precision medicine movement. Precision medicine is essentially sequencing an individual's genome in order to develop targeted medical interventions. The professional of social work, the article argues, has work to do in terms of becoming integrated with associated

practice and ethics of this movement. This commentary was published in the journal *Social Work* in May 2016.

This dissertation focuses on the intersectional nature of social work's interface in specialty healthcare – particularly in rural and diverse contexts. The products are connected by the common thread of viewing the healthcare patient as “whole.” Ecological theory, epistemologically rooted in social work practice, values, and ethics, is used as a conceptual framework throughout the three products. The contextual rural environment is integral in understanding patient experiences in order to address healthcare disparities.

*Keywords: Rural health, Health Disparities, Psychosocial Oncology, Oncology Social Work*

Dedication

This project is dedicated to my dear friend Jodi Gabler Cosgrave, whose beauty, intelligence, tenacity, and bravery inspired me to begin this doctoral journey in order to bring a voice to those facing cancer. Your spirit lives on in your three amazing daughters Alexis, Avery, and Abigail, and the many people you graced with your laughter and illuminous zest for life.

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I would like to first and foremost thank my children (Christopher, Mary, and Jude) for giving up so many weekends and activities so I could work on my studies or even just think about writing. Thank you for your heart lights that sustain and inspire me every day! Thank you also to Sam, who was always willing to run for a late night diet pop to give me some energy to keep writing, as well as providing wordsmithing consultation. Thank you to my parents, who continue to encourage me to keep going despite what life throws – for telling me over and over to tackle one thing at a time. Thank you to my advisor, Dr. Robin Whitebird, and to all of the amazing professors who guided and supported me along the way. I am fortunate for the lifelong friendships I have gained in my doctoral journey: especially Dr. Amy Fischer, my Cohort 1.5 comrade; Dr. Will Wong, who shares my affinity for pandas and reminds me the universe has my back; and my roommates: Dr. Carey Winkler, Dr. Amanda Greubel, and Dr. Rebecca Hoffman. Thank you to all of my students – past and present – who taught me to fall in love with social work all over again. Thank you to Home of Hope Cancer Wellness Centers for introducing me to the field of oncology and the important work that you do supporting people with cancer and their families. Thank you to all of the people who were willing to trust me with sharing their story. I hope to honor your voices.

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## Social Work's Dynamic Role in Oncology:

### Providing Leadership for Environmental Responsiveness

The scholarship agenda of this dissertation focuses on the social work profession's role in providing psychosocial oncology services in rural areas. The importance of screening for distress in cancer care, and subsequent psychosocial services to treat distress, was highlighted in the Institute of Medicine (IOM) Report: *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* (2008). This report highlighted the need to improve healthcare quality in the United States (U.S.) by attending to social, behavioral, and emotional issues faced by those with chronic illness. The report offers an overview of the reach of cancer and issues of health-related distress along with diverse psychosocial needs and services in outpatient oncology settings. The IOM Report (2008) furthermore outlined 10 recommendations for actions, including psychosocial health services as a standard of care and increasing psychosocial competency across all cancer care providers. Oncology social work, guided by the Association of Oncology Social Workers (AOSW) has risen to the challenge of cancer – related distress treatment and prevention by creating and maintaining psychosocial care methods at cancer treatment centers around the world. When examining rural areas already facing behavioral health shortages, these specialized psychosocial oncology services are urgently needed.

The Center for Disease Control's previous acting Director, Anne Schuchat stated, "While geography alone can't predict your risk of cancer, it can impact prevention, diagnosis and treatment opportunities – and that's a significant public health problem in the U.S." (CDC, 2017). Community partnerships, Dr. Schuchat discusses, are key in confronting cancer disparities that exist in rural areas (CDC, 2017). Not only is the prevalence of some types of cancer higher in rural areas than urban areas, cancer-related mortality is higher. In addition,

cancer related to tobacco and cancer types prevented by early screening are higher in the rural context. Rural residents face unique barriers associated with cancer disparities, including an aging population, higher poverty rates, unemployment, behavioral health workforce shortages, and fewer cancer prevention programs than urban settings. The interplay of these barriers and higher cancer mortality rates requires further study and intervention. (Downey, 2013).

Social workers in rural settings are prepared with generalist and advanced generalist practice skills that may provide value in connecting with clients among systems in the context of oncology. Social workers, using ecological theory and the person-in-environment perspective, overcome barriers in healthcare by mobilizing environmental and individual resources and strengths. Cultural responsiveness is included in the skillset of generalist and advanced generalist social workers. In rural contexts, people with minority status experience greater healthcare needs and greater social concerns than dominant groups (Ginsberg, 2011). Social workers must mobilize in order to utilize skills of cultural responsiveness to create appropriate services and practice frameworks that address disparities experienced by people living in rural contexts, especially people with intersectional diverse identities, such as rural Indigenous people.

This dissertation challenges both the healthcare field and the profession of social work to elevate social work and the provision of essential psychosocial services to build culturally responsive coalitions that mobilize strengths and resources to confront the numerous barriers associated with cancer care in the rural context. Furthermore, social work's use of ecological theory and ability to interface with a variety of systems and system levels situates social work as an important professional influence to develop environmentally responsive rural health initiatives that address disparities. Additionally, social work's value of social justice sounds the call for social workers to advocate for equal access to health prevention and treatment no matter

socioeconomic, cultural, or environmental circumstance. The first product of the dissertation outlines some unique aspects of cancer care with rural Indigenous communities. The second product is exploratory research designed to better understand experiences of cancer patients in a rural county in Illinois. The third product is a commentary calling for social work as a profession to include genomics as an integral part of our Code of Ethics and educational standards in order to advocate for and understand potential ethical complexities of the precision medicine movement.

### **Conceptual Framework**

“You treat a disease, you win, you lose. You treat a person, I’ll guarantee you’ll win.”  
-Patch Adams (Shadyac, 1998)

The conceptual framework for this Banded Dissertation is ecological theory, which focuses on the interaction and interdependence of the person and environment. In social work practice, ecological theory provides a culturally responsive framework for understanding environmental influences on a person’s life. When social workers are able to discover and identify environmental influences on a system, interventions may be constructed and the change process can begin (Segal, Gerdes, & Steiner, 2013). This theoretical foundation is important to rural social work practice in that systemic development may be viewed as circular interactions that promote growth rather than a linear, prescribed process (Gitterman & Germain, 2008). Another assumption of ecological theory is that a person interacts with the environment as a set of interrelated systems within levels of the environment. This assumption includes the belief that “a system is a set of orderly elements that are related to make a whole” (Hepworth, R. Rooney, G.D. Rooney, & Strom-Gottfried, 2013).

Ecological theory relates to psychosocial oncology as it involves a developmental relational interaction of an individual and his or her contextual environment. Furthermore, ecological theory involves the importance of psychosocial aspects of an individual, including biological factors, cognitive factors, and behavioral characteristics (Gitterman & Germain, 2008). As biomedicine sounds the call for increased attention to the “whole person,” this concept reflects the above components of ecological theory. In the rural context, the “whole person” additionally involves the unique challenges of rural healthcare, such as access to physicians, transportation, and higher health needs (Ginsberg, 2011)(IOM, 2008). Social workers use ecological theory in practice by considering cultural, environmental, and systemic influences.

In this dissertation, ecological theory will be applied to the topic of psychosocial oncology care with rural Indigenous communities, experiences of rural cancer patients in Illinois, and social work's role in precision medicine. Biomedicine lacks the understanding and influence of incorporating environmental and cultural knowledge in practice. In rural areas, the importance of the interconnectedness of systems, including the natural environment and geographical terrain, draws out the role of social work in culturally responsive cancer care. Social workers are trained to understand the impact of the intersectionality of diversity with other factors, such as geographical location and disease. For this reason, social workers may facilitate culturally responsive communication, programs, and frameworks in biomedical systems.

Ecological theory involves four components. The first component involves how the developmental process impacts the relationship of the person within their contextual environment. This is guided by relation of person in the context of their relationship with the environment, specifically the rural context. The second component of the ecological framework includes psychosocial aspects of an individual, including realms of biology, cognition, and

behavioral characteristics, and how these aspects impact development. This involves a systems perspective of the oncology patient including the individual's family, financial situation, psychological wellbeing, history of trauma, community connections, cognitive abilities, ability to cope with pain and demanding treatments, and employment status (IOM, 2008). Third, developmental processes include levels of systems. This scholarship agenda explores levels of systems including micro (person), mezzo (family and small community support systems), and macro (institutions and rural context). Finally, development over the lifespan involves multiple dimensions that influence change (Gitterman & Germain, 2008, p.51). Ecological theory, central to social work practice, is a diversion from linear approaches to human development and allows for an emphasis on the importance of diversity and difference across systems.

### **Summary of Banded Dissertation Products**

The first product of this dissertation is a conceptual paper related to the topic of rural psychosocial oncology with the additional dimension of a diverse perspective in terms of rural Indigenous communities. Electronic databases were searched with the purpose of accessing available peer-reviewed articles related to psychosocial oncology background, needs, strengths, and best practices in the unique context of rural communities. An aspect of this product is the lens of intersectionality: in essence, what are the psychosocial needs of Indigenous people living in rural communities and how are these needs being met in the context of cancer care. This paper argues that social work as a profession must be considered integral to cancer care in micro, mezzo, and macro levels in order to confront health care disparities. Barriers to service, such as historical oppression, discriminations, transportation, and availability of culturally responsive services are explored in this product as well as the importance of mobilizing community strengths.

The second product is exploratory research focusing on cancer-related distress and psychosocial oncology services in the rural community of Lee County, Illinois. This community is located along the Rock River in Lee County, Illinois and is considered a rural county in Illinois by the standards set by the U.S. Housing and Urban Development (HUD, 2010). The area is part of the rural rustbelt, with many social problems related to deindustrialization in the early 2000s, such as poverty and high unemployment (Ginsberg, 2010). This area is largely agricultural, with many shuttered factories throughout.

The rural communities in Lee County support a small cancer wellness center, Home of Hope. This center provides free psychosocial oncology services, coordinated and often provided by one social worker. Services fall under the categories of support, wellness, and education. Support services include individual and group counseling. Wellness services provided are massages, reiki, yoga, and healing touch. Educational programs are educational “lunch and learns” with an oncology nurse, nutritional education, and disease-specific informational groups. Services are provided at no cost for patients, caregivers, and families of all ages – the only requirement is that someone has been impacted by cancer (Home of Hope, n.d.)

The exploratory study includes qualitative interviews with 18 cancer patients. The sampling included a convenience sample of adult cancer patients who were diagnosed within one year of the interview date. The study included a series of semi-structured interview questions, grounded in ecological theory and concepts identified in available rural psychosocial oncology literature. The semi-structured interviews took place in person at Home of Hope service locations and were audio recorded and transcribed. Transcriptions were then organized into categories and coded using content analysis with support from the qualitative coding software MAX-QDA.

Results indicated overarching themes of overall cancer experience, distress, social work services, environmental pollutants, and the rural context.

The third product for this dissertation is an article published in *Social Work* as a commentary on social work's role in precision medicine. This article discusses an important disconnect in social work's evolution into the 21<sup>st</sup> Century in terms of medical genomics testing and care. This piece was submitted to the National Association of Social Workers (NASW) Press and accepted for publication in *Social Work* by the Editor-in-Chief on June 22, 2015. The article went through an anonymous peer-review process prior to acceptance for publication in February of 2016. Together, these products comprise a unified work guided by the dynamic role of the social work profession in addressing the urgent need of addressing psychosocial healthcare disparities.

### **Discussion**

“The good we secure for ourselves is precarious and uncertain until it is secured for all of us and incorporated into our common life.” – Jane Addams

Social work has a long standing historical relationship with healthcare. Beginning with the settlement house movement in the early 1900s, social work has carried the mission of improving lives of society's marginalized and oppressed. Certainly, the profession has aimed to promote improved health and wellbeing of systems at micro, mezzo, and macro levels. This dissertation discusses the need for social workers to serve as leaders to improve cancer care systems and reduce health disparities of rural residents. Cancer is at the forefront of healthcare discussion as it is the second leading cause of death for all people in the U.S., is the leading cause of death for Indigenous people in the U.S. (CDC, n.d.). Wellness and community oriented approaches to health offered by rural Indigenous communities in the U.S. are often overlooked

by urban or academic cancer centers, leading to delays and declines in cancer treatment and a lack of culturally congruent care (Doorenbos, et al., 2016).

Rural Indigenous communities offer strengths that are often overlooked in the context of cancer care. A deficits perspective is often used when referencing health disparities. Social workers, equipped with the strengths perspective, are well suited as leaders in developing relationships with systems needed to provide and ensure culturally responsive cancer care services. Social workers may also interact with and understand environmental barriers that serve as health determinants in order to craft effective community-oriented solutions. Social work must be integrated in rural oncology practices, particularly for Indigenous communities. With the worst cancer mortality rates in the nation, mobilization of strengths and an understanding of environmental barriers (including the role of historical trauma) is a start to the provision of culturally responsive cancer care.

In the exploratory research of cancer patients in rural Illinois, results indicated several recurrent themes. Overarching themes included: Overall Experience, Distress, Social Work, and Other (environmental pollutants and rural context). Several exemplar quotes were selected to highlight each theme and subtheme. A highlighted example is that participants spoke of the importance of the oncology social worker's knowledge of the rural context and community. Participants also spoke of important attributes of an oncology social worker as warm, friendly, and compassionate. Many participants identified hardships to experiencing cancer in the rural environment, especially related to travelling long distances for treatment and financial hardships. The essence of many of the responses included the importance of community and the strong social support networks found in various systems of the rural context.

Innovative medical technologies, such as genomic sequencing, have transformed cancer treatment. In order to keep up with treatment interventions, healthcare teams must reconstruct patient care. Social work as a profession is a mandated component of many healthcare teams, such as cancer care, palliative care, and hospice. Social work's ethical value of social justice may benefit healthcare systems in complex bioethical predicaments related to novel genomic therapies. As genetic counselors are often in the role of psychotherapist and social worker on the genetic team, social work must keep pace with other professions interfacing with genomic therapies.

### **Implications for Social Work Education**

Browne, et al. (2017) discusses that as nearly half of all social workers are employed in health settings, social work students would benefit from infusing health related topics into the Council on Social Work Education's (CSWE) Educational Policies and Accreditation Standards (EPAS) (p. 229). As social work leaders have aimed to improve the profession's role in healthcare delivery, improvements in social work education may include healthcare leadership and health policy specific competencies in the generalist curriculum (Browne, et al., 2017). Given social work's mission to serve as change agents to improve wellbeing, infusing health related practice, research, and policy knowledge across the social work curriculum would align with and benefit social workers in nearly every practice context.

The Affordable Care Act in 2010 fundamentally shifted the U.S.'s healthcare delivery system to an outcomes-oriented, patient-centered, and preventative approach. This shift, along with healthcare initiatives addressing healthcare disparities and innovations, such as precision medicine, provides an opportunity for social workers to enhance healthcare systems by integrating our ethics and values related to the person-in-environment framework and social

justice in health policy (Browne, et al., 2017). Social work is fundamentally positioned to lead dynamic shifts in healthcare to examine social determinants of health related outcomes and support health related equity. Through educating social workers to increase competency in health practice, social workers would gain needed leadership skills to improve national health outcomes and reduce health disparities of marginalized groups.

Social work education may also include aspects of culturally responsive healthcare at all system levels throughout the curriculum in order to elevate the profession to provide leadership within cancer care systems. Cancer care providers are increasingly recognizing the value of cultural awareness and diversity training. As healthcare social work becomes a dominant branch of the social work profession, the interfacing of social work values and ethics with host medical settings must be incorporated in educational systems and policies. Social work education must rise to the challenge of graduating tomorrow's leaders that will increase the health of our nation.

### **Implications for Future Research**

Research implications of this dissertation center around increasing the understanding the experiences of people with cancer in rural settings. Although awareness of the relationship between health related distress and health outcomes has gained much attention in recent years, psychosocial experiences of cancer patients in rural communities is not well documented. As found in Smith, et al., (2011) rural residents with cancer experience higher rates of distress than their urban counterparts. Further research is also needed to assess for appropriate distress instruments and assessment tools for use in the rural environment. Although numerous barriers found in the rural context have been discussed, additional evaluation of strengths in the rural environment and how strengths may be mobilized to reduce health disparities.

Social work scholars, using ecological theory, are needed to engage in research involving intersections of human experiences and identities in order to increase environmental responsive care delivery frameworks in diverse settings. This dissertation discusses the barriers of engaging Indigenous people in healthcare research. Additional research in the area of including ethically sound research methodologies and study designs in psychosocial cancer is needed. Prior to exploratory studies with rural Indigenous people experiencing cancer, it may be necessary to understand the historical trauma associated with healthcare research and the research context.

Social work as a profession is well suited to provide leadership in stakeholder relationship building and environmental responsiveness when discerning and selecting responsive study designs. Although this dissertation focuses on the rural context, social workers are equipped with skills necessary to support and interact with other unique contexts to create intersectional environmental responsiveness. Social work scholars must advocate for the profession to be recognized by interdisciplinary health care researchers as leaders in environmentally responsive practice and research. Cancer disparities in the U.S. likely result from complex systemic dysfunction. Understanding the barriers and strengths associated with health outcomes requires innovative research methodologies and designs.

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Product One

Psychosocial Oncology Disparities:

Treating the Whole Person in Rural Indigenous Communities

J. Sky Niesen

Saint Catherine University/ University of Saint Thomas

Author Note

The author would like to acknowledge Stephanie Bradford and Dr. Catherine Marrs-Fuschel for helpful comments on previous versions of the manuscript. Correspondence should be addressed to the author at St. Catherine University and the University of St. Thomas, 2004 Randolph Avenue, St. Paul, MN, 55105. E-mail: [smit0603@stthomas.edu](mailto:smit0603@stthomas.edu)

### Abstract

In recent years, psychosocial services have been viewed as paramount in treating cancer, yet disparities exist in psychosocial services for rural cancer patients. Using ecological theory, cancer care focuses on more than medical intervention, favoring treatment of the “whole” person. For Indigenous people experiencing cancer, responsive psychosocial interventions and practice frameworks are needed to address health-related distress. Using the intersection of diversity and environment, this conceptual paper argues that social workers, given educational experiences and practice frameworks, are essential culturally-responsive providers of psychosocial oncology services for cancer centers serving rural Indigenous people. Social workers must be utilized and mobilized as health care leaders in order to improve quality of life by advocating for culturally responsive services for people confronting cancer. Social workers have knowledge and skills to be front-line providers, service mobilizers, and program developers of culturally-responsive psychosocial oncology services.

*Keywords:* psychosocial oncology, health disparities, rural healthcare, health-related distress

### Psychosocial Oncology Disparities:

#### Treating the Whole Person in Rural Indigenous Communities

A medical diagnosis is often a traumatic experience for an individual, impacting an individual's sense of homeostasis (IOM, 2008). Psychosocial functioning of people with cancer is dependent on access to proper medical care. In the rural context, individuals are often unable to access adequate psychosocial care in order to treat symptoms of distress during a medical crisis. For rural Indigenous people who reside in what is now known as the United States (U.S.), culturally responsive psychosocial cancer care may support effective communication among family members and biomedical teams. Although some knowledge exists in regard to biomedical services for rural Indigenous cancer patients, scant literature exists in the topic of elevating social work as essential in providing needed psychosocial oncology services. Health-related distress in cancer patients is influenced by cultural and environmental factors. Social workers have knowledge and competence in the area of working with these factors in levels of systems in order to understand individuals and families.

### **Background**

Indigenous people in what is now known as the United States often receive medical care through the Indian Health Services program. This program, under the Department of Health and Human Services, maintains a goal to provide culturally responsive comprehensive health services to Indigenous people. (Indian Health Services, n.d.) Indian Health Services includes 12 regional offices and various medical clinics. For oncology care, Indian Health Services interfaces with specialty providers who maintain contracts to provide medical care with Indian Health Services. This interface may include travel arrangement and expenses (particularly for rural residents) as well as cancer care medical coverage. This paper argues that social workers, with

specialized knowledge of culturally responsive practice frameworks, are integral in cancer care with rural indigenous populations. Social work educational policies, ethical standards, and practice theoretical frameworks allows social work to be well-positioned as a profession in providing and facilitating psychosocial oncology services to indigenous communities.

Culture is often a restraining force, or barrier, to meeting healthcare needs in rural areas. Although 15% of minorities live in rural areas, minorities comprise over 30% of those living in rural poverty (Ginsberg, 2011, p. 352). Additionally, using the lens of minority status, greater disparities exist in healthcare even when other variables are comparable (Centers for Disease Control, n.d.). Racial and ethnic minorities not only experience higher rates of cancer, but high rates of mortality due to surgeries and advanced diagnostic stage. Warne and Lajimodiere (2015) state that Indigenous people experience the “worst health disparities in the nation,” (p.567) with significant cancer mortality rates. In fact, Indigenous people living in what is now known as the U.S. have the highest mortality rates from cancer than other racial groups (Itty, Hodge, & Martinez, 2014).

### **Healthcare Delivery**

Rural Indigenous people live in geographically diverse areas in the U.S., often in remote and isolated areas and face elevated rates of depression, suicide, and chemical dependency (U.S. Dept. of Health and Human Services, 2010). As the result of geographical isolation, medical care in rural Native American communities is often provided by general practitioners, rather than specialists, serving as an additional barrier in accessing psychosocial oncology services (Ginsberg, 2011, p. 251). Social workers, using a multi-dimensional ecological framework, are well-versed in incorporating culture as an essential component of practice. Medical host settings for social workers often struggle with cultural responsiveness (Doorenbos, Morris, Haozous,

Harris, & Flum, 2016) which highlights the importance of including social workers in addition to biomedical providers in cancer care.

Haozous, Knobf, and Brant (2011) discuss the unique ethical challenges of studying cancer care involving patients with Tribal affiliations and interfacing with Indian Health Services. In this context, approval from a Tribal Council is often necessary, with barriers in place associated with historical unethical conduct of researchers, which makes sampling potentially challenging (Haozous et al., 2011). Yet, culturally sensitive and appropriate psychosocial research may lead to improved care, offering distress relief for Indigenous cancer patients. Social work researchers may be used to better engage and understand tribal and community systems to support appropriate research designs and methodologies in order to increase awareness of challenges faced by Indigenous cancer patients.

### **Social Work Education**

Social work Educational Policies and Accreditation Standards (EPAS) require that social work students develop competency in diversity and difference in practice with individuals, families, and communities. Throughout the social work curriculum, the intersection of diversity and other factors are understood as important factors in the human experience. Ecological theory related to the nonlinear relationship of the person and the environment is a unique framework of practice that is integral to the social work field. As the lack of culturally responsive biomedical care in oncology may reduce patients' understanding of disease, impact quality of life, and impede psychosocial well-being, social workers are essential cancer care team members in order to understand strengths, systemic influences, and resources in rural Indigenous communities. Certainly, diverse rural contexts, with increased and unique psychosocial and medical concerns, require psychosocial treatment models that may vary from the psychosocial standards outlined

by the IOM (2008) Report. As the result of social work's specialized training in understanding diversity and the person-in-environment perspective, social workers can be leaders in crafting culturally appropriate screenings, interventions, and treatment models in cancer care.

### **Conceptual Frameworks**

#### **Intersectionality**

Intersectionality, or the overlapping and intersecting of identity and culture, is an important concept to understanding in the relationship of rurality and culture. As psychosocial cancer care is uniquely conceptualized in rural areas, the additional lens of Indigenous culture is necessary in order to understand and evaluate the intersection and relationships of environmental systems. Social work, particularly in rural areas, considers the impact and interconnectedness of terrain, geography, weather, location, cultural and economic factors on individual and family systems. Additionally, the strengths of rural populations are integrated by rural social workers in mobilization of scant resources (Mackie et al., 2016). This culturally-responsive framework for practice is integral in considering the "whole" person in cancer care with rural Indigenous people. Social workers, using a framework of intersectionality theory, would provide an essential voice as members of an oncology care team when treating cancer in rural indigenous communities.

#### **Strengths Perspective**

In the rural context, especially in regard to rural indigenous populations, much research and literature focuses on a deficits perspective (Mackie, Zammitt, & Alvarez, 2016). In social work practice and research, the strengths perspective is commonly used in order to assist client systems in recognizing and mobilizing resources already in place. This paper includes strengths as an important component of examining psychosocial oncology in rural Indigenous

communities. Although much research exists looking at healthcare disparities and the lack of resources in the rural context, conceptually, this paper is guided by the strengths perspective. When systems are viewed as more than their deficits, resources already in place may be mobilized in order to grow and develop necessary areas in order to benefit systems.

Rural environments often involve isolation of individuals, and so strengths are important to consider in terms of the dependence upon talents of people and services (Mackie, et al., 2016). Indigenous people, in particular, have demonstrated incredible strength and resilience in adapting to discrimination, cultural genocide, and changing environmental influence. These strengths and traditions are essential in linking cancer patients to appropriate resources. Traditional healing paradigms are often sidelined and minimized in biomedical care yet may provide important resources for distress management (Itty et al., 2014). Social work practice uses ecological theory in forming a strengths perspective essential for working with diverse rural populations. A component of culturally responsive practice is identifying cultural strengths in micro, mezzo, and macro systems. Indigenous knowledge is an example of macro-level incorporation of cultural responsiveness, especially as it relates to Westernized biomedical protocols. Social workers, using the strengths perspective, may facilitate communication and brokering among various macro-level paradigms in cancer care, particularly among tribal members, Indian Health Services, and medical providers.

### **Indigenous Methodologies**

A key component to research and practice with Indigenous people is the epistemological shift from Western positivist paradigms to culturally responsive paradigms, which includes indigenous knowledge. Recognizing the historical marginalization and trauma of Indigenous people, ecological theory provides a culturally responsive framework that includes components

of a non-linear relationship of the mind, body, spirit, natural world, and community. (Haozous, Doorenbos, & Stoner, 2016). Research and practice with indigenous populations includes a holistic framework that is, “well-ness oriented, community-based, focused on indigenous knowledge, and designed for bidirectional learning” (Haozous et al., 2016).

## **Literature Review**

### **Rural Context**

**Barriers.** Barriers exist in cancer care for people living in the rural context, perhaps most notable is the transportation barriers people face in order to access cancer care and treatment. For indigenous people who may access primary care at Indian Health Services locations, travel for specialized care may take people out of their communities for length treatment stays in metropolitan areas at large treatment centers. (Humble & Slater, 2011) These treatment centers may include additional layers of psychosocial and physical barriers, including lack of cultural responsive frameworks, limited housing options, lack of community resources (Humble & Slater, 2011, p. 645). Additionally, rural areas often lack psychosocial care necessary to support patients and family members while they access care and endure cancer treatments. These barriers increase risk of social, geographical, and emotional isolation and subsequent psychosocial issues for rural Indigenous people (Thewes, Butow, & Stuart-Harris, 2009).

Hale, Cotton, Drentea, and Golder (2010) reveal barriers in rural areas that expand on socioeconomic macro-system concerns. For one, rural areas experience “brain drain” in which educated professionals leave family systems for opportunities provided by urban and suburban environments. This not only leads to impoverished resources in rural areas, but isolation of individuals as well (Hale et al., 2010). In terms of education, rural residents have a greater chance of dropping out of school as well as lower math achievement than urban/ suburban

residents. These factors may impact understand of health-related conditions and treatments (Hale et al., 2010).

In psychosocial cancer care, Andrykowski, Steffens, Bush, and Tucker (2014) identifies the above barriers and others in terms of mental health (MH) services for cancer survivors. This study discusses several rural-specific barriers impacting access to and acceptance of psychological services. These barriers include lower education and income, greater family responsibilities, reduced internet access, stigma associated with acceptance of psychological services, reduced access to health information, limited access to other cancer survivors, and greater stress and fear overall (Andrykowski et al., 2014, p. 428). In minority rural communities, these socioeconomic, healthcare, and environmental disparities are even greater than nonminority rural communities.

Itty et al., (2014) identify barriers specific to Indigenous cancer patients living in rural/reservation. As physicians and treatments are sparse in rural areas, misdiagnosis and late diagnosis of cancer is often found in this population. Also, physical barriers such as treatment distance and lack of transportation was identified as complications of cancer care in rural areas. Supportive cancer services, such patient navigators or social workers, may be limited in access. Geographic and social isolation was also noted by Indigenous rural cancer patients. Access to specialized cancer care may be financially exhausting or unobtainable given rural-specific barriers. For example, gas and hotel expenses for travel to an urban/ academic medical center is often an overwhelming financial barrier (Itty et al., 2014).

**Protective factors.** Biomedical providers must mobilize community and family strengths as a way to assist patients in coping with cancer. As a protective factor, rural indigenous communities often incorporate healers in that facilitate connections among family and

community systems during an illness. This healing, or traditional medicine, is often considered just as essential as chemotherapy and radiation for Indigenous cancer patients. Patients may feel as though these healing methods are not taken seriously by treatment facilities. Cultural strengths found in healing traditions may decrease distress levels in Indigenous people receiving cancer treatment. These traditional healers prevalent in rural/ reservation settings and may be used as a way to provide balance during cancer treatments (Itty et al., 2014).

**Rural cultural constructs.** Rural families are often socially constructed in the relationship with the land. This relationship with the land is not only found in farming families, but in an overall awareness and emphasis on weather and other environmental influences on agriculture. Sociological concepts used to better understand rural culture involve the terms “Gemeinschaft” and “Gesellschaft.” Gemeinschaft refers to the importance of the relationship of local and regional communities on family systems. Gesellschaft is the importance of the influence of the larger society. In rural areas, the concept of Gemeinschaft is important in understanding familial influences. Since individuals and families are often isolated, the impact of local communities is far greater than broader influences. Although television and internet may provide exposure connecting rural individuals and families to broader society, this exposure may seem far away and abstract (Mackie et al., 2016, p. 121). For the purposes of this paper, the intersection of rural and Native culture provides a unique challenge in cancer care that increases the need for the influence of oncology social workers practicing in this context.

### **Culturally Responsive Care**

Practice with Indigenous cancer patients involves the concept of trust, especially given the historical traumas and cultural genocide associated with this population. Haozous et al., (2016) explores the concept of mistrust of clinicians as a lack of effort on the part of clinicians in

cancer care to understand Indigenous culture. Results of this study indicate the need for even very basic understanding of Indigenous culture as paramount in establishing trust and improving communication between clinicians and patients. For example, Haozous et al., (2015) discuss the importance of community in indigenous culture. Hospitals may limit visitors to small groups or immediate family, thus creating a sense that the community is “shut out” from patient care. This impacts trust of providers and an increased sense of patient isolation (Haozous et al., 2016). Doorenbos et al., (2016) discuss the need for oncology surgeons to gain cultural competence when practicing with Indigenous people. Findings of Doorenbos et al., (2016) indicate surgeons place a high value on cultural competence when working with diverse patients. Although the surgeons in the study indicated a motivation to increase cultural sensitivity, the authors argue the need for a comprehensive model in cancer care for “improved, theory-based interventions to achieve the goal of genuinely culturally competent care.” (Doorenbos et al., 2016, p. 6)

Itty and colleagues (2014) identify culture as a significant role in managing cancer-related symptoms in rural Indigenous communities. Indigenous people living in rural areas view providers' understanding of Indigenous culture as lacking. This poor communication and lack of cultural responsiveness from providers contributed to a misunderstanding of course of treatments, treatment options, and treatment side effects. Additionally, the patients in the study reported feeling that questions regarding treatment decisions were often left unanswered by the medical team, who used medical terminology rather than culturally responsive communication (Itty et al., 2014). Oncology social work may be used in facilitating and supporting cultural responsive communication between patients and biomedical providers.

### **Psychosocial Distress**

Haozous and Knobf (2013) discuss distress in terms of “emotional pain” experienced by Indigenous people. This emotional pain mirrors the definition of distress as it includes, “sadness, depression, existential pain, and frustration or anger with cancer, its treatment, and the overall cancer journey” (p. 1054). In the context of systems, emotional pain is exacerbated by family obligations and the importance of community. Participants in the study reported feeling isolated from family members by accepting medical treatments. In addition, fatigue and pain related to cancer treatment kept participants from participating in ceremonial and spiritual practices. Overall, the side effects of cancer treatments involve all of the above components. Haozous and Knobf (2013) describe participant experiences with coping with psychosocial distress. For example, one participant describes the difficulty of separating physical, emotional, and spiritual pain by stating, “sometimes you can’t tell the difference where you’re actually hurting” (p. 1055). Using ecological theory, an essential component of culturally responsive cancer care with indigenous communities is including historical trauma as an aspect of psychosocial distress.

Hodge, Itty, Cadogan, Martinez, and Pham (2016) examined cancer-related fatigue (CRF) in Indigenous cancer survivors as a possible quality of life concern in this population as it was explained by the study participants as being “out of balance” (p. 1237). CRF is explained as part of a cultural construct impacting quality of life, as equilibrium, balance, and harmony are integral concepts in Indigenous cultures. Although CRF may be the result of medical treatment, study participants feared being viewed as lazy or out of balance – essentially at fault for this common side effect of treatment. Additionally, participants described CRF as a separate disease from the cancer and the result of chemotherapy, or as participants described, poisoning ones’ body. Overall, Hodge et al., (2016) discussed the importance of culturally responsive interventions to CRF. Although the study did not directly cite health-care related distress, CRF

closely reflects an important element of distress in terms of an experience which impacts the ability to cope with cancer.

### **Web-based Psychosocial Services**

Shepherd et al., (2006) examined the impact of a web-based brief cognitive-behavioral treatment (CBT) support group intervention for breast cancer patients. Results of the study indicated a significant improvement of quality of life, distress, and anxiety. The authors argue that a web-based model of psychosocial service delivery may serve as a viable option for patients living in remote, rural areas (Shepherd et al., 2006). Doorenbos et al., (2010) evaluated a web-based psychoeducational support group design specifically for Indigenous cancer survivors. The groups were facilitated by nurses or social workers and followed a curriculum focusing on educational and support needs, including how to discuss a cancer diagnosis with family members. Groups were held at various sites with videoconferencing equipment (Doorenbos et al., 2010). Although web-based support services have shown effectiveness in delivering psychosocial services, a larger problem exists in terms of patient access of proper technology for these services. In the rural context, a disparity exists in internet use when compared to urban areas. This includes access to high-speed internet services as well as access to technology (Hale et al., 2010).

### **Historical Trauma and Healthcare**

Cancer care focusing on rural indigenous populations must address the issue of historical trauma related to biological, emotional, developmental, spiritual, and systemic well-being. Warne and Lajimodiere (2015) discuss the historical relationship of Indigenous people and Western medicine from a lens of colonization. Although the rural context may provide an environmental rationale for healthcare disparities of Indigenous Americans, the inter-

generational basis for disparities must also be examined. A model for conceptualizing chronic disease brings gestational, childhood, and adulthood experiences into account for understanding and treating disease. Using this model, distress in cancer care evokes a historical trauma response where loss must be addressed and validated from a historical lens across micro, mezzo, and macro systems. The traumatic experience of cancer brings about feelings of loss of connection with ancestors and culture resulting from historic genocide (Warne & Lajimodiere, 2015). Using the ecological lens coupled with indigenous culture, the relationship of past, present, and future should become integrated in treating the whole person.

### **Oncology Social Work**

The field of oncology social work involves providing psychosocial services for cancer patients and their families. The provision of psychosocial services improves quality of life and health outcomes in regard to cancer care. Oncology social workers follow a framework of identifying and screening patients in need of psychosocial services, assessing and developing plans that link patients to resource and services, coordinating and brokering services between patients and medical providers, and monitoring and evaluating effectiveness of services provided. This last step also includes adapting services for patients as needed. Social workers in cancer care also consider how a cancer diagnosis impacts interrelated environmental systems, such as families and communities (Ginsberg, 2011, p. 388). This framework for practice includes the person-in-environment perspective. In rural areas, particularly with minority populations, oncology social work is elevated in importance in terms of connecting isolated individuals and families to resources.

Social work may provide an important role in culturally responsive cancer care. Rural social workers, specifically, have advanced knowledge of navigating rural ethics and systems,

especially in managing dual relationships and community contexts (Ginsberg, 2011). In addition, social workers mobilize resources in order to draw on client strengths. Many Native American communities have tremendous resiliency, which includes a strong sense of family and community. Effective partnerships that focus on community strengths may increase collaboration among cancer care clinicians and indigenous communities in order to create culturally responsive constructs (Haozous & Neher, 2015). Dr. Judith Kaur, an oncology researcher focusing on Native Health states that, “tribes are taking ownership of their health care and are interested in working together in partnerships” (Twombly, 2008, p. 295). For these reasons, social workers are important in treating the “whole” person in the context of cancer care in rural indigenous communities. Cancer does not simply involve medical treatment, but treatment of the psychosocial, cultural, environmental, and spiritual aspects of a patient (IOM, 2008).

## **Discussion**

### **Social Work Professional Standards**

Social work education in the United States is monitored by the Council on Social Work Education's (CSWE) Educational Policies and Accreditation Standards (EPAS, 2015) and includes nine interrelated competencies with corresponding practice behaviors that ensure the development of competent, ethical, and dynamic social work professionals. Of the nine competencies, the second competency strongly relates to the point of this paper: that social workers are adept culturally-responsive professionals and must be included in cancer care teams that serve rural Indigenous patients in order to increase quality of life, facilitate culturally appropriate communication with biomedical providers, honor cultural heritage, and decrease health-related distress. Competency 2 emphasizes that social workers not only understand diversity and difference, but also how the intersection of diverse constructs shape the human

experience. Furthermore, social work education includes an understanding of oppression, discrimination, marginalization, and power (CSWE, 2015). For Indigenous people, an understanding of historic oppression is essential in cancer care. Social workers have the practice behaviors and skills that address complex constructs related to historic discrimination.

The National Association of Social Workers (NASW) has a Code of Ethics that includes ethical obligations to clients. One example of social work's emphasis on culturally responsive practice is Ethical Responsibility 1.06: Cultural Competence and Social Diversity. This responsibility includes understanding the role of culture, recognizing cultural strengths, demonstrating cultural competence, and obtaining education related to diversity. One of the social work profession's core values is the "importance of human relationships" (NASW, 1999). This professional emphasis again highlights the essential use of social workers as providers of psychosocial cancer care for rural indigenous communities. Racial and ethnic minorities may even decline cancer treatment based on a perceived lack of cultural responsiveness from biomedical providers (Doorenbos et al., 2016). Social workers, in this sense, may provide a life-saving role in terms of building and facilitating cultural responsiveness in cancer care. In order to fully reduce healthcare disparities, biomedical systems must fully synthesize the profession of social work in micro, mezzo, and macro systems of care. This may involve including social workers in medical education systems, in leadership roles in healthcare delivery systems, and engaging patients and families within clinics and hospitals.

### **Cultural Responsiveness in Psychosocial Oncology**

In order for social workers to provide essential culturally responsive psychosocial oncology services, the formal services that address psychosocial health needs must contain an ecological framework of practice delivery. The IOM Report (2008) outlines formal psychosocial

services that respond to psychosocial needs. These formal services encompass interventions including education about disease to increase understanding of treatment and treatment options, support groups, psychotherapy, self-care promotion, monitoring of health behaviors, accessing resources such as transportation, support of the family and caregivers, support for life disruptions, financial planning, and health and disability insurance support (p. 82). This paper outlines the need for nearly all of these services in rural indigenous communities. Social workers, with culturally-responsive educational backgrounds and ethical responsibilities that include understanding diversity, are paramount to providing these services in cancer care teams. Biomedical providers, often lacking in understanding of cultural constructs, require social workers to enhance well-being and quality of life of diverse patients.

#### **Conclusion: The Whole Person**

Biomedicine has created remarkable advances in cancer care. Cancer, which was once considered a death sentence, is now often a treatable disease. However, cancer technology is insufficient to manage the impact of disease on a patient's psychological, social, and environmental systems. Ignoring psychosocial barriers impedes the patient's ability to manage cancer treatments and negatively impacts health-related outcomes. Given the remarkably high cancer-related mortality of Indigenous people, improved psychosocial care is needed. Using the intersection of rurality and diversity, strengths and barriers must be assessed and addressed by social workers in order to optimize biomedical care. In reviewing available research, there is scant information including social workers as providers of psychosocial services for indigenous people. Although biomedical providers may receive some education related to diversity, the ecological, person-in-environment framework may not be included. Social workers, given our

required culturally responsive educational standards and ethical responsibilities, combined with our non-linear ecological orientation, are urgently needed as leaders in cancer care systems.

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Product Two

*People Out Here Really Care:*

Exploring Cancer Experiences in the Rural Environment

J. Sky Niesen

Saint Catherine's University/ University of Saint Thomas

Author Note

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Correspondence should be addressed to the author at Minnesota State University, Mankato; Mankato, Minnesota 56001; sky.niesen-smith@mnsu.edu

## Product Two

### Abstract

This qualitative study explores the cancer-related psychosocial experiences of 18 cancer patients in Lee County, Illinois. Ecological theory was used as a theoretical framework for this study in terms of the relational aspects of rural barriers and protective factors, impact of the environment, and the psychosocial realm of patient care. Rural areas in the United States contain unique contextual factors that interact with psychosocial experiences of a cancer diagnosis. Using content analysis of transcribed patient interviews, the author identified common themes in overall experiences with cancer, distress, social work roles, and other items specific to the rural environment. Participants discussed various subthemes, examples including the role of social support, helpful attributes of an oncology social worker, transportation concerns, and environmental pollutants related to the rural context. Implications for research and psychosocial and medical practice frameworks are discussed.

*Keywords:* rural cancer, psychosocial oncology, distress, oncology social work

### Introduction

Every year, nearly 1.4 million Americans are diagnosed with cancer. Although medical care has improved to focus on early detection and an improvement of long-term survival, the experience of cancer often carries significant consequences to one's health and sense of well-being (Institute of Medicine [IOM], 2008). The topic of this research involves the psychosocial realm of cancer care in the rural context. The importance of psychosocial cancer care was brought to light by the Institute of Medicine (IOM) Report, "Cancer Care for the Whole Patient" (IOM,2008). Psychosocial cancer-related distress, viewed as the "6<sup>th</sup> Vital Sign" in the IOM (2008) report, is vital to understanding the cancer patient as a "whole person." The IOM Report (2008) describes the importance for screening, prevention and treatment of distress and other psychosocial problems, as caused and exacerbated by cancer and cancer treatment, impacting patient suffering, overall quality of life, and even disease outcomes (IOM, 2008).

Rural areas in the United States tend to evoke visions of a healthy, peaceful life in the country (Ginsberg, 2011, p. 347). However, healthcare in rural areas contradicts this vision. The Agency on Healthcare Research and Quality cites that nearly one in three adults in rural areas have poor to fair health. Additionally, nearly half of rural adults have at least one chronic illness (Machlin & Soni, 2013). Certainly, in rural areas, with disparities in overall medical care combined with physical and social isolation, psychosocial oncology is an area in need of attention and research (Galambos, 2005). Regarding cancer specifically, in rural areas there are higher rates overall, as well as mortality rates when compared to urban areas (Ginsberg, 2011, p. 386). Despite greater healthcare needs, only 10% of physicians practice in rural areas (Ginsberg, 2011, p. 386). For the purpose of this research, "rural" is defined by the U.S. Health Resource and Service Administration (HRSA) Rural Grants Eligibility Analyzer website.

For the purpose of this study, the IOM (2008) definitions of distress and psychosocial services are used as a framework. Distress is characterized by unpleasant experiences that serve as barriers to coping with cancer treatment. Distress can be considered a continuum from common feelings associated with cancer treatment to disabling symptoms of depression, anxiety, and/or panic (IOM, 2008). Psychosocial services support patients and families in managing the psychological, social, and behavioral aspects of cancer in order to improve health-related outcomes (IOM, 2008). Literature in the area of rural psychosocial distress suggests higher levels of distress in rural areas in the United States than in urban/academic centers (Smith, Limesand, & Alikhan, 2011). With this knowledge, this study used a qualitative exploratory design, interviewing cancer patients in rural Illinois, with the hope of further understanding the distress experiences and available resources of rural cancer patients.

### **Literature Review**

#### **Cancer Treatment in Rural Communities**

**Barriers.** There are many unique barriers that exist for rural cancer patients. Humble and Slater (2011) discussed several barriers associated with accessing appropriate cancer treatment. One of the most notable barriers in the rural context is transportation, as rural patients often have to travel long distances for both medical and psychosocial services related to cancer treatment (Humble & Slater, 2011). Additional rural-specific barriers include a lack of culturally responsiveness in providers, patient access to psychosocial services, and overall community resources due to poor socioeconomic conditions (Humble & Slater, 2011). Further, rural areas often lack specialty care and professional training in order to meet psychosocial oncology needs (Thewes, Butow, & Stuart-Harris, 2009).

Hale, Cotton, Drentea, and Golder (2010) discuss barriers in the rural environment that relate to socioeconomic disparity. Rural areas experience a workforce shortage for professional positions, particularly in healthcare. This leads to economic impoverishment, isolation, and quality concerns in healthcare and service settings. (Hale et al., 2010). Rural areas often experience educational disparities in terms of high school graduation rates and lower math and reading test scores in educational settings. All of these factors interrelate and impact patient education and understanding of disease as well as quality of healthcare (Hale et al., 2010).

Psychosocial care for cancer patients is also suffering in rural areas. Andrykowski, Steffens, Bush, and Tucker (2014), identify socioeconomic and educational barriers in the rural context that impact mental health (MH) services for rural cancer patients. Access to MH services, particularly from MH provider workforce shortages in the rural context, serves as a significant barrier to receiving needed psychosocial support during a cancer diagnosis. Other environmental barriers include higher rates of poverty, family burden of caring for a loved one with cancer, reduced access to technology and high speed internet, and stigma associated with MH support. These environmental barriers lead to greater distress experiences of cancer patients who reside in rural areas (Andrykowski et al., 2014, p. 428).

**Protective factors.** Strengths, or protective factors, in the rural context largely include family and community support systems. Ginsberg (2011) describes the hidden “treasures” of rural life that can be “hidden in plain view” (p.33). These include strong community coalitions, important cultural influences, and rich historical connections. In addition, support networks in rural communities tend to have closely knit characteristics that provide strong support. However, this strength may also serve as a barrier to accessing psychosocial services, as noted in a study by Bates (2011). Because of the tightly woven nature of some rural communities, cancer patients

may have concerns about seeking psychosocial services due to stigma and a lack of confidentiality. Bates (2011) states, "Earlier studies suggest that in some small, rural communities, social norms cast doubt on individuals who access help in the form of support groups, psychologists, spiritual counselors, or psychotropic medications" (Bates, 2011). So, these same strengths of rural communities may also serve as barriers in terms of accessing and accepting psychosocial services.

### **Psychosocial Oncology Services in Rural Areas**

**Social work services.** Social workers are essential psychosocial oncology providers in terms of social work's incorporation of ecosystems theory and the person-in-environment framework. Social workers are used to mobilize resources that address restraining forces, or barriers to unmet need. Biomedicine sounds the call for increased attention to the "whole person." This concept of the "whole person" certainly resembles values of the social works' person-in-environment perspective in viewing an individual within the context of interrelated systems (IOM, 2008). In the rural context, the "whole person" involves the unique challenges of rural healthcare, such as access to physicians, transportation, and higher health needs (Ginsberg, 2011). As such, the service of oncology social work is an important component in addressing cancer-related distress in the rural context.

**Patient navigation.** Patient navigation, often delivered by either a trained nurse or social worker, refers to the professional guidance and support of a cancer patient. Swanson and Koch (2010) describe the Oncology Nurse Navigator (ONN) as a professional who "collaborates with all members of a patient's medical team to ensure that information about the diagnosis and plan of care is understood by all team members, including doctors, nurses, ancillary staff, and especially the patient and his or her family members". Interestingly, in assessment distress levels

of patients, Swanson and Koch (2010) found a significant decrease in patient distress levels with ONN in-person services when the patients were from rural areas. This same study found no change in distress levels for urban/academic centers using this same intervention (Swanson & Koch, 2010). This study supports the positive impact of an in-person professional for distress management.

**Cancer wellness.** Cancer-related distress often has a negative impact on the course of cancer treatment and quality of life (Strauss & Northcut, 2014). Cancer wellness programs promote patient health and self-care with the goal of managing health-related distress and support for patients to gain a sense of control in the midst of a cancer diagnosis. Wellness programs emphasize physical fitness, nutrition, spiritual growth, psychosocial coping, and finding meaning. Wellness programs, also referred to as complementary or integrative therapies, involve a mind-body-spirit connection focusing on many aspects of the cancer patient as a “whole” person (Vachon, 2008). Further, mindfulness practices taught in cancer wellness programs may assist patients in coping with anxiety associated with the many intense decisions involved in cancer treatment (Strauss & Northcut, 2014).

A study by Smith et al. (2011) examined the acceptance of off-site (not hospital affiliated) wellness services, as well as distress levels of patients in rural Illinois. This study also supported the results of above studies in that rural cancer patients experience higher levels of distress than their urban counterparts. This study assessed acceptance of off-site cancer wellness services, including support groups, yoga, exercise, and massage. Of the patients who experienced clinical levels of psychosocial distress, only about 10 percent accepted these psychosocial services (Smith et al., 2011). Reasons identified by patients as barriers to accepting psychosocial care included transportation, time constraints, and a belief that psychosocial services are

unnecessary (Smith et al., 2011). Although wellness services are effective in distress management for cancer patients, wellness programs may require rural-specific and responsive recruitment strategies and interventions.

### **Summary**

In the review of available literature, numerous articles discuss the barriers in the rural context related to cancer care. Studies that measure distress and quality of life in rural areas indicate effectiveness of psychosocial interventions. However, a gap exists in the literature examining the role of a social worker in providing and coordinating psychosocial interventions, as most rural social workers take on a generalist or advanced-generalist scope of practice, rather than a specialized oncology role (Ginsberg, 2011). Also, available literature often focuses on disease-specific samples, especially breast cancer, which leaves room for research focusing on a variety of cancer types. Some literature exists involving qualitative data from patients involved in cancer care, yet the scant overall research available on rural psychosocial cancer care is focused on quantitative surveys alone.

## **Methods**

### **Qualitative Design**

While several mono-method studies exist in rural psychosocial oncology research, a gap exists in terms of linking environmental and contextual barriers to patient experiences and psychosocial distress levels. This study uses an exploratory qualitative design to address this gap in the literature and enhance understanding of cancer-related experiences in the rural environment. Ecological theory guided the semi-structured interview questions to explore the environmental, social, emotional, and behavioral experiences of cancer patients in rural Illinois. Ecological theory involves the importance of psychosocial aspects of an individual–biological

factors, cognitive factors, and behavioral characteristics. This framework is important when viewing the person with cancer as a “whole” patient: merging psychosocial care with biomedicine for an integrated understanding of the cancer experience (Gitterman & Germain, 2008). The research questions guiding this study are as follows:

RQ QUAL A: What factors are contributing to cancer-related distress for patients in the rural context?

RQ QUAL B: What services are assisting rural patients in managing cancer-related distress?

RQ QUAL C: How does the role of oncology social work serve patients in rural areas?

### **Sample**

**Context.** This study was located in a rural community in northwest Illinois. The area is located along the Rock River in Illinois and harkens as “[President Ronald] Reagan Country.” As part of the rural rustbelt, the area struggles with social problems related to deindustrialization, such as poverty, brain drain, and high unemployment (Ginsberg, 2010). This location is surrounded by fields of corn and soy beans, with dilapidated abandoned factories spotting the landscape. This area supports a small cancer wellness center, Home of Hope, which provides free psychosocial services, provided by one social worker, who meets with patients at both the wellness center and chemotherapy and radiation treatment centers. Clients represent five rural counties. Clients at the wellness center must carry a diagnosis of cancer, identify as a cancer survivor, identify as a caregiver or loved one to a cancer patient or survivor, or have lost a loved one to cancer (Home of Hope, n.d.; HRSA, 2013).

**Participants.** The study included a convenience sample of adult cancer patients living in rural Illinois. Eighteen patients were recruited at the wellness center by a recruitment poster.

Participants contacted this researcher to schedule interview appointments at wellness center service sites. Selection criteria included adults who are current cancer patients residing in a rural area with a cancer diagnosis in the last calendar year who consented to the study. The qualitative semi-structured interviews involved a purposive non-probability sample based on the selection criteria listed on the recruitment poster.

**Protection of human participants.** The study participants were given a Consent Form to review, as indicated and defined by the Minnesota State University–Mankato Institutional Review Board (IRB) approval. Study participants, recruited by study recruitment poster, contacted this researcher to schedule an interview. Each semi-structured interview lasted 45-60 minutes. The researcher explained Informed Consent, which included Consent to Audio Record and Transcribe the Interviews, to each participant. All patients who proceeded with interviews voluntarily signed Informed Consent after the verbal explanation and having the opportunity to read the document. Interviews were recorded and transcribed by this researcher on a passcode protected laptop. The researcher took field notes for each interview, which are kept along with signed consent forms in a locked filing cabinet in the researcher's office.

Ethical concerns regarding this process include confidentiality and professional boundaries. The researcher addressed confidentiality in reviewing the Consent Form with participants before conducting the in-person interviews. Information published in this study has been de-identified and excludes any sensitive qualitative information that would impact participant anonymity. Regarding professional boundaries, this researcher gave participants information about available local services. The researcher explained in clear terms that the role of this researcher did not include counseling or psychotherapy interventions. Emergent or safety

concerns, although none were identified, would have been addressed by the wellness center social worker.

## Procedures

**Qualitative interviews.** The study involved semi-structured interviews with study participants. During the semi-structured interviews, this researcher asked questions regarding contextual barriers of the rural environment and the role of psychosocial oncology services. The interviews were recorded and transcribed on this researcher's laptop. The interview recordings were transcribed by the researcher verbatim using the Analysis Software MAXQDA 12. Field notes were taken in order to begin to identify recurrent themes. Interview questions were as follows:

- Demographic Information:
  - Do you live in a rural area?
  - What is your age?
  - What is your gender?
  - What is your marital status?
  - Have you been diagnosed with cancer in the past year?
  - What is the primary location of your cancer? What stage?
- What is your overall experience with being diagnosed with and treated for cancer?
  - When were you diagnosed with cancer?
  - Do you receive medical care locally or do you travel for treatment?
  - How has your diagnosis impacted you and your family?
  - How has your diagnosis impacted your quality of life?
- What distress, if any, have you experienced?
  - What factors contribute to your feelings of distress?
  - How do you cope with feelings of distress?
  - What services are available to assist you and your family with feelings of distress about your diagnosis?
    - Are these support services offered locally?
    - How have you received information about support services?
- Have you met with a social worker?

- If so, what services has the social worker offered?
  - What services have you found helpful?
  - Do you have any suggestions on how social workers may assist cancer patients in rural areas?
- Is there anything else you would like to tell me?

**Data analysis.** The qualitative transcribed responses to survey questions were compiled on MAXQDA 12 software. The standard coding technique of content analysis, using a color-coding process on the analysis software, was used in order to identify recurring themes. The qualitative coding software was necessary in to organize and visually relate identified themes from the study content. To streamline and organize the coding process, qualitative data was coded in several stages. First, in order to first make sense of the data, codes were broadly organized by responses to study questions (Hammersley & Atkinson, 1995). Next, categories of codes were identified from focused responses to study questions. Third, themes were identified that included phrases or words that are demonstrative of patterns or trends in responses. Themes may exemplify a category or code or may connect categories across codes. (Saldana, 2016).

### **Results**

The study participants were interviewed at Home of Hope service locations in a private setting. In order to ensure confidentiality of the transcribed interviews, information included in the study has been de-identified for the protection of study participants. The following results indicate themes and subthemes parallel with the guiding research questions and semi-structured interview questions. Overall themes were coded into overarching themes of Overall Experience, Distress, Social Work, and Other. The final heading, “Other” indicates themes that arose from the final question, “Is there anything else you would like to tell me?” Themes and subthemes were included if discussed by two or more participants.

**Participants**

The 18 study participants varied in degree of rurality, although all participants resided in the same rural region of Illinois. Participants, all Caucasian, described living either “in town,” “country,” or “on a farm.” Seven participants identified as male and eleven identified as female. Participants ranged in age from 37-84. Five participants were in either their 30s or 40s; four participants were age 50-59; three participants were age 60-69; four participants were ages 70-79; and two participants were 80-89. Types of cancer varied with six of the participants indicating primary breast cancer; four participants with colorectal cancer; two participants with skin cancer; one participant with uterine cancer; one participant with ovarian cancer; one participant with primary bone cancer; one participant with esophageal cancer; and two participants with bladder cancer. Eleven of the participants identified marital status as married; five widowed; and two indicated divorced.

**Overall Cancer Experience**

Following demographic information, the next set of open ended questions related to the participants' overall experience with cancer. Responses from this portion of the interview resulted in four subthemes: transportation barriers, quality of life, role of support system, and role of faith. Regarding overall experiences, participants offered range of responses. When asked to describe the overall experience with cancer, one participant stated:

The impact of cancer? There's not enough time in the day.

Other participants added:

I have sadness. You do get sad. I have faith I'm gonna get through this. I try to stay active as much as I can. But you get tired. There are people a lot worse off than I am. I'll get through it.

I just knew it was cancer. I had the attitude I have too much to live for and it wasn't going to beat me. I said I'm going to beat this. I got a mammogram every year. I was surprised it was so advanced. It isn't going to beat me I'm going to beat it! Now there is better treatment and I have made it a year. I have the best possible treatment I could get. Now they can't find the tumor. It's gone!

I've never been through this. Going through cancer is a learning experience. It is scary.

**Transportation barriers.** Most participants described local access for chemotherapy and radiation treatment and access to a local Oncology office, yet many reported travelling for several hours for surgery and specialized testing. Several participants discussed the hardship of driving or finding rides for even daily treatment, particularly in terms of cost of transportation. Regarding transportation, participants shared:

I travel 50 miles every day for treatment Monday through Friday. That gets a little expensive for gas. But we're ok. Thank god for Medicare and a supplement.

I live about 45 min from treatment. And for the operations I have to go up to UW Madison. I travel for treatment every 2 weeks.

**Quality of life.** Quality of life is included in the interview questions to explore the impact of cancer on the quality of everyday living activities. Quality of life encompasses the physical and emotional side effects of cancer treatment. This concept of Quality of Life was asked as an open-ended question and participants responded:

You can't make long terms plans because you don't know how you're gonna feel.

Definite impact on quality of life. Chemo and radiation made me very sick. I ended up in the hospital. I was out of work for a couple of months. After I had the operation, I came home and recovered pretty fast - I went back to work in 5 weeks. Then, when I started

follow up chemo, I had an allergic reaction to it. It was a bad reaction, so they stopped that type. At that point, I was ready to give up on chemo and put my faith in God. I decided the doctor could try this other treatment. It has been an inconvenience to say the least. Losing pay from work -- financially. the time commitment to come for treatments. All the time I've lost my life, unable to work or do anything at home.

Cancer changes your activities day to day. It is emotional talking about it. It is something nobody expects to hear. You have to change what you do. The chemo treatments are the hardest. For me, I kept working throughout it all. I took off the day of chemo, otherwise I kept working to keep up a routine as much as I could. It was hard. It's not an easy thing, but I had to for my sanity. If you don't get up, you lose yourself. Just trying to stay routine. I think that's the worst. On the weekends, I don't do anything because I save my energy for working.

As far as doing things I've never done, I am just happy being simple and being with my kids and doing things I like to do.

I was an avid golfer. I try to still golf and stay as busy as I can.

**Role of support system.** Most of the participants discussed the importance of a strong support system in the overall cancer experience. Family and social support has been identified as both a strength and barrier in the rural context (Ginsberg, 2011). Participant responses included the role of strong social support:

The group of moms I am in got tattoos for me. Everyone is very supportive. I am gonna kick this [cancer] right in the can.

I have my parents and my brother taking care of me and bringing me meals. It helps that others are caring about you and they are concerned.

I think there is a strong possibility I will die from this. It's a struggle to do things I enjoy. It is amazing how many friends contact me. I get cards every day from people that contact me. It is humbling to see how many people have supported me.

Do not allow depression and sadness take over life because then it is a waste. With all the prayers that I have behind me, all the support, every day I find something that encourages me.

We were always a close family I think it [cancer] made us a little closer.

One participant discussed the role of social support as a troubling experience, stating that her friends and family view her as different now that she has cancer:

It's hard the way people see you. You don't want people to feel sorry for you. I feel people are looking at me differently because of my diagnosis. Sometimes you learn that it seems like you lose friends. Certain friends distance themselves from you. They might

not want to communicate because of the diagnosis. I think it hurts them to look at me. I don't want them to feel sorry for me. It is what it is.

**Role of faith.** Most of the participants (fifteen) discussed the role of Christian prayer and faith as important in the overall experience with cancer. Participants discussed support received from prayer chains and emotional support from church members. Further, a belief that God has a plan and is looking out for and protecting participants was a strong theme. Some examples of statements about faith are as follows:

I really think God did His magic and did a miracle and made this so it is so much easier for me.

I'm determined. I'm a fighter. I've got God on my side.

Basically, my feeling is it's in God's hands. Really any of us, we all have something we have to deal with in our lives. It is just inevitable.

I'm a Christian so I turn it over to God.

I have a lot of faith in God I go to Him a lot. I lay flat on my stomach for [radiation] treatments. Those are times I talk to God. I ask Him to be with me. I think faith helps me get through all this.

God is speaking and working. I couldn't do this without Him.

**Distress**

Most of the participants identified that they completed a distress thermometer (DT) at appointments with the local Oncology clinic. When asked about distress experiences, some patients described the initial shock of receiving a cancer diagnosis as the most distressing period of the overall treatment course. Some responses detailing distress in the initial stage of diagnosis are:

Initially, it was very scary and devastating. The doctor did tell me the cure rates for the type I have is extremely high and this is not a death sentence. It is still scary.

When I was diagnosed, that first month was my worst month. it has gone up from there.

Other responses involved increased distress levels during times of disease status changes, or following surgery, such as mastectomy:

I had a wonderful attitude for 10 months. When surgery didn't happen, it is like 20 horses kicked me. For 2 weeks, the sun was only shining for a few minutes. It was gloom and rain. It took me awhile to climb up and get my hope back. Now I'm on a rope with no knot. This year alone I have been in the biggest roller coaster ride of my life.

Part of my distress is not feeling like a woman. I miss not carrying a full-time job. The idea of not being able to do things for myself is the hardest part. I just avoid the situation instead of asking for help. It took my self-worth. Cancer took away lot of things. It robbed me... it just never goes away.

**Contributing factors.** Aside from the shock of initial diagnosis and disease status change, participants identified financial concerns, treatment side effects, and parenting as additional contributing factors to elevated distress levels. Participants shared:

This last diagnosis has impacted my life as far as, my husband and I lost our house, cars, we lost everything that we owned. I had three young kids of my own. I was mad. I was not a nice person. I was just mad. I went to doctors, psychologists, and nobody answered my questions or made me feel better. They just wanted to give me medications and I do not want to take medications that mess with my emotions. I went about it on my own. I drank a lot.

To a certain extent I don't let it get me down. Property taxes contribute. I get distraught at time of taxes. You can own a house but you don't own that house because every year I have to pay [taxes.] Where's it coming from when you're on social security? Don't want to lose the house. Financial impact is big.

You've got bills to pay and have to provide for my family. I've been using sick time, I would take family medical leave, but that is without pay and doesn't pay bills.

**Coping.** Many participants openly shared coping strategies for cancer-related distress. Many participants were stoic in discussing the role of family support, prayer, and self-help in coping with a cancer diagnosis. Participants shared some thoughts about coping as follows:

Prayer—avid walker and golfer—I ride my bike for eight miles every week. I try to put good food in my body and keep attitude up. I think those three things put a dent in this cancer. I have zero to lose. The dr. says go by how I feel. Every morning I wake up when my feet hit the floor—they are numb and I haven't felt them for six months. The good lord has blessed me for another day. I have to look at it like that.

I am not feeling distress because I am getting the support from my family. That includes my church family. They have been very supportive. We have a prayer group. They pray for me. They have me on the prayer list. My pastor calls me and checks up on me.

Cry, self-talk, meditation, visualization, visualize a “pac-man” eating the cancer cells.

I talk to my family. My wife. That has been enough for me. Some people deal with things differently. I am one of those people that with anything I don't really ask for help. For the most part, I deal with this on my own. I'm a very strong person.

### **Social Work**

**Services.** Social work services in this area were offered by one BSW-level oncology social worker and a social work intern. Participants did not always identify the social workers as social work professionals, but mostly by first name. Participants eagerly shared attributes and roles association with the social worker. Some responses about the social worker were:

[The social worker] is always there with a hug. You don't get it much other places. Even when we saw her at the doctor's office, she came right over hugging me and she goes out of her way to give love and comfort and support.

She's a sweetheart. She has told me where to get a walker. She has offered counseling. Massages. I went to one of their make-up. They gave me bright red lipstick. I said ok which corner should I stand on and gave 'em a laugh.

I enjoy having them visit and encouragement they bring. It gives me another area of support. They have been wonderful even though I haven't needed it. I do have such a good support system that it helps.

### **Other**

**Environmental pollutants.** Several study participants commented on the role of environmental pollutants in causing cancer in the local area, and rural areas in general. These statements followed the final question, "Is there anything else you would like to tell me?" One participant added, "You haven't asked the most important question of all. What is causing all of this cancer?" Other responses are:

The whole town is full of cancer People have died left and right. Years ago, there was a flood and the entire south side of the tracks the whole town has died massive cancer deaths. The railroad did nothing about it. They covered it up. Now all these people are dying on one side of the tracks. So many deaths out there. Somebody needs to investigate that part.

There is so much cancer in this area. More research needs to find out why cancer rate is so high. Why does Mayo ask if you are from this area? That is alarming.

The US and medical field are crooked so that they have a stick up their ass so the only thing you can do is take a pill and make money.

I hate this disease, but the government lets it roll. They get population control from it.

There are people out here who are suffering and don't even know it. They don't even know they have cancer. That is terrifying.

### **Rural context**

Participants openly shared responses to the semi-structured interview questions. At times, many of the participants wept following questions related to distress and coping. Participants were each given information about the cancer wellness center services if needed. The participants were open and engaging and seemed thankful to talk about their experiences with cancer. This certainly, as a researcher, brought up feelings of gratitude and humility. Rural environments are full of disparities and barriers as well as a richness of character and strength.

As one participant stated:

The people out here are fantastic They are so good. I couldn't imagine going to Chicago and going through cancer treatments. People out here really care. The technicians. They show that. The doctors take all the time in the world to explain everything to you. If he needs to take a half hour to talk to you, he will. I don't think you'll find that in a big city. Here, they will take their time and help you.

## Discussion

The interview findings suggest an array of implications for oncology practice frameworks in the rural context. Responses were transcribed and coded into the broad themes of Overall Experience, Distress, Social Work, and Other. The broad themes were categorized into subthemes related to the more specific interview questions under the broad overarching questions. Implications for research, practice, and theory were explored using the identified thematic categories. This discussion uses ecological theory as a framework for relating the interconnected nature of the participants and the broader systemic and environmental context.

### Implications for Overall Experience

Most of the respondents discussed the initial feeling of shock when first diagnosed with cancer. Participants shared that the first month or two were the most difficult emotionally. Then, as participants developed a support network and treatment routine, that cancer became more manageable. Only one of the participants stated that a social worker assisted during this time, and said he requested that a social worker assist him in explaining his diagnosis to his children, especially in terms of coping with cancer and what to expect emotionally. Some participants openly wept when asked about overall experience – greatly impacted by the disease. Most often, intense emotions were coupled with statements of fighting the disease and not giving up hope. From the participants' reports, social work services are most needed during this initial phase of finding out about cancer and developing a cancer treatment plan.

**Transportation.** Transportation was a theme requiring ongoing discussion in the rural context. Although many participants received chemotherapy and radiation treatment locally, several participants reported daily travel for more than 60 minutes to receive medical care. A few of the participants shared that although the radiation oncology center was close to their home, it

was across the river and they were not able to access a bridge for miles. One participant even joked that a “cancer boat” was necessary to transport cancer patients from her town to the treatment center. Often, participants shared that surgery and specialist care was over two hours away from their home at large academic medical centers. Most of the participants referenced the financial impact of transportation barriers in terms of gas costs. Implications related to transportation may involve increased financial support, such as funds to offset gas expenses, as well as social work intervention from larger, academic centers that target the needs of rural cancer patients travelling long distances to receive care.

**Quality of life.** Participants bravely discussed the impact of cancer on their overall quality of life. Themes of physical activity, activities of daily living, and spending time with loved ones were discussed by participants as most important to overall quality of life. Most of the participants did not want to rely on others and saw it as a personal character weakness to ask for help from others. Participants discussed the ability to keep living life through pain and avoid depression and distress by keeping a routine. Further quality of life studies in the rural context are warranted in order to understand this concept and how it relates to rural cancer care.

**Support system.** Cancer researchers have long highlighted the collective experience of a cancer diagnosis. Cancer care models place the patient at the center of the care team, yet promote family and caregiver support as crucial in providing support and enabling positive patient outcomes (Haozous, Doorenbos, & Stoner, 2016). The implications of this study reinforce including family members in cancer treatment and education. Participants described the importance of family members in terms of rides to treatment, advocacy, financial support, housing, and emotional support. Further, participants seemed to view the cancer care team, including the social worker, as a part of their family support. In rural areas, where cancer patients

may reside in isolated areas, the concept of social and family support needs to be strongly supported in oncology practice.

**Faith.** Spirituality was discussed by most of the participants in the study as paramount as a part of the cancer experience. Patients identified the supportive role of a “church family” and the important role of prayer. Cancer centers, including social workers, may need to partner with churches and other faith organizations in order to enhance access to spirituality support of patients. The participant’s discussion about using his radiation treatment time to “talk to God” emphasizes the necessity of spiritual support in rural cancer care.

### **Implications for Distress Screening and Treatment**

Interestingly, when asked about completing the distress thermometer, many participants indicated they selected “no distress” at the oncologist’s office yet expressed qualitatively that they experienced high levels of distress. This concept, when compared to the Smith et al. (2011) study indicating elevated distress levels in the rural environment as compared to urban/academic center counterparts, may suggest further study in regard to the distress thermometer’s validity in the rural setting. Perhaps additional quantitative and qualitative methods are necessary for screening and measuring patient distress experiences. Certainly, distress screening and treatment requires further study and consideration in the rural context. Contributing factors, such as physical, emotional, financial, and spiritual domains, were discussed and identified as related to distress experiences, yet participants seemed to disconnect their own distress levels from identifying distress as quantifiable.

### **Implications for Social Work**

**Role on the oncology team.** Oncology social work’s role is defined by the Association of Oncology Social Work (AOSW) as “providing psychosocial services to patients, caregivers,

and families as a part of the oncology health care team” (AOSW, n.d.). The vision statement of this association is: “AOSW envisions a global society in which oncology care meets the physical, emotional, social and spiritual needs of all people affected by cancer (AOSW, n.d.). Certainly, in the context of rural cancer care, rural-competent social work is urgently needed to address these cancer-impacted domains. As one participant stated, social workers need to “take time to know the people here. We can tell if people are fake.” In order to bridge provider-patient trust, a culturally congruent care framework must align patient needs with clinician knowledge and skills. Social workers, using our person-in-environment framework, are well suited to support culturally congruent cancer care for rural cancer patients and the cancer care team.

**Services.** Participants identified helpful social work services in terms of presence and referrals. Many participants praised the oncology social worker for her warmth and presence: meeting patients with friendly conversation and a hug prior to oncology appointments. The attributes of kindness and empathy seemed to be what participants valued most about the oncology social worker. Another social work service identified as helpful was the service of referrals. Participants appreciated wellness (massage and healing touch) and financial support referrals from the social worker. Implications for oncology social work practice in the rural context arising from the study highlight the need for presence and practical referrals.

### **Implications for Broader Rural Context: “Other”**

**Environmental pollutants.** At least five of the participants discussed the role of environmental pollutants and toxins related to causing cancer in the rural environment. Participants discussed agricultural and industrial chemicals as an oppressive force, leaving some residents feelings marginalized and used. Some participants were eager to share their opinions and experiences related to feeling preyed upon and forgotten by larger society. This theme was

somewhat surprising to this researcher, and further study is warranted, especially given the current political climate involving the “forgotten” rural America.

**Rural character and strength.** Most notable in all of the participant interviews was the theme of bravery and courage. Participants were courageous in expressing strength related to “fighting” cancer and bravery in facing changes in disease status. Although many of the participants discussed the role of positive thinking, a stoicism about unknown and real outcomes of disease also existed. Participants eagerly shared experiences of coping with cancer in order to, as some participants shared, help others facing the disease. This strength of character, from this researcher’s perspective, was inspiring and spoke to the nature of the rural context. As Tom Vilsack once stated, “16% of our population is rural, but 40% of our military is rural. I don’t believe that’s because of a lack of opportunity in rural America. I believe that’s because if you grow up in rural America, you know you just can’t keep taking from the land. You’ve got to give something back” (Ginsberg, 2011).

### **Strengths and Limitations of the Study**

The study was limited by the qualitative methodology, including the nonprobability convenience sampling of participants. The study was also limited by research time, as participant interviews were scheduled in a one-week time frame due to researcher travel constraints. Interestingly, participants were eager to sign up for interviews and a theme of wanting their voices heard emerged as a motivating factor for study participation. Participants were recruited from one rural region in Illinois, so the research would have benefited from a broader sampling pool including other rural areas. Another limitation was the study does not account for psychosocial experiences of racial and ethnic minorities and LGBTQ cancer patients. Strengths of the study were supported by the openness and bravery of study participants to share their

experiences and the partnership of the cancer wellness center to share confidential interview spaces.

### **Conclusion**

Commonalities have been identified in marginalized communities and cancer care experiences. These commonalities include poor communication between patients and providers, difficulty in accessing cancer care, financial distress, and lack of access to reliable transportation (Haozous et al., 2016, p. 633). The rural context, viewed broadly as a marginalized community, maintains common psychosocial barriers and strengths that impact the cancer experience. Emerging themes resulted from this Illinois study that support further exploration of cancer experiences in the rural context. These themes include the importance of family support, the role of spiritual support, the questionable validity of distress screening in the rural context, environmental justice concerns, and strength of character found in rural culture. Furthermore, this research may support ongoing patient-centered research in order to develop innovative oncology psychosocial and medical practice frameworks congruent to rural cancer care needs.

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Product Three:

Catching a Speeding Train:

Social Work's Disconnect with Medical Revolution

J. Sky Niesen

Saint Catherine University/ University of Saint Thomas

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### Abstract

In recent years, cancer care has grown to include genetic counseling, genetic risk assessment, and genetic testing. Since the Human Genome Project was completed in 2003, numerous genomic technologies have transformed healthcare practice. Social work as a profession – in both practice and education – must include competencies related to genomics in our educational policies and accreditation standards and in our ethical scope of practice. From a historical perspective, we must learn from our past: social work's educational history has been closely aligned with the unethical pseudoscience of eugenics. In order to support our ethical value of social justice, social work as a profession must work closely with biomedical providers in order to advocate for underserved and marginalized groups in the context of the precision medicine movement.

**Keywords:** Genomics, Medical Social Work, Ethics, Genetic Testing

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### Commentary

#### Catching a Speeding Train: Social Work's Disconnect with a Medical Revolution

J. Sky Smith

President Obama announced last year in his State of the Union Address a “federal precision medicine initiative” designed to harness new genomics technologies (State of the Union Address, 2015). Social work education has a lot of ground to make up, and fast, as the pace of discovery in genetics and genomics not only transforms our ability to understand and treat disease, but also, in many cases, challenges deeply held senses of self and identity. In anticipation of the Council on Social Work Education's 2015 updates, it is time to establish new guidelines that prepare social work practitioners on genomics and the sometimes-intense psychosocial implications of knowing one's genetic information.

The Human Genome Project (HGP) was completed in 2003 at a cost of \$3 billion over 13 years (“The Human Genome Project Completion,” 2010). Today, scientists and physicians can collect and interpret the same amount of genetic information for a few thousand dollars over several days. The train has left the station in terms of incorporating genomic information into clinical care. Many predict that within five to 10 years this will become a routine part of medical care. Some even suggest that in the near future, every newborn baby will have his or her genome

fully sequenced and analyzed before birth (Personalized Medicine Coalition [PMC], 2014). This certainly will carry powerful psychological, social, and ethical implications. Social workers need to be front and center during debates that will shape policies around these issues, in addition to serving as integral members of multidisciplinary treatment teams (Taylor-Brown & Johnson, 1998).

In medical settings, genetic counselors routinely serve as care team members who help patients understand and interpret results of genomic testing. They help patients understand the implications of genomic sequencing and can provide information for family planning (Ormond, 2013). Given genetic counselors' educational background in biology and genetics, they have proven indispensable in helping translate complex testing into meaningful information for patients and their families. However, in the absence of adequately trained social workers, genetic counselors have assumed the additional role of psychotherapist or family counselor (Ormond, 2013). Results of genomic testing can truly challenge a person's identity. Imagine: An individual discovers "dad" is not his biological father during genomic testing for other diseases; a patient receives information that she carries a high-risk genetic condition that can be passed on to future generations. As a general standard in complex care situations, a trained social worker is a part of the multidisciplinary team, working with patients and providing psychosocial expertise regarding the systems that are affected by a medical diagnosis. Genomic medicine should be no exception to this standard.

More broadly, *all* social workers need to be prepared for the implications of such a changing world and participate in the dialogue to shape practice standards. The potential for groups of individuals to be marginalized and oppressed due to their genetic code is great. Prior to the completion of the HGP, social work leaders Susan Taylor-Brown and Ann Johnson (1998)

recognized this possibility and sounded the call for social work to engage with genomics and genomic medicine. Since that time, little has been done to promote social workers' training and understanding of this complex topic. The medical field, meanwhile, has charged ahead with continuing to deepen our scientific understanding of our most basic selves. The potential for these genomics technologies to transform medical practice is immense (PMC, 2014). Equally possible is the potential for mass genomic sequencing to create an entirely new vulnerable population: the genetic "underclass." Now is our opportunity to rise to the challenge of working for ethics to address this coming issue in education, policy, and practice.

We not only need to look toward the future, but need to reflect on our past role in ethics regarding genetics. In the late 19<sup>th</sup>/ early-20th-century United States, social reformists sought to advance society by the science of eugenics, or selective breeding (Anastas, 2012). In Nazi Germany, Nazi physicians sterilized those deemed unfit, including Jewish people, the mentally ill, and disabled (Pilgrim, 2009). In the United States, social work has played a despicable role in the perpetration of eugenics onto vulnerable populations. Finishing school education during the early 20th century included eugenics in preprofessional training for social workers (Dorr, 2008). Social work workers during this time were professionalized to serve as frontline workers in the sterilization of those deemed unfit (Kennedy, 2008 .) Even social work founders, such as Jane Addams, Sophonisba Breckinridge, and Mary Richmond promoted practices rooted in eugenic ideology. (Kennedy, 2008)

In 2011, Rock Center featured a group of social workers in North Carolina who recommended sterilization of children as young as nine because of perceived promiscuity. Social workers in the story threatened to withhold public assistance benefits if their clients refused to complete the sterilization. From 1929 to 1974, the State of North Carolina sterilized over 7,600

people: mostly poor, black women. Those recommended for sterilization were often victims of sexual assault (Rock Center, 2011). National Public Radio (NPR), in the 2011 report, “A Brutal Chapter in North Carolina’s Eugenics Past,” describes that social workers in North Carolina were the “middlemen” in selecting patients for sterilization (NPR, 2011).

A 2011 article by Kingsberry, Mickel, Wartel, and Holmes, “An Education Model for Integrating Genetics and Genomics into Social Work Practice,” discusses education models for incorporating genomics in social work education. The authors propose a “two-pronged” approach of including competency in genomics in all foundation social work courses, as well as specialization courses. Additionally, the authors argue that social work practitioners in the field must be engaged in the integration of this knowledge.

The medical revolution of genomics requires a broad application to social work education and practice. As a group of professional providers, social workers are unprepared, or underprepared, to practice in this changing world. For social work, as a profession, to rise to the challenges of 21st-century practice, genomics must be included in the new Educational Policy and Accreditation Standards, as an integral component of the human condition. Because, as George Santayana would have put it, “those who cannot remember the past are doomed to repeat it.” Certainly, this shifting time in our history is an opportunity to engage with scientific researchers, medical practitioners and ethicists, and policymakers to do all we can to promote social justice and support ethical psychosocial practices in genomic medicine. In fact, it is social work’s ethical obligation to do so.

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