CONSIDERATIONS FOR RURAL RESIDENTS UNDERGOING RADIATION THERAPY FOR CANCER TREATMENT

by

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ABSTRACT

Cancer is a disease that will affect roughly one in three Americans in their lifetime. Of those who choose to undergo cancer treatment, approximately 60% will be treated with radiation therapy (XRT). In order to contain health care delivery costs, specialty medical centers that offer XRT are often centralized, making access to necessary treatment difficult for rural residents. Researchers have identified accessibility to services, required travel, being away from family and friends, locating accommodations during treatment, financial burdens, emotional stress, quality of life, and treatment options as burdens to this population. Research has been conducted in other areas of the world to identify commonalities amongst rural residents undergoing XRT but no such studies have been conducted within the United States. The purpose of this study was to identify considerations for rural residents who have been diagnosed with cancer and are undergoing external beam radiation therapy for treatment. A convenience sample of rural residents who were currently or had in the last year received external beam XRT for cancer treatment at a regional cancer treatment center in south central Montana were asked to participate in this study. Surveys were mailed anonymously to 49 persons meeting study criteria. Twenty one surveys containing demographic, multiple choice, and Likert scale questions focusing on travel, lifestyle changes and accommodation during XRT, the financial implications and psychosocial significance of XRT, and treatment decisions were completed and returned. Responses to the survey were entered into a database where descriptive statistics were used to summarize the data. The results suggest that travel and distance to services continues to be a challenge for most rural residents, that rural residents often alter lifestyles and believe costs are greater for them during XRT. Data also showed that participants did not base treatment decisions on cost or distance nor did they feel they were overly stressed or anxious during XRT. Implications for nursing include identification of variables associated with a rural lifestyle, increasing education for rural persons, and being aware of available resources to assist persons undergoing XRT for cancer treatment.

CHAPTER 1

Introduction

Cancer is a disease affecting millions of people throughout the United States each year. According to data collected by the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program, men have a 44% lifetime risk and women a 38% lifetime risk of being diagnosed with any type of cancer (Horner et al., 2009). Based upon data gathered in 2005, of the 1.3 million cases of newly diagnosed cancer cases, there were 4,961 people diagnosed with cancer in Montana (Centers for Disease Control [CDC], 2010). Statistics have shown that Montana's statewide incidence rates for new cancer cases exceed the United States averages for all cancer types except those occurring in the colon and rectum (CDC, 2010).

Of those Americans choosing to undergo treatment for their cancer, approximately 60% will be treated with radiation therapy, either alone or in combination with other treatment forms including surgery and chemotherapy (National Cancer Institute [NCI], 2004). In order to contain health care delivery costs, specialty medical centers are often centralized (Hegney, Pearce, Rogers-Clark, Martin-McDonald, & Buikstra, 2005; Mathews, West, & Buehler, 2009). Therefore, according to Martin-McDonald and colleagues (2003), "the majority of cancer treatment centers are located in areas where the cost-benefit ratio per head of population is consistent with the principles of economic rationalism" (p. 177). As a consequence, rural communities are without services and rural residents are often required to travel to access these specialty services.

The need to travel for specialized medical services, especially radiation therapy which can require anywhere from five and upward to 50 treatments, can create a large and unique impact on the life of a rural resident. Commuting for radiation treatment often means being away from home and loved ones, finding temporary living accommodations near the treatment center, feelings of isolation, financial and travel burdens, and may influence treatment choices (Burman & Weinert, 1997a, 1997b; Gray, James, Manthorne, Gould, & Fitch, 2004; Hegney et al., 2005; Martin-McDonald, Rogers-Clark, Hegney, McCarthy, & Pearce, 2003; Montana Department of Health and Human Services [MDPHHS], 2008).

Purpose

The purpose of this study is to identify unique considerations for rural residents who have been diagnosed with cancer and are undergoing external beam radiation therapy for treatment.

Background

Shortly after the discovery of x-ray technology by physicist Wilhelm Roetgen in 1895, the field of radiation therapy began to develop. By the early 1900s, the first patients were receiving radiation therapy to treat disease and over the next century treatment delivery was refined, regimens developed, and equipment technology advanced. Due to an increased commercial availability of radiotherapy equipment throughout the United States and Europe, radiotherapy became a common and widespread treatment option for

oncology patients in the 1960s (University of California, San Diego Radiation Oncology, 2010).

Radiation therapy, although a mainstay of cancer treatment today, presents unique challenges to patients due to the overall treatment regimen. The majority of persons undergoing external beam radiation therapy will receive therapy once a day, five days a week for a period of two to ten weeks depending on cancer type and overall goal of treatment (NCI, 2009). Not only can the treatment schedule be demanding but the accessibility of specialty cancer services to some, especially rural residents, can further complicate the process.

Due to the overall breadth and geography of the state, rural residents within Montana and bordering states may face challenges unique to their counterparts in other areas of the country. Montana is the fourth largest state in regard to landmass, yet ranks 48th in population density with only 6.8 people per square mile (U.S. Census Bureau, 2011). According to Sullivan et al. (1993), rural Montana families dealing with cancer face many obstacles in obtaining health care including geographic isolation; distance from health care and lack of transportation; lack of health care providers and services; health care policy inequities; and poverty. Rural values, beliefs, and lifestyles may also affect cancer treatment choices. Therein 2009, there were only ten facilities in eight towns/cities within Montana that provide radiation therapy (S. Rachac, personal communication, February 18, 2010).

Statement of the Problem and Research Question

Due to the geographic isolation, lifestyle, and lack of access to many healthcare services, rural residents encounter unique circumstances when faced with a medical condition requiring treatment. Due to the necessary frequency of treatments associated with radiation therapy these circumstances can be exaggerated. What are common variables encountered by rural residents undergoing external beam radiation therapy for cancer treatment?

Conceptual Framework

The social ecological model of health behavior is the basis of the framework for this study. The term *ecology* references the relationship between organisms and their environment. The ecological perspective and the use of ecological models, however, focus more specifically on the connections and transactions that people have with their physical and sociocultural surroundings (Sallis & Owen, 2002; Stokols, 1996). According to McLeroy, Bibeau, Steckler, & Glanz, (1988), "the purpose of an ecological model is to focus attention on the environmental causes of behavior and to identify environmental interventions" (p. 366). Ecological theories propose that individual perceptions can be influenced either directly or indirectly by intrapersonal, sociocultural, policy, and/or physical-environmental factors, all of which are likely to interact (Sallis & Owen, 2002).

Stokols focused more specifically on the social ecology of heath behavior and developed four accompanying assumptions: (1) health is influenced by multiple facets of physical and social environments; (2) environments are multidimensional and can be

either social or physical, actual or perceived; (3) human-environment interactions can be described by various means of aggregation: individuals, families, organizations, communities, or whole populations; (4) feedback exists between the different levels of environments and groups of persons (Sallis & Owen, 2002; Stokols, 1996).

Figure 1: Human and Environmental Interactions Within the Social

Utilization of the social ecological framework can be used to further understand the experiences of rural residents undergoing external beam radiation therapy. Figure 2 illustrates the complexities of how social ecology affects an individual's behaviors in regard to accessing quality healthcare. Physical-environmental factors influencing the individual's experience may include distance to health care services, weather, geography, and transportation availability. Policy influences may be illustrated via personal finance and health insurance, whereas intrapersonal factors may be represented by individual

health behaviors and psychological characteristics (Sallis & Owen, 2002; Stokols, 1996). The social ecological framework, which focuses on transactions between people and their surroundings, may yield further insight into the experiences of rural persons undergoing XRT. According to Stokols (1996), "environmental analyses reveal the direct and often imperceptible effects of people's physical and social surroundings on their wellbeing, which can undermine the benefits of favorable health practices or exacerbate the negative outcomes..." (p. 285).

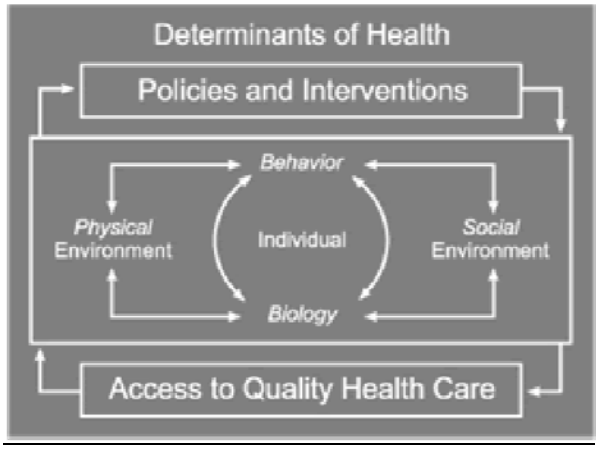

Figure 2: Social Ecological Determinants of Health (Georgetown University, n.d.)

Definitions

There are many different ways that the term "rural" can be defined or classified. For the purpose of this study, the United States Census Bureau definition of rural will be utilized. According to this definition, rural is an area comprised of mostly open country with settlements containing fewer than 2,500 residents (US Census Bureau, 2010).

Cancer treatment is a wide array of therapies utilized to prevent, cure, control, or palliate the disease (Polovich, Whitford, & Olsen, 2009). Radiation therapy (XRT), a commonly prescribed form of cancer treatment, is the utilization of energy to damage genetic material within cancer cells making it impossible for them to replicate (NCI, 2004). This process can be harnessed to cure, stop, or slow the growth of cancer cells or palliatively to reduce cancer symptoms such as pain (NCI, 2009). XRT can be utilized to treat nearly every type of solid tumor and has also been used to treat hematological malignancies like leukemia and lymphoma. Radiation therapy can be delivered by external, internal, or systemic routes. External beam radiation, the most common treatment form, is utilized as a local treatment and delivered via machine. Internal radiation therapy, or brachytherapy, is accomplished by placing a solid radioactive source within the body. Systemic radiation therapy, on the other hand, is the use of unsealed radioactive materials that may travel throughout the body (NCI, 2004).

Assumptions

The following assumptions are integral to this study: (a) rural residents undergoing external beam radiation face unique challenges in obtaining specialty care and treatment; (b) there are many different facets to the experiences rural residents have with receiving external beam radiation for cancer treatment; (c) nurses play an important role in assisting rural residents with access to care and education; and (d) utilization of the social ecological framework will allow further investigation into the role that environment plays upon health behaviors and experiences.

CHAPTER 2

REVIEW OF LITERATURE

MEDLINE, The Cumulative Index for Nursing and Allied Health Literature (CINAHL), and PubMed databases were searched for material printed from January 1991 through November 2011 and containing keywords radiation therapy or radiotherapy (XRT), cancer, chronic illness, rural, and ecological theory. Inclusion criteria included limiting references to research reports written in English, containing abstracts, and published in health-science journals within the last 20 years.

A review of the literature pertaining to external beam radiation therapy as a form of cancer treatment within the rural population revealed that although there are studies addressing common trends and factors, none of these studies focus on rural populations within the United States. This study seeks to build upon this body of research by identifying the barriers and burdens of external beam radiation therapy within the rural population and the role that environment plays upon health behaviors and experiences.

Studies conducted in Australia (Hegney et al., 2005; Martin-McDonald et al., 2003), Scotland (Smith & Campbell, 2004), and Canada (Gray et al., 2004; Mathews et al., 2009), have identified many consistent areas of concern for the rural oncology patient. Accessibility to services and required travel were identified in all countries as a burden to this population. Other areas identified included being away from family and friends, locating accommodations during treatment, financial burdens, emotional stress, quality of life, and treatment options. Research has also been conducted on the rural

oncology population living in Montana (Burman & Weinert, 1997a, 1997b; Sullivan, Weinert, & Cudney, 2003; Sullivan, Weinert, & Fulton, 1993) with findings consistent with those in other countries. Despite the availability of data regarding the cancer experience for rural Montanans, no research has focused specifically on those receiving external beam radiation for cancer treatment.

During the literature review, there was no published information located to indicate that the social ecological framework has been utilized to determine associations amongst rural residents undergoing XRT for cancer treatment.

Chapter 2 will contain a summary of the literature findings regarding XRT within the rural population, barriers and hardships encountered by rural residents, and the interaction between the environment and health behaviors in relation to the social ecologic framework. This chapter will be organized into five sections: (a) travel, (b) lifestyle changes and accommodation, (c) financial implications, (d) psychosocial significance, and (e) treatment decisions.

Travel

According to ecologic theory, "environmental influences on disease have been recognized for centuries" (Sallis and Owen, 2002, p. 464). Nowhere is this statement more true than when distance exists between an ill person and their source of health care. The necessity and burden of travel in order to obtain specialty medical services may place people from rural areas at a disadvantage (Hegney et al., 2005). Traveling as frequently as five days a week for radiation treatments can become a hardship to many and may

most severely impact the elderly and those living the furthest away from treatment centers (Smith & Campbell, 2004). Prior studies have cited safety as a concern while traveling for treatments due to the pain and fatigue often experienced as a side effects of radiation (Hegney et al., 2005), unfamiliar or increased traffic (Martin-McDonald et al., 2003), impaired health status, and hazardous driving conditions related to geography and weather (Sullivan et al., 2003).

When Montana residents were questioned regarding their travel experiences many spoke of the distances in which they were required to go. In a study conducted by Sullivan et al. (1993), participants being interviewed regarding their needs as rural dwellers reported that distance was a large inconvenience. Of the 420 participating families, nearly half were traveling an average of 140 miles for treatments and some residents living in more isolated areas were traveling distances of greater than 200 miles round trip. One Montana woman, enrolled in a study detailing chronic illness management shared with her peers on a computer messaging platform, "I just returned from a 190-mile trip for my 20-minute radiation treatment. I HATE it" (Sullivan et al., 2003).

The greatest challenge regarding transportation is presented to rural residents who have no personal vehicle or those who have reached the point where they are physically or cognitively unable to drive themselves. The lack of public transit to rural and remote areas exacerbates the situation and this group often must rely on others for transportation. Not only does the commute then become an inconvenience to them, but also to the

friends and family members who accompany and transport them to and from their appointments (Hegney et al., 2005).

Lifestyle Changes and Accommodation

Extensive distances, frequency of treatments, and overall health status often require rural residents to stay in or relocate to the areas where they are receiving radiation therapy (Gray et al., 2004; Hegney et al., 2005; Martin-McDonald et al., 2003). The simple act of locating accommodations can become a stressor if information is not readily available and the treatment destination unfamiliar (Bettencourt, Schlegel, Talley, & Molix, 1997). The majority of rural participants seeking treatment in metropolitan areas tend to stay in a hotel or motel and the minority make arrangements to stay with family or friends in the treatment city (Hegney et al., 2005; Martin-McDonald et al., 2003).

The move from a familiar environment to one that is often unknown and disliked can cause rural residents to forego routines and alter their schedules (Martin-McDonald et al., 2003). Common activities like preparing meals, providing care for dependent family members, taking children to and from school and extracurricular activities, shopping, and running a household often become increasingly more difficult and stressful. The alteration of the household dynamic can lead to changes in its overall infrastructure. Frequently, extended family members, friends, and neighbors will begin to take on roles that those undergoing cancer treatment can no longer maintain (Hegney et al., 2005).

Financial Implications

Geographic isolation and distance to centralized treatment centers can often translate into a greater financial burden for the rural resident. In their study detailing rural populations, Burman and Weinert (1997b) found that nearly 75% of individuals with cancer and/or their caregivers were concerned about the financial impact of cancer. Common financial burdens experienced by cancer survivors undergoing treatment include increased fuel and food costs, increased vehicle maintenance due to additional wear and tear, maintaining two places of residence (home and temporary accommodations), and additional travel costs of family members (Hegney et al., 2005).

Rural residents tend to be poorer in terms of income than their metropolitan counterparts (Martin-McDonald et al., 2003) and are more likely to be self- or seasonally-employed (Mathews et al., 2009). Illness can often necessitate an unanticipated alteration in one's ability to work or maintain employment. Individuals with cancer have reported concern regarding their job security (Burman & Weinert, 1997a), loss or reduction in wages, lack or absence of paid time off, and the pressure to continue working despite their illness (Hegney et al., 2005). Since many rural residents lack full-time employment outside of the home they may also have difficulty securing and affording health insurance (Mathews et al., 2009). If an individual is able to purchase health insurance independently it may come with higher premiums and deductibles, both of which can exacerbate financial stress (Gray et al., 2004).

Psychosocial Significance

Dealing with a cancer diagnosis often produces emotions ranging from fear, shock, anxiety, anger, grief, loss, helplessness, hopelessness, sadness and vulnerability (Kenny, Endacott, Botti & Watts, 2007). Adding the additional burden of a long commute, possible relocation for radiation therapy, and associated financial stresses may place a large amount of psychosocial distress on rural residents with cancer. Studies have shown that rural persons with cancer are at an increased risk of serious psychological dysfunction when compared to urban dwellers due to lack of access to services and overall geographic isolation (Burman & Weinert, 1997a; Kenny et al., 2007). As a 43 year old woman with cancer stated, "...cancer is, for rural people, a very lonely experience..." (Sullivan et al., 1993).

It has been shown that rural residents are generally self-reliant, independent, and tend to rely on informal systems of help such as family, friends, and their communities (Bales, Winters, & Lee, 2006). The demands of external beam radiation treatment can often necessitate individuals being away from their support systems for extended periods of time. Martin-McDonald et al. (2003) summarized this phenomena well, stating: "It appears that at a time when the participants' health, and perhaps life, is threatened, and when they would benefit most from the comfort of their loved ones and the security of what is familiar to them, rural people who require radiotherapy are deprived of those very sources of support during a time of intense stress (p. 181)."

Treatment Decisions

A study conducted by Mathews et al. (2009) found that when compared to urban residents, rural residents were twice as likely to consider financial costs when making decisions regarding care and treatment. Investigators have also found that distance to specialty health centers can often influence treatment decisions. Rural breast cancer survivors are less likely to undergo breast conserving surgery (BCS) coupled with radiation treatment and instead have a higher instance of modified radical mastectomies or choose not to undergo treatment at all when compared with urban breast cancer survivors (Bettencourt et al., 1997; Gray et al., 2004; Hegney et al., 2005; MDPHHS, 2008). Gray and colleagues (2004) found the reasons that rural Canadian breast cancer survivors pursued mastectomies "most often related to the distance involved in travelling for radiation treatment, with associated impacts on childcare/family responsibilities, finances and work" (p. 46).

An analysis of Montana breast cancer survivors found that women living 100 miles or further from a radiation oncology center were nearly three times more likely not to have radiation therapy than women who lived within 100 miles of the treatment center (MDPHHS, 2008). The fact that many rural women elect to have mastectomies in preference to BCS and radiation therapy should illustrate the disruption and inconvenience that many may feel this particular cancer treatment induces.

According to Lee and McDonagh (2006), "Rural dwellers define health primarily as the ability to work, to be productive, to do usual tasks" (p. 20). Ecological models have long focused on the link between a person's environment and the impact it has upon their

lifestyles. Barker (1968) conducted long-term observational studies of persons in their everyday environments. Based upon his findings he was able to determine that more can be deduced about behaviors when knowledgeable about the situations and everyday lives of people, rather than having familiarity with their individual characteristics. Therefore, use of the social ecological framework will allow greater exploration into the treatment decisions and the influencing factors for rural Montanan's undergoing XRT for cancer treatment.

Summary

The effect of being a rural resident can have a marked effect on one's illness, lifestyle, personal life, and treatment modality. Scott (2000) summarized this phenomena well, stating, "Rural persons with illnesses have unique health care access challenges related to available health care personnel to provide services, distance to services, and fiscal resources to obtain services" (p. 21). For many patients undergoing cancer treatment, radiation therapy may mean a temporary change in residence, increased travel, lifestyle changes and modifications, financial burdens, psychosocial implications, and the potential for modifications to treatment regimens. It is important to look at the person's place of residence and identify potential stressors related to their environment.

CHAPTER 3

METHODS

Research Design

This cross sectional descriptive study was designed to identify common variables among rural residents undergoing external beam XRT and whether there were any noted differences between those currently undergoing treatment and those who had completed treatment. The foundation of a descriptive quantitative study allows commonalities within a population to be identified (Bushy, 2008) while maintaining an objective perspective (Carr, 1994). The study design will also allow for interpretation of the social ecological framework to ascertain the ways in which the environment influences access to cancer treatment and its subsequent effects on individuals seeking care.

Population and Sample

A convenience sample of rural residents who were currently or had in the last year received external beam XRT for cancer treatment at a regional cancer treatment center in south central Montana constituted the target population for the study. Adults, aged 21 years of age or older who could speak, read, and write English, were undergoing or had received XRT in the last year for cancer treatment, and resided in a rural settlement containing 2,500 people or less were eligible for the study.

Setting

The study was conducted at a regional cancer treatment center which provides external beam radiation therapy to a large geographical area including central, south-central, and eastern Montana and northern Wyoming. Radiation therapy services are available on an outpatient basis Monday through Friday.

Procedures for Data Collection

Recruitment

An instructional guideline was provided by the primary investigatory to cancer treatment center staff detailing participant inclusion criteria to facilitate identification of participants (see Appendix A). Patient records were then screened by the cancer treatment center staff to identify patients meeting study criteria and living in nearby areas with populations of 2,500 or less. A total number of 49 patients were identified by cancer treatment center staff as meeting study criteria. Once these patients were identified a research packet was mailed to them. The packet contained an introduction letter from the primary investigator inviting them to participate in the study (see Appendix B), details of the study which included all the components of an informed consent (see Appendix C) the study questionnaire (see Appendix D), and a postage-paid sealable envelope with a return address to the cancer treatment center. The patient was given a three week time period to complete the questionnaire and return it to the cancer treatment facility.

Data Management

Mailings, including addressing the envelopes to the potential participants, were conducted by cancer treatment center staff, thereby ensuring anonymity. Questionnaires returned to the cancer treatment center were held by the center's staff until collected by the primary investigator. Instructions contained within the mailing indicated that there be no identifying information (name, birth date, return address, social security) placed on either the questionnaire or return envelope to further ensure confidentiality. Participants were assigned an identification number to assist with data organization. All data were labeled with an identification letter and kept in a locked cabinet in the primary investigator's office.

Instruments

The questionnaire used for this study consisted of 1) standard demographic questions (age, ethnicity, income, occupation, hometown, cancer diagnosis, overall length of XRT treatment course and their current stage of treatment) and, 2) questions developed by the primary investigator that focused on common themes found during the literature review including: travel, lifestyle changes and accommodations, the financial and psychosocial implications of treatment, and treatment decisions. Open response, multiple choice and the use of a 7-point Likert scale were the methods of obtaining answers from participants. The Likert scale measured patient's perceptions of their experiences during XRT by gauging responses of 1 (*strongly disagree*) to 7 (*strongly agree*). There was an option for respondents to further explain their answers if they chose the "other" option on

some multiple choice questions and also an area at the end of the questionnaire for free response of experiences, thoughts, and feelings related to their XRT.

Human Rights Protection

Approval for this study was received from the Institutional Review Board (IRB) at Montana State University. Permission to conduct the study was also obtained from the chief executive officer of the cancer treatment center at which the study took place. An introduction letter included within the mailing informed patients that due to the confidential nature of the study the return of the completed questionnaire constituted a consent to participate in the study and therefore, no signed consent form was needed. The voluntary nature of the participant's involvement in this study was emphasized and they were informed that they may choose to drop out of the study at any time without effect to the care they received at the cancer treatment center. Each participant received contact information for the primary investigator, thesis chair, and a member of the Montana State University IRB.

Data Analysis

The dependent variables in this study were responses pertaining to travel, lifestyle changes and accommodations, the financial and psychosocial implications of treatment, and treatment decisions. The independent variable in this study was completion of treatment. Data were organized and analyzed using Microsoft Excel. Responses to the survey were entered into the database by the primary investigator. Descriptive statistics,

such as frequencies, percentages, means, and standard deviations were used to summarize the data. The results are presented in Chapter 4.

CHAPTER 4

RESULTS

Sample Demographics

Data collection for the study occurred during February 2012. Of the 49 eligible participants, 44.9% (n=22) agreed to participate and returned questionnaires. Of the questionnaires received, three were partially incomplete, one contained responses suggestive of misunderstanding the Likert scale, and one was ineligible for the study as it did not meet enrollment criteria. Therefore, data were collected from a total of 21 participants. Table 1 contains demographic data for the sample.

The majority of the participants were female (57%, $n = 12$), older ($M = 65.4$ years, $SD = 12.25$), with high school educations or higher (88%, $n = 17$), married (66%, $n = 14$), and lived with their spouse or significant other (57%, $n = 12$). Most participants (26%, $n = 5$) reported an average annual income of $25,000 - $34,999. Incomes ranged from $10,000 - $14,999 (16%, $n = 3$) to greater than $75,000 (21%, $n = 4$) annually. Most participants reported they were retired (38%, $n = 8$) or self employed (19%, $n = 4$) and were not financially supporting any dependents (66%, $n = 14$). All participants were white (100%, $n = 18$), non Hispanic or Latino (100%, $n = 15$). Three participants did not disclose their race; six did not indicate their ethnicity; two did not indicate their age; two did not include information regarding income, and two did not indicate their level of education. The majority reported living in a small rural town (40%, $n = 8$), followed by

those who reported living on a farm or ranch (30%, *n* = 6). Most participants lived in or closest to an area with a reported population of less than 2,500 residents (70%, *n* = 14).

Table 1. Demographics

Variable		**Number Of Cases**	**% of Total Sample**
Age (*n* = 19) *M* = 65.4 *SD* = 12.25	20-29 40-49 50-59 60-69 70-79 80-89	1 1 2 6 8 1	5% 5% 10% 32% 42% 5%
Gender (*n* = 21)	Male Female	9 12	43% 57%
Ethnicity (*n* = 15)	Not Hispanic or Latino	15	100%
Race (*n* = 18)	White	18	100%
Marital Status (*n* = 21)	Married Divorced Widowed Never Married/Single	14 2 4 1	66% 10% 19% 5%
Living Arrangement (*n* = 21)	Live Alone Live with spouse or significant other Live with family member Live with family & spouse	5 12 2 2	24% 57% 9.5% 9.5%
Description of residence (*n* = 20)	On a farm/ranch In a rural area (not a farm/ranch) In a small rural town In a small town	6 4 8 2	30% 20% 40% 10%
Population of nearest City/Town or residence (*n* = 20)	<500 people 501 - 1,000 people 1,001 - 2,000 people 2,001 - 2,500 people 2,501 - 5,000 people 5,001 - 10,000 people 10,001 - 30,000 people	7 3 2 2 2 3 1	35% 15% 10% 10% 10% 15% 5%

Table 1. Demographics - Continued

Education (*n* = 19)	Nursery school to 8th grade	1	5%
	9th, 10th, or 11th grade	1	5%
	High school graduate	9	47%
	Some college / did not graduate	3	16%
	Associate degree	2	10%
	Bachelor's degree	2	10%
	Master's degree	1	5%
Annual Household Income (*n* = 19)	$10,000 - 14,999	3	16%
	$15,000 - 19,999	2	10%
	$20,000 - 24,999	2	10%
	$25,000 - 34,999	5	26%
	$35,000 - 49,999	2	10%
	$50,000 - 74,999	1	5%
	>$75,000	4	21%
Employment (*n* = 21)	Employed for wages	2	9.5%
	Self-employed	4	19%
	A homemaker	2	9.5%
	Retired	8	38%
	Unable to work	1	5%
	Self employed / A homemaker	3	14%
	Unable to work / A homemaker	1	5%
Number of Dependents (*n* = 21) *M* = 0.57 *SD* = 0.925	0	14	66%
	1	3	14%
	2	3	14%
	3	1	5%

Nearly all participants had completed XRT (95%, *n* = 19), only one was currently receiving treatment when the completed questionnaires were submitted, and one participant did not indicate. Most participants were being treated for breast cancer (55%, *n* = 11), followed by prostate cancer (25%, *n* = 5), colorectal cancer (10%, *n* = 2), melanoma (5%, *n* = 1), and bone cancer (5%, *n* = 1). One participant did not indicate their diagnosis. Travel distance varied largely throughout the group of participants (*n* = 19). Average travel distance for treatment one way was 108 miles (*SD* = 58.32) with an average travel time of 109 minutes (*SD* = 53.58) one way. Distances ranged from 22 miles one way upward to 260 miles one way. Travel times were as short as 20 minutes

one way for one participant and upwards of 210 minutes for another. Participants (n = 19) traveled an average of 3.6 days per week (SD = 1.54) for treatment with some travelling only 2 days per week and others travelling 5 days per week. Treatment regimens varied greatly for participants (n = 19). One participant completed their XRT in six treatments and others underwent 50 treatments overall. The average number of treatments reported from the sample were 27.5 (SD = 13.12). All participants (n = 21) reported that they had some form of health insurance.

Table 2. XRT Treatment Summary

Stated cancer diagnosis (n = 21)	Breast - 11 Prostate - 5 Colorectal - 2 Melanoma - 1 Bone - 1 Not Indicated - 1
Currently undergoing treatment (n = 21)	Yes - 19 No - 1 Not Indicated - 1

	Sample size	Mean	Range	Standard Deviation
Average distance traveled (in miles) one way for treatment	19	108	22 - 260	58.32
Average travel time (in minutes) one way for treatment	19	109	20 - 210	53.58
Number of days per week traveled for treatment	19	3.6	2 - 5	1.54
Total number of XRT treatments completed	19	27.5	6 - 50	13.12

Rural Resident's Perceptions Regarding XRT

Questions within the participant survey focused upon the five common themes uncovered within the literature review: (a) travel, (b) lifestyle changes and

accommodation, (c) financial implications, (d) psychosocial significance, and (e) treatment decisions. Results regarding these themes will be discussed separately.

Travel

Participants agreed that they were able to find a way to get to radiation treatment appointments without difficulty. The majority (58%, *n* = 11) made it to their XRT appointments by driving themselves and traveling alone to their appointments (53%, *n* = 10). Most felt that traveling for their appointments was difficult either some of the time or a little of the time (68%, *n* = 13) but accessing medical care and driving within the treatment city was easy. Participants agreed that traveling for XRT during poor road conditions would make it difficult for them attend their appointments.

Table 3. Sample Responses Regarding Travel

Variable		**Number of Cases**	**% of Sample**
Mode of transportation to/from XRT appointments (*n* = 19)	Driving self	11	58
	Riding with family member	6	32
	Riding with friend	1	5
	Public transportation	0	0
	Other	1	5
Participant was accompanied to XRT by (*n* = 19)	No one	10	53
	Spouse or significant other	4	21
	A relative	3	16
	A friend	1	5
	Other	1	5
Traveling for XRT was difficult (*n* = 19)	All the time	0	0
	Most of the time	2	10
	Some of the time	6	32
	A little of the time	7	37
	None of the time	4	21
Accessing medical care in the treatment city was (*n* = 18)	Easy	11	61
	Somewhat easy	4	22
	Somewhat difficult	2	11
	Difficult	1	6
	Neither easy nor difficult	0	0

Lifestyle Changes and Accommodation

Participants were asked a total of four multiple choice questions and 10 Likert scale questions related to lifestyle modification and accommodations while undergoing XRT. Overall, participants agreed that their job did not interfere with their ability to attend XRT, it was not difficult to take time away from work to attend XRT, nor did XRT make the type of work they did more difficult. Participants (n = 20) felt that XRT interfered with social activities more often than not, that their ability to maintain their households wasn't greatly altered, and they somewhat agreed that their daily routines were not altered by XRT. Participants neither agreed or disagreed that they were able to perform everyday physical activities while undergoing XRT but most somewhat agreed they were satisfied with their level of physical functioning during XRT. They overwhelmingly agreed that they tended to be independent people who did not routinely rely on others for assistance and that they felt healthier when they were able to be productive. All responding participants (n = 20) felt they were able to accomplish what they needed to within their personal lives during XRT some, most, or all of the time. In regard to accommodations while undergoing XRT, most participants (48%, n = 8) drove home each day after treatment, 26% (n = 5) stayed in lodging provided through a medical program or funded by an organization within the treatment city, and 21% (n = 4) stayed with family in the treatment city.

Table 4. Sample Responses Regarding Lifestyle Changes and Accommodations

Variable		Number of Cases	% of Sample
During XRT I most often: (n = 19)	Drove home every day	8	42
	Stayed with family in the treatment city	4	21
	Stayed with friends in the treatment city	0	0
	Stayed in a hotel/motel in the treatment city	0	0
	Stayed in lodging provided through a medical program or funded by an organization in the treatment city	5	26
	Other	2	11
During XRT I felt like I accomplished what I needed to in my personal life: (n = 20)	All of the time	4	20
	Most of the time	10	50
	Some of the time	6	30
	A little of the time	0	0
	None of the time	0	0
If I needed help with a task or errand during XRT someone was available to help me: (n = 21)	All of the time	12	57
	Most of the time	5	24
	Some of the time	2	9
	A little of the time	0	0
	None of the time	0	0
XRT interfered with social activities like visiting friends, attending events, spending time with others: (n = 20)	All of the time	1	5
	Most of the time	5	25
	Some of the time	8	40
	A little of the time	1	5
	None of the time	5	25

Financial Implications

Within the survey questionnaire, participants were asked three multiple choice questions and two Likert scale questions regarding the financial implications that XRT may have had on them. Of the 19 total respondents, all but 2 (89%) stated that during XRT they thought about the cost(s) of treatment anywhere from a little of the time to all the time. Most (76%, n = 16) felt that costs for them during XRT were either somewhat

or much more expensive than costs for someone who lived in the treatment city. Although the entire sample (n = 21) stated they had health insurance, three participants (14%) felt their insurance did not adequately cover the costs of their radiation treatments. Respondents somewhat agreed that the cost of gas or car repairs might make it harder for them to attend XRT.

Table 5. Sample Responses Regarding Financial Implications

Variable		**Number of Cases**	**% of Sample**
During XRT I thought about the cost(s) of treatment: (n = 19)	All of the time	3	16
	Most of the time	3	16
	Some of the time	6	32
	A little of the time	5	26
	None of the time	2	10
Compared to someone who lives in the treatment city, costs for me are/were: (n = 21)	Less expensive	2	10
	The same	3	14
	Somewhat more expensive	11	52
	Much more expensive	5	24

Psychosocial Significance

Questions regarding the psychosocial impact of XRT were asked both via multiple choice and Likert scale. Overall, participants did not report that they felt overly stressed by XRT, but rather, the majority (76%, n = 16) reported that they were stressed only some of the time to none of the time. They also said they neither agreed or disagreed that they felt anxious about radiation therapy. Participants did report feeling they were supported by others "all the time" during their XRT (71%, n = 15), and that side effects such as nausea, pain, and fatigue didn't necessarily make it difficult for them to travel to their XRT appointments. Participants also agreed that they readily trust healthcare

providers who are not from their community and somewhat disagreed that they would rather receive treatment at a center staffed by people from their own community.

Table 6. Sample Responses Regarding Psychosocial Significance of XRT

Variable		Number of Cases	% of Sample
XRT has been/was stressful for me: (n = 21)	All of the time	2	9
	Most of the time	3	14
	Some of the time	6	29
	A little of the time	4	19
	None of the time	6	29
I felt supported by others during the time I was undergoing XRT: (n = 21)	All of the time	15	71
	Most of the time	4	19
	Some of the time	1	5
	A little of the time	0	0
	None of the time	1	5

Treatment Decisions

There were two Likert scale questions related to participant's treatment decisions. One question related to whether or not the overall distance to the treatment center influenced the participant's decisions regarding cancer treatment. Responses to this question ranged from "strongly disagree" (26%, n = 5) to "somewhat agree" (11%, n = 2), however, the sample mean indicated that overall, participants disagreed with this statement. The other question asked was whether or not participants considered the cost of treatment before deciding to undergo radiation. Most respondents strongly disagreed (54%, n = 7).

Table 7. Sample Responses to Treatment Decisions

Variable		**Number of Cases**	**% of Sample**
Distance to the treatment center influenced my decisions regarding cancer treatment (n = 19)	Strongly Disagree	5	26
	Disagree	5	26
	Somewhat Disagree	1	5
	Neither agree nor disagree	6	32
	Somewhat agree	2	11
	Agree	0	0
	Strongly Agree	0	0
I considered the cost of treatment before deciding to undergo XRT (n = 13)	Strongly Disagree	7	54
	Disagree	2	15
	Somewhat Disagree	3	23
	Neither agree nor disagree	1	8
	Somewhat agree	0	0
	Agree	0	0
	Strongly Agree	0	0

CHAPTER 5

DISCUSSION

The purpose of this study was to identify unique considerations for rural residents who have been diagnosed with cancer and are undergoing external beam radiation therapy for treatment. This study focused on five key components identified within the literature review that tend to commonly affect this patient population. Those components include: (a) travel, (b) lifestyle changes and accommodation, (c) financial implications, (d) psychosocial significance, and (e) treatment decisions. The study also utilized the socio-ecologic framework, which considers the transactions between people and their surroundings to yield further insight into the experiences of rural persons undergoing XRT.

The findings of this study indicated that there were many aspects the rural residents experienced that aligned with data reported from studies conducted elsewhere in the world, as well as many aspects that may be fairly unique to the geographic area in which the sample population dwells. Looking at the demographic profile of the sample, it was interesting to note that only persons defining their race as "white" completed and returned the questionnaire. This is not completely unexpected as the population of Montana is 89% Caucasian (U.S. Census Bureau, 2012), but it would be interesting to see if greater racial diversity within the sample population would have altered any of the findings. Of the sample, 90% reported being a high school graduate or obtaining

education beyond that level. This coincides with the Montana average of 91% of adults aged 25 or older being high school graduates (U.S. Census Bureau, 2012).

Findings related to travel aligned with findings from the literature review. Many persons had to travel significant distances in order to receive XRT. One participant stated they drove to XRT each day and drove home each night, a distance of 220 miles round trip, 5 days per week for a total of 10 weeks. That means this one participant traveled a distance of 11,000 miles total in order to receive treatment. Unfortunately, the cost of travel is not included in standard health insurance policies and is typically and out of pocket expense. Not surprisingly, this participant strongly disagreed that they were able to find a way to get to XRT appointments without difficulty, strongly agreed that traveling when road conditions were poor and that the cost of gas or car repairs would make it harder for them to attend XRT. Although this participant drove the most of all others within the sample, even utilizing the averages from the study reveals that each person would travel a total of 216 miles round trip from their home to treatment and make that journey an average of 3.5 times per week for a little over five weeks. Also worth noting, the one participant who drove the lowest one way distance out of all respondents, 22 miles, stated in the comment section, "I live 215 miles from [the] treatment center. I stayed with family fairly close to treatment."

No participant claimed they utilized public transit as this is a service typically not available within rural communities. The majority of participants (58%, $n = 11$) drove themselves to XRT and traveled alone (53%, $n = 10$). Traveling long distances unaccompanied with the potential for poor road conditions, side effects such as nausea,

pain, and fatigue, and other hazards of travel may place this population at a disproportionate risk for safety concerns (Hegney et al., 2005). Most participants (79%, *n* = 15) felt that traveling for their XRT appointments was difficult a little of the time to most of the time. This sentiment is also echoed within the literature. What was interesting to note is that most participants (83%, *n* = 15) also felt that accessing medical care within the treatment city was either easy or somewhat easy.

In regard to the overall cost of treatment, 24% (*n* = 5) of participants believed that compared to someone who lives in the treatment city their costs were either the same or less expensive. However, the majority still believed costs were more expensive for them, which is consistent with current literature. Participants (89%, *n* = 17) indicated that they thought about the costs of their treatment a little of the time to all the time and only two participants (11%) reported they never thought about treatment costs. Of the two participants indicating they never thought about treatment costs, one was within the highest reported annual income bracket of >$75,000 and surprisingly the other was in the lowest reported income bracket of $10,000-14,999 annually. Both persons reported that they had health insurance and believed it adequately covered the costs of their treatment. In regard to utilizing charitable funds to help pay for expenses, one participant wrote the following in the open response area of the questionnaire, "Assistance with gas and meals through [a local organization who assists cancer patients with costs] was very helpful and very much appreciated. What a blessing!"

All participants (*n* = 21) reported they had some form of health insurance. Of these, only three felt the cost(s) of their XRT was not adequately covered by their

insurance. Within the area on the survey to include further comments no one chose to address why they believed this, nor was there an area for them to further clarify their answer. The impact of XRT-associated costs could be considered to be higher in a population who did not have health insurance.

A variable not fully explored within the study but one that may yield greater insight regarding the associated costs of XRT includes the cost of dependents. The majority of the study sample (67%, *n* = 14) reported no dependents. Further exploration of whether or not there is a perception of increased expense for those who have dependents may provide interesting results.

In regard to accommodation, all residents reported either traveling home each day following treatment (42%, *n* = 8), staying with family in the treatment city (21%, *n* = 4), utilizing lodging provided through a medical program or funded by an organization within the treatment city (26%, n = 5), or a combination thereof (11%, *n* = 2). No one in this study indicated that they paid to stay at a hotel or motel during XRT. This finding is contrary to Hegney and colleagues (2005) who found the majority of rural adults stayed in a motel or other private accommodation during XRT. This study illustrates the importance of medical-lodging programs to house those undergoing treatment for illness. One participant stated, "[I] stayed one week in an apartment provided by the cancer center, which was great... highly recommend this for ones coming from out of town."

When questioned regarding changes to their routines and lifestyles during XRT, participants believed they were able to continue accomplishing what they wanted to in their personal lives some to all of the time (100%, *n* = 20) but conversely, most (70%, *n* =

14) reported that XRT interfered with their social activities some of to all the time. These responses may point to the fact that participants placed greater emphasis on achieving personal tasks than extracurricular activities like attending social events, visiting friends, or spending time with those outside their family. The fact that participants overwhelmingly agreed they felt healthier when they were able to accomplish tasks and that they tend to be independent people correlates strongly with the rural persona identified by Lee and McDonagh (2010) and Bales, Winters, & Lee (2010).

Nearly half the sample (48%, $n = 10$) reported being either retired or unable to work. Therefore, information related to the effects of XRT on employment, receiving time away from work, and perceptions of one's ability to perform their job tasks adequately during times of illness cannot be fully or accurately deduced.

Data from previous studies have indicated that rural residents were more likely to consider costs when making decisions regarding cancer care (Mathews, West, & Buehler, 2009).This did not seem to be the case in this study, however. When asked if they considered the cost of treatment before deciding to undergo radiation, the mean response of the sample ($n = 13$) was "disagree." Participants also disagreed that distance to treatment influenced their decisions regarding cancer treatment. As one participant wrote, "I did what I had to do to live."

It is likely, however, that these responses could be common for the sample selected. In other words, those who had already chosen to undergo XRT may represent a very different mentality than other rural adults who opted out of undergoing XRT.

Considering there is no comparison population of rural residents who chose not to undergo XRT, it is difficult to state whether this finding is significant.

There was only one participant who indicated they were currently undergoing XRT at the time the questionnaire was completed. As a result, it was impossible to compare responses and feelings for those who have completed XRT and those who are currently being treated.

Participants in this study also agreed that they readily trust healthcare providers who are not from their community and somewhat disagreed that they would rather receive treatment at a center staffed by people from their own community. This is in direct contrast of rural nursing theory which states most rural residents are more hesitant to trust those they view as "outsiders" and prefer to receive medical care from those within their community (Long & Weinert, 2010). It is important to note, however, all participants in this study required specialty care not available in their community and agreed to receive treatment from a facility outside of their community. As a result, this finding may not accurately represent the rural population base, including those who chose not to undergo XRT.

Utilization of the socio-ecologic framework was helpful to further understand participant responses. Participants validated that physical-environmental factors like distance to health care services, weather, geography, and transportation availability can influence an individual's experiences and perceptions. Participants indicated they felt supported throughout XRT, had help available if it was needed, and related minimal amounts of stress and anxiety while completing treatment. According to socio-ecologic

theory, participants may feel more supported either through their choices, their families, communities, healthcare providers, or any combination thereof. The feedback within their social ecological environment has the potential to increase positive health behaviors and decrease negative effects like psychosocial distress. Policy behaviors, including insurance and overall treatment availability did not appear to be a factor within the study sample. It can be argued, however, that all participants having health insurance may alter the validity of this finding.

Study Limitations

The study was conducted in one community cancer treatment facility, in one geographic area of one western state in the US, over a limited period of time. There is a potential for bias given the individuals who chose to participate in the study may differ from rural residents who did not participate and from rural residents in other areas of the country; therefore, the results may not be generalized to all rural populations. There was also no control group within the study to validate the uniqueness of responses.

Another limitation to this study is the small sample size ($n = 21$). A small sample size decreases the power of the data and the ability to apply the findings to the larger population.

This study also utilized questions written specifically for this study. Some questions were multiple choice, leaving participants with limited choices. There is the possibility that participants may have answered questions differently had they received

other options. Lastly, the study questions had not undergone rigorous testing to demonstrate validity or reliability, thereby creating a limitation within the study's design.

Implications

Despite identified limitations, the results of the study have implications for both nursing practice and nursing research. This study highlighted considerations unique to rural residents undergoing XRT for cancer treatment. It is important for healthcare providers to understand the potential for unique factors that rural residents may encounter while undergoing XRT; the ability to attend appointments, maintain financial solvency during treatment, maintain relationships, cope with side effects, locate accommodations, travel lengthy and potentially hazardous distances, and alteration of routines and way of life during the treatment period. Nurses and healthcare providers should ensure that rural residents are provided with information prior to the initiation of XRT regarding facilities, funds, and assistance that may be available to them during treatment. It is also recommended that nurses and healthcare providers explore with patients and families their areas of concern or psychosocial problems that may occur during XRT, rather than focusing solely upon physical side effects.

There were findings within this study that contradict data from prior studies. In regard to rural nursing theory and participants from this study willfully trusting healthcare providers from outside their community, additional research is needed to determine whether this statement may be generalized to other illnesses or whether it is unique to the oncology population. Further research is also indicated in regard to

participant response that they did not consider the costs or travel distances when choosing treatment. The use of a comparison populations in future research would aid understanding of whether participant responses may be unique to rural residents, those seeking treatment for cancer, or those currently undergoing treatment versus those who have completed treatment.

The acknowledgement and integration of information regarding potential barriers for rural residents to access care into collegiate and acute care nursing settings is important. Further research may increase awareness and consideration of potential limitations within the rural population and may yield a more holistic, creative, and understanding exchange of ideas and services.

Conclusion

It is known that rural residents face unique challenges and circumstances when accessing health care. This study has illustrated that these may be exacerbated when facing the rigorous regimens commonly associated with radiation therapy for cancer treatment. Participant responses related to travel, lifestyle changes and accommodation during XRT, the financial implications and psychosocial significance of XRT, and treatment decisions both reinforced and refuted current literature. Sullivan, Weinert, and Fulton (1993) wrote, "For health care services to be effective, they must be acceptable and available and must accurately address the needs of individuals and families who are attempting to maintain a quality lifestyle while living with cancer" (p. 49). Unfortunately, the lack of specialized cancer services in most rural areas due to economic rationalism

has made accessing care a challenge for many. However, addressing needs, concerns, and showing interest and empathy and providing support to those seeking care is available regardless of location and should be a skill set cultivated by all health care providers.

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APPENDICES

APPENDIX A

INSTRUCTIONS FOR CANCER CENTER STAFF

January 18, 2011

Frontier Cancer Center Staff:

I would like to thank you for agreeing to assist me with data collection for my Master's of Nursing thesis. The focus of my thesis is to explore the many variables that rural residents experience when being treated with external beam radiation therapy for cancer treatment. I am focusing on residents in eastern Montana and also northern Wyoming. In order to collect information from residents meeting my study's criteria, I am asking you to help me locate them and mail them a packet.

Each packet will contain a letter to each potential participant outlining the research study, a questionnaire for them to complete, and a postage paid envelope for them to return the questionnaire. In order to maintain complete anonymity for the participants I ask you to please address and mail the packets for me. Instructions are included within the mailing that participants should return the packets to me, care of Frontier Cancer Center, with no identifying information on the envelopes.

I am asking you to mail the packet to rural residents in eastern Montana and northern Wyoming:

1. Adults (21 years and older), AND
2. Currently undergoing external beam radiation therapy, OR
3. Completed external beam radiation therapy in 2011 and 2012.

In order to exclude areas of larger population density, do not mail the packet to persons living in:

1. The following zip codes: 59101, 59102, 59103, 59104, 59105, 59106, 59107, 59108, 59111, 59112, 59114, 59115, 59116, and 59117, OR
2. Red Lodge, Laurel, or Billings, Montana or Cody or Powell, Wyoming.

It is my goal to mail approximately 50 packets to participants.

After all packets have been mailed I will allow participants two weeks to return them. They will then be collected by me from your facility. Upon complete analysis of the responses I will be more than willing to share the results with anyone interested.

Thank you for your assistance with this. I am truly grateful!

Sincerely,

Alana Barber, RN, BSN, OCN
Master's of Nursing, Family Nurse Practitioner Option
Montana State University

Survey Mailing Instructions

1. IDENTIFY PATIENTS who meet the following criteria:
    a. Adults (21 years and older), AND
    b. Currently undergoing external beam radiation therapy, OR
    c. Completed external beam radiation therapy in 2011 and 2012.
3. EXCLUDE PATIENTS living in the following zip codes and areas:
    a. 59101
    b. 59102
    c. 59103
    d. 59104
    e. 59105
    f. 59106
    g. 59107
    h. 59108
    i. 59111
    j. 59112
    k. 59114
    l. 59115
    m. 59116
    n. 59117
    o. Red Lodge
    p. Laurel
    q. Billings
    r. Cody, WY
    s. Powell, WY
4. MAIL the packet:
    a. Participant letter
    b. Survey
    c. Self-addressed return envelope
5. Continue to mail packets until 50 packets have been mailed.

APPENDIX B

QUESTIONNAIRE COVER LETTER

CONSIDERATIONS FOR RURAL RESIDENTS UNDERGOING RADIATION THERAPY
Alana Barber, RN, BSN, OCN
Participant Explanation Form

I am a graduate nursing student at Montana State University studying to become a family nurse practitioner. I am interested in learning about the experiences of rural residents who are currently undergoing or have recently completed radiation therapy for cancer treatment. Frontier Cancer Center has recommended you as someone who may be willing to complete a questionnaire about your experiences during radiation therapy. Please take approximately 20 minutes to complete the attached questionnaire and return it via the enclosed postage-paid envelope. Your participation is strictly voluntary and anonymous. Please do not write anything that may identify you on either the questionnaire or return envelope.

If you decide to complete the survey, you will help me better understand the unique circumstances rural residents may encounter when receiving radiation therapy. Your answers will be grouped with other peoples' answers and reported as part of a research study I am conducting as part of my graduate nursing studies. Your name will not be known to me or be made public. While people often enjoy sharing information regarding their feelings and experiences, others do not. If you do not wish to complete the questionnaire, you are not obligated to do so.

You are welcome to contact me, Alana Barber, RN, BSN, OCN, should you have any concerns or questions about the survey. I can be reached at (406) xxx-xxxx or emailaddress@msu.montana.edu. You may also contact my instructor, Dr. Charlene Winters at (406) 243-4608 or winters@montana.edu. If you have concerns about your rights as a research participant, please contact Dr. Mark Quinn, the Chairman of the Institutional Review Board at Montana State University at (406) 994-4707 or mquinn@montana.edu.

Thank you for your time.

Sincerely,
Alana Barber, RN, BSN, OCN

APPENDIX C

STUDY DETAILS FOR PARTICIPANTS

Title: Considerations for Rural Residents Undergoing Radiation Therapy for Cancer Treatment

Principal Investigator: Alana C. Barber, RN, BSN, OCN

Co investigator (Instructor): Charlene Winters, PhD, ACNS-BC

STUDY DETAILS

A. Introduction and Purpose

You are being asked to participate in a research study conducted by a graduate nursing student from Montana State University, College of Nursing. The purpose of this study is to explore the experiences of rural residents undergoing external beam radiation therapy for cancer treatment.

B. Procedure

You will be asked to complete the questionnaire that has been mailed to you. The approximate time needed to complete this questionnaire is 20 minutes. When you have completed the questionnaire please place it inside the postage-paid return envelope and place it in the mail.

C. Benefits

There is no direct benefit to you if you participate in this study. The information obtained from this study may allow nurses to better understand the unique needs associated with cancer treatment, especially for those living farther away from treatment centers.

D. Risks

No risks or additional effects are likely to result from your participation in this study. In the unlikely event of harm arising from your participation, no reimbursement, compensation, or free medical treatment will be offered by Montana State University, or the researcher. If you become distressed due to the questions on the study questionnaire you will be referred to discuss this with your oncologist.

E. Voluntary Participation/Withdrawal

Your participation in this study is voluntary and you are free to withdraw at any time. If you should choose to withdraw from the study you will in no way

be compromised. Because we are not asking you to sign this questionnaire or for any
other identifiers, your information will not be identifiable.

F. Costs

There are no costs involved in your participation in this study.
The student investigator has received no funding to complete this study.
The funding necessary to conduct this study is the sole responsibility of the student investigator. There is no financial incentive for this research to be conducted and the student investigator has no financial support to disclose.

G. Compensation

There is no compensation being offered for your participation in this study.

H. Confidentiality

All information collected from the course of this study will be kept confidential to the extent permitted by law. All identification in the research records will be by ID number only, and the completed questionnaires will be stored in a locked file cabinet that will be accessible only to the investigator. All results will be summarized and presented in aggregate; no individual participant will be identifiable.

I. Questions

If you have any questions about the items on the questionnaire or the purpose of the study, please feel free to contact the investigators at your earliest convenience. Ms. Barber can be contacted at 406-xxx-xxxx. Dr. Winters may be contacted at 406-243-4608. If you would like information regarding your rights as a research participant, please feel free to contact Chairman of the Institutional Review Board at Montana State University, Mark Quinn. He may be reached at 406-994-4707.

J. Consent to participate in a research study

The return of your completed questionnaire is evidence of your willingness to participate in this study. You will not be asked to sign a separate “willingness to participate” document because of participant anonymity. Please retain this information letter in case you have any questions or would like additional information about this study.

APPENDIX D

RESEARCH QUESTIONNAIRE

CONSIDERATIONS FOR RURAL RESIDENTS UNDERGOING EXTERNAL BEAM RADIATION THERAPY

Answer the following questions to the best of your ability by entering the information requested in the blank provided. Please provide only one answer per question.

1. Are you (check only one answer):

A. Currently receiving radiation therapy ☐

B. Finished with radiation therapy ☐

2. How far do/did you travel (ONE WAY) for your radiation treatments? (*Please try to be as accurate as possible when recording the distance. For example: 8 city blocks or 3.75 miles, etc. Please answer both questions.)*

A. Number of miles (one way)_____

B. Approximate travel time (one way)_____

3. How many days a week do/did you travel for your radiation treatments? _____

4. What is/was the duration of your radiation treatment? (*For example: 12 treatments total, or 5 days a week for four weeks, etc.)*

_____

5. For what diagnosis are/did you receive radiation therapy?_____

6. In what state do you live?_____

For the following questions, place an "X" next to the answer that best matches your response. Mark only one answer per question.

7. Where would you describe yourself as living? (*Check the answer that best corresponds with your living situation.)*

_____On a farm/ranch
_____In a rural area (not a farm/ranch)
_____In a small rural town
_____In a small town
_____Other (please specify)_____

8. Which best describes the size of the city/town you are currently living in or is closest to you?

_____Less than 500 people
_____501 - 1,000 people
_____1,001 - 2,000 people
_____2,001 - 2,500 people
_____2,501 - 5,000 people
_____5,001 - 10,000 people
_____10,001 - 30,000 people
_____More than 30,001 people

The following questions relate to your experiences during the time of your radiation therapy. For these questions, please choose the response you feel is most accurate and place an "X" next to it.

9. I made it to my radiation therapy appointments by:

_____Driving myself
_____Riding with a family member
_____Riding with a friend
_____Public transportation (taxi, bus, shuttle)
_____Other (please explain)_____

10. During radiation therapy I was accompanied to my appointments by:

_____No one
_____My spouse or significant other
_____A relative
_____A friend
_____Other (please explain)_____

11. During radiation therapy I felt like traveling for appointments was difficult

_____All of the time
_____Most of the time
_____Some of the time
_____A little of the time
_____None of the time

12. During the time I was undergoing radiation treatment I most often:

_____Drove home every day after treatments
_____Stayed with family in the treatment city
_____Stayed with friends in the treatment city
_____Stayed in a hotel or motel in the treatment city
_____Stayed in lodging provided through a medical program or funded by an organization in the treatment city
_____Other (please explain)_____

13. After my diagnosis, accessing medical care in the treatment city was:

_____Easy
_____Somewhat easy
_____Somewhat difficult
_____Difficult
_____Neither easy nor difficult

14. During the period I received radiation I thought about the cost(s) of treatment:

_____All of the time _____A little of the time
_____Most of the time _____None of the time
_____Some of the time

The following questions relate to your experiences during the time of your radiation therapy. For these questions, please choose the response you feel is most accurate and place an "X" next to it.

15. Compared to someone who lives in the treatment city, I feel costs for me are/were:

_____Less expensive
_____The same
_____Somewhat more expensive
_____Much more expensive

16. Radiation therapy has been/was stressful for me

_____All of the time _____A little of the time
_____Most of the time _____None of the time
_____Some of the time

17. I felt supported by others during the time I was undergoing radiation therapy

_____All of the time _____A little of the time
_____Most of the time _____None of the time
_____Some of the time

18. During the time I was undergoing radiation therapy I felt like I accomplished what I needed to in my personal life

_____All of the time _____A little of the time
_____Most of the time _____None of the time
_____Some of the time

19. If I needed help with a task or errand during the time I was undergoing radiation therapy someone was available to help me

_____All of the time _____A little of the time
_____Most of the time _____None of the time
_____Some of the time

20. During the time I was undergoing radiation therapy it interfered with my social activities like visiting friends, attending events, spending time with others

_____All of the time _____A little of the time
_____Most of the time _____None of the time
_____Some of the time

The following questions relate to your feelings about radiation therapy. For each question indicate your level of <u>agreement</u> or <u>disagreement</u> by circling the appropriate number (only <u>ONE</u> number per statement).

	Strongly disagree	**Disagree**	**Somewhat disagree**	**Neither agree nor disagree**	**Some-what agree**	**Agree**	**Strongly agree**
21. The distance to the radiation center made it difficult for me to access my treatment	1	2	3	4	5	6	7
22. I was able to find a way to get to radiation treatment appointments without difficulty	1	2	3	4	5	6	7
23. If I had to travel to radiation therapy appointments when road conditions were poor it would be difficult for me to attend	1	2	3	4	5	6	7
24. The cost of gas or car repairs might make it harder for me to attend radiation therapy	1	2	3	4	5	6	7
25. It is/was easy for me to drive in the town where I received radiation therapy	1	2	3	4	5	6	7
26. My job does/did not interfere with my ability to attend radiation therapy appointments	1	2	3	4	5	6	7
27. Side effects (pain, fatigue, nausea, etc) from cancer treatment made it difficult for me to travel to radiation appointments	1	2	3	4	5	6	7

28. Undergoing radiation therapy was difficult because of the type of work I do	1	2	3	4	5	6	7
	Strongly disagree	**Disagree**	**Somewhat disagree**	**Neither agree nor disagree**	**Some-what agree**	**Agree**	**Strongly agree**
29. It was difficult to take time away from my work to attend radiation therapy	1	2	3	4	5	6	7
30. I readily trust healthcare providers who are not from my community	1	2	3	4	5	6	7
31. I would rather receive treatment at a center that is staffed by people from my community	1	2	3	4	5	6	7
32. Radiation therapy affected with my ability to maintain my household	1	2	3	4	5	6	7
33. Radiation therapy altered my routines	1	2	3	4	5	6	7
34. During radiation therapy I was able to perform everyday physical activities	1	2	3	4	5	6	7
35. I was satisfied with my level of physical functioning during radiation therapy	1	2	3	4	5	6	7
36. I tend to be an independent person	1	2	3	4	5	6	7
37. When I am able to be productive I feel healthier	1	2	3	4	5	6	7

38. In my day to day life I often rely on others for assistance	1	2	3	4	5	6	7
39. I felt stressed during my radiation therapy	1	2	3	4	5	6	7
40. I have felt anxious about radiation therapy	1	2	3	4	5	6	7
41. Distance to the treatment center influenced my decisions regarding cancer treatment	1	2	3	4	5	6	7
	Strongly disagree	**Disagree**	**Somewhat disagree**	**Neither agree nor disagree**	**Some-what agree**	**Agree**	**Strongly agree**
42. I considered the cost of treatment before deciding to undergo radiation	1	2	3	4	5	6	7

For the following questions, please mark the answer that best describes you.

43. How old were you on your last birthday?

_____years

44. Gender:

Male_____ Female_____

45. Ethnicity:

_____Hispanic or Latino

_____Not Hispanic or Latino

46. Race:

_____American Indian/Alaskan Native

_____Asian

_____Native Hawaiian or Pacific Islander

_____Black or African American

_____White

47. Education:

Please indicate the highest degree or level of school you have completed. If you are currently enrolled, mark the previous grade or highest degree received.

_____No schooling completed
_____Nursery school to 8th grade
_____9th, 10th, or 11th grade
_____12th grade, no diploma
_____High school graduate - high school diploma or GED
_____Some college / did not graduate
_____Associate degree
_____Bachelor's degree
_____Master's degree
_____Professional/Doctorate degree

For the following questions, please mark the answer that <u>best</u> describes you.

48. Employment Status *(Please mark all that apply)*:
Are you currently...

_____Employed for wages
_____Self-employed
_____Unemployed
_____A homemaker
_____A student
_____Retired
_____Unable to work

49. Annual household income:

_____Less than $10,000
_____$10,001 - $14,999
_____$15,000 - $19,999
_____$20,000 - $24,999
_____$25,000 - $34,999
_____$35,000 - $49,999
_____$50,000 - $74,999
_____$75,000 or more

50. Marital Status:

_____Married
_____Living with Significant Other
_____Single/Never Married
_____Widowed
_____Divorced
_____Separated

51. Living Situation:

_____Live alone
_____Live with spouse or significant other
_____Live with family member(s)
_____Live with friend or roommate

52. Dependents:

How many dependent persons/children are you currently supporting financially?

_____None
_____One
_____Two
_____Three
_____Four
_____Five or more

53. Insurance:

A. Do you currently have health insurance?

_____Yes
_____No

B. If you answered "yes," do you feel your insurance adequately covers the cost of your radiation treatment?

_____Yes
_____No

Please feel free to include any other information you would like to share regarding your experiences, thoughts, or feelings during radiation therapy in the space below.

Thank you for taking the time to complete this questionnaire! Please return your completed questionnaire in the enclosed postage-paid envelope. Please do not put anything on the return envelope that may identify you.