

Treatment-Related Needs of Statewide Cancer Survivors

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Abstract

Introduction: Research on surviving cancer treatment is a national priority and there is a need to understand the experiences of survivors from predominantly rural areas. The purpose of this study was to identify the perceptions of treatment and post-treatment issues for cancer survivors living in South Dakota. Multidimensional aspects of cancer-related needs were explored, including: psychosocial, physical, spiritual, health promotion and access to care issues.

Methods: The design was a cross-sectional survey of cancer survivors who completed their course of treatment at five accredited cancer treatment centers in South Dakota two years prior to the study. The survey was derived from a synthesis of other published instruments, with added items that focused on issues of interest to rural dwellers. There were 524 of 1933 mailed surveys returned (27 percent response).

Results: Respondents identified needs for help coping with various emotions more frequently than needs related to finding support and taking care of practical issues post-treatment. Specifically, coping with uncertainty and finding hope were priority needs (33 percent and 36 percent, respectively), while accessing counseling services and financial planning were low priority (9 percent and 14 percent, respectively). There were limited numbers of participants who reported that access to care (time, expense, travel) interrupted their cancer treatment.

Conclusions: Perceptions of treatment-related needs of cancer survivors living in South Dakota include broad health promotion, practical and, most commonly, emotional concerns. Health care providers who assess for and identify these needs require a keen awareness of community resources to support South Dakota cancer survivors.

INTRODUCTION

A cancer diagnosis can impact all aspects of an individual's personal and family life. In a recent state of the science paper on cancer survivorship, the authors classified these issues into three categories.¹ Acute issues are those that resolve after completion of treatment (e.g., nausea, alopecia). Insidious issues persist over time and thus become chronic (e.g., fatigue, memory problems, fear of recurrence). Emergent issues occur months or even years after cessation of treatment (e.g., osteoporosis, insurability). In addition, there are psychosocial and financial issues that often pervade these time periods. The science of understanding and improving these health and quality of life concerns for cancer survivors is unfolding, yet there is a need to focus additional research on understudied and underserved populations, including cancer survivors from predominantly rural areas.¹⁻⁴

Rural communities are characterized as having greater poverty, older populations, service access issues, lack of privacy and isolation.⁵ These integral aspects of rural life produce what have been described as rural values: self-reliance, independence, conservatism, a distrust of others, work orientation, family-centered, religion, individualism and fatalism.⁶ Cancer survivor needs during treatment may be different for residents of rural cultures, where independent and self-reliant values predominate in judgments about perceived needs. Access to care issues are identified as critical issues for rural dwellers, but perceptions of these as important cancer care concerns may be tempered by rural values.

Previous studies of cancer survivor needs have focused on specific cancers such as breast,^{7,8} prostate,⁹ couples and partners,¹⁰ young adults¹¹ and other geographic areas, including northeastern states in the US,¹² England¹³ and

Australia.¹⁰ The needs of 420 rural families living with cancer and who resided in rural Montana or Wyoming were explored.¹⁴ Self-identified needs included coping with cancer and with change, knowledge, support, spiritual and group support, as well as interpersonal relationships and other less frequently cited issues. A synthesis of 41 qualitative and quantitative studies that focused on rural women with breast cancer identified four predominant survivor issues: access to treatment and treatment type, access to medical providers and health information, psychosocial adjustment and coping needs, and both social and psychological support services.¹⁵ These authors also cite that rural women have less access to mental health resources. No prior studies have been conducted with a population-based sample of all cancer survivors who completed their course of treatment at a cancer treatment center in a rural Northern Plains state where they reside.

The purpose of this study was to identify the perceptions of treatment-related issues for cancer survivors who received their treatment in South Dakota. Multi-dimensional aspects of cancer treatment needs were explored, including: psychosocial, physical, spiritual, health promotion and access to care issues.

METHODS

Design & Participants

The design was a cross-sectional survey of adult cancer survivors who completed their course of treatment at one of the seven cancer treatment centers in South Dakota two years prior to the study. Of the seven cancer treatment centers, two did not participate due to staffing and budget constraints. The time interval of two years post-treatment was selected so that patients would be at least one year beyond their first full course of treatment, and, therefore, past any acute problems associated with chemotherapy. Of the 1,933 surveys mailed, 524 were returned (27 percent). There were seven respondents who did not complete the full survey. The two-page survey was derived from a synthesis of three published instruments,^{13,16,17} with added items that focused on issues of interest to rural dwellers. Items examined personal, practical, emotional and spiritual concerns and factors influencing access to care.

Measures & Procedures

The South Dakota Cancer Survivor Survey was developed by members of the South Dakota Comprehensive Cancer Control Coalition and evaluated by South Dakota cancer survivors prior to the study. The two-page survey contained 43 questions, which were either derived from related instruments,^{13,16,17} or specifically developed for the target population of survivors from a predominately rural area. Rural-focused items included questions about distance traveled to receive treatment and whether or not the cost of travel or lodging caused a lapse in the cycle of treatment.

Existing instruments focused on quality of life or psychosocial needs, which limited their applicability in this effort to understand broader issues. Survey items examined the presence of multi-dimensional aspects of needs during and after cancer treatment, including personal, practical, emotional and spiritual concerns and factors influencing information, education and access to care. Respondents checked the issues that applied to their experience.

The survey was pilot tested with seven cancer survivors using a simple evaluation tool published by the National Cancer Institute.¹⁸ The form was modified to include a lead statement as follows: "Consider what a meaningful way of asking cancer survivors about their needs would be like, please document your evaluation of the survey." The evaluation used a six-point Likert response scale (1=excellent to 6=unacceptable). Written comments were requested. Decisions about retaining, revising or rejecting the survey were based upon a minimum acceptable mean score of < 3.0 (3=good) for each item in the tool. Results indicated that the draft survey was easily interpreted and meaningful. There were suggestions to add more information on healthy living, such as exercise, healthy eating, tobacco cessation and reducing alcohol intake. The survey was easy to understand, took 10 minutes to complete and was acceptable to the target population.

Institutional Review Board approval was obtained from the cancer treatment centers prior to the study. All cancer survivors who completed their course of treatment two years prior to the study were surveyed. A cover letter, the two-page survey and a stamped return envelope were mailed by the cancer treatment centers to each eligible participant. A project liaison from each cancer treatment center mailed the completed surveys to the study's coordinator. Participant consent was implied by completing the survey. The only identifiers on the return mailing were codes that identified the treatment center where participants received care.

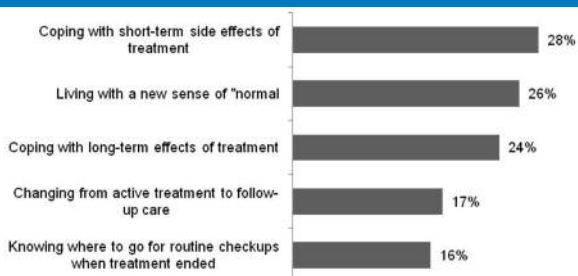
Analysis

Data were entered into a Microsoft Access database independently by two individuals and cross-checked for errors and analyzed using the Statistical Package for the Social Sciences®, version 16.0. Item responses are reported using frequency counts. An analysis of variance (ANOVA) was conducted to determine differences in treatment needs among survey respondents of varying income levels and distances traveled to receive treatment.

RESULTS

Demographics

Respondents were primarily Caucasian (98 percent), 2 percent were Native American and fewer than 1 percent were Black, Asian or Hispanic. Gender distribution was 66 percent female, 34 percent male and 70 percent were

FIGURE 1. Percent of respondents who could have used more help with the following treatment and post-treatment issues.

married. Participants were primarily older adults (mean=65.7, SD=14.3). Seven percent were age 85 or older, 21 percent were ages 75 to 84 and 24 percent were ages 65 to 74. In the younger than age 65 group, 20 percent were 55 to 64, 15 percent were ages 45 to 54 and 5 percent were under age 44.

Twenty-six percent had completed four or more years of college and 26 percent had completed one to three years of college, while 37 percent completed high school or a GED, and 10 percent reported less than a high school education. Thirty-five percent of respondents had an annual income under \$20,000, 41 percent had an annual income of \$20,000 to \$50,000, and 23 percent had an annual income of \$50,000 or higher.

Cancer and Treatment

More than 50 percent of female respondents were breast cancer survivors, while nearly 50 percent of male respondents were prostate cancer survivors. Nine percent of female respondents and 14 percent of male respondents were colorectal cancer survivors. The most common form of cancer treatment was surgery (72 percent). One-half of the respondents had received radiation and 41 percent had received chemotherapy.

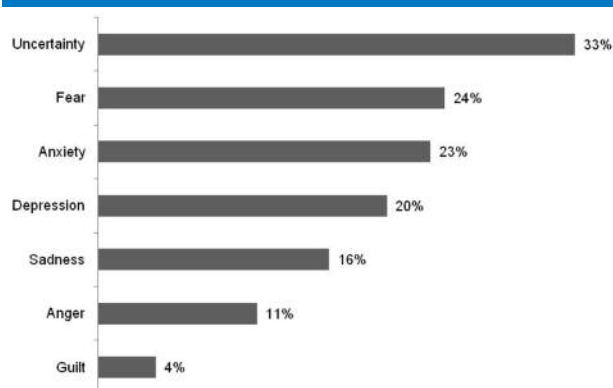
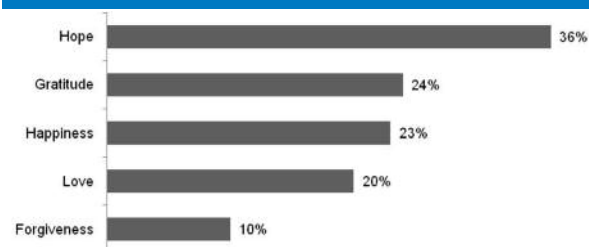
Cancer-related Needs

Health Promotion

The two items related to health promotion needs were eating healthfully and quitting tobacco. Twenty-nine percent of respondents indicated that they could have used more help with or teaching about eating healthfully while 8 percent indicated they would have or could have used more help with quitting tobacco.

Treatment and Post-Treatment

Five items addressed treatment or post-treatment related needs. The most frequently cited needs were: coping with short-term side effects (28 percent), living with a new sense of "normal" (26 percent) and coping with the long-term effects of treatment (24 percent). Less frequently cited needs were: changing from active treatment to follow-up care and knowing where to go for routine check-ups when treatment ended (Figure 1).

FIGURE 2. Percent of respondents who could have used more help with the following feelings.**FIGURE 3. Percent of respondents who could have used more help with the following feelings.**

Practical/Personal

Four items addressed practical and personal issues related to cancer care. Less than 20 percent of respondents identified that they could have used more help with or teaching about: keeping the household running (17 percent), financial planning (14 percent), returning to work (11 percent) and other practical issues (8 percent), such as emotional support for family members and finding cancer-related resources.

Psychosocial, Spiritual and Emotional

Eighteen items addressed psychosocial, spiritual and emotional needs. Some participants identified that they could have used more help with finding support (13 percent) and accessing alternative therapies (12 percent) and counseling services (9 percent). Seven items addressed coping with various emotions, and 33 percent of respondents identified uncertainty as an emotion they could have used more help with, followed by fear (24 percent), anxiety (23 percent) and depression (20 percent) (Figure 2).

Five items addressed the experience of positive emotions, and 36 percent of respondents identified "hope" as an emotion they could have used more help with (Figure 3). Some participants identified that they could have used more help with understanding changing relationship with family (31 percent), friends (22 percent) and co-workers (11 percent).

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Information, Care and Support

The most common ways respondents preferred to receive cancer information was from written material (40 percent), a health care specialist (36 percent) or a cancer survivor (31 percent) (Figure 4). There were 22 percent who preferred to use the Internet. Six percent of respondents indicated it was hard for them to find information about cancer.

During treatment, approximately two-thirds of respondents saw a surgeon (66 percent) and/or an oncologist (71 percent), and 46 percent saw a primary care provider. A family member served as the primary caregiver during treatment (68 percent) and as a support mechanism (80 percent). Other common means of support were church/faith (53 percent) and friends (52 percent) (Figure 5). Less-frequently cited sources of support were books/articles, community members, the Internet and cancer-related organizations or groups.

Access to Care Needs

Nearly three-fourths of respondents had private health insurance and 52 percent were covered by Medicare. Only 4 percent were covered by Medicaid, and 2 percent did not have health insurance. Prior to their cancer diagnosis, 38 percent indicated they had cancer insurance. Since finishing treatment, 80 percent cited no insurance changes or difficulties. For those with insurance changes or difficulties, specific issues included: having problems because cancer is a pre-existing condition, not being able to get the desired treatment because of issues with the insurance provider, not being able to obtain health insurance, losing health insurance and reaching the health insurance lifetime maximum.

Distance traveled to access cancer treatment was explored. Nearly one-half of participants traveled less than 50 miles to receive treatment. About one-third of participants traveled 50 to 99 miles to access treatment (Figure 6). The most common modes of transportation were family members (63 percent) and self (49 percent).

The added cost and time away from home due to overnight travel for treatment was of interest. Nearly one-third of respondents (31 percent) reported treatment-related overnight stay at a hotel (46 percent), the hospital (41 percent) or a friend or family member's home (21 percent). Frequency of overnight travel was reported as the number of nights per month. Most overnight stays were for three or more nights per month (60 percent). Extended stays of seven nights or more were reported by 26 percent. Shorter stays of one to two nights per month were reported by 40 percent. Survivors were asked whether travel costs or overnight arrangements caused them to miss treatment. While only 1 percent cited missing treatment due to these issues, there was 17 percent who reported that the cost of travel was a financial hardship.

FIGURE 4. Percent of respondents who preferred the following modes to receive health information.

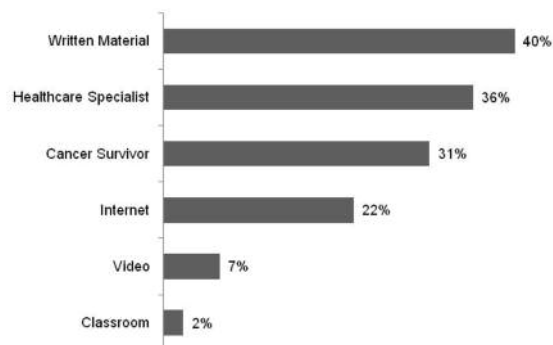


FIGURE 5. Percent of respondents who used the following means of support during cancer experience.

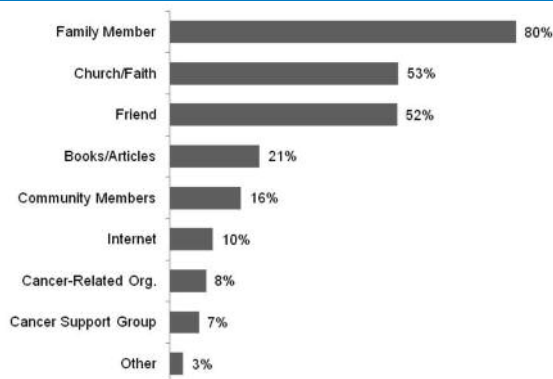
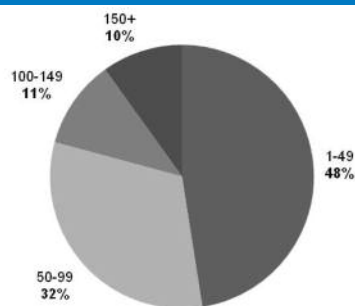


FIGURE 6. Percent of respondents who traveled the following number of miles to treatment (n=327).



Effect of Cancer Treatment on Employment

Survivors were asked whether their employment status changed after completing cancer treatment. More than one-half (54 percent) reported employment prior to treatment initiation. Following treatment, 44 percent were employed. Reasons for changes in employment status were due to retirement, unemployment or disability. There was a 4 percent increase in the number who indicated that they

were retired from pre-treatment (32 percent) to post-treatment (36 percent). There were less than 1 percent of participants who were unemployed prior to treatment, but this percentage increased to 4 percent after treatment. Trends in disability status changed in the same direction, with 2 percent of participants reporting a disability prior to treatment and 5 percent reporting a disability after treatment.

DISCUSSION

In this cross-sectional study, psychosocial issues were at the forefront of cancer survivor needs post-treatment. Coping with emotions, looking for the bright side and understanding changing relationships were frequently cited needs. Coping with stresses and changes that resulted from the cancer diagnosis was also the main challenge expressed by rural Montanans, who are demographically similar to the participants in this study.¹⁴ These results are also similar to another study that examined the unmet psychosocial concerns of cancer patients and discovered that emotions and social identity were the most significant unmet needs rather than clinical or physical experiences.¹³ A smaller proportion of the study participants, who were from the United Kingdom (UK), experienced these needs compared to this sample of survivors living in the rural Northern Plains region of the US. In the UK study, 10 percent reported coping with fear as an unmet need, while 24 percent of the survivors in this study reported the same need.

Access to care issues (i.e., travel costs and overnight arrangements) were not frequently cited as barriers to receiving treatment. Another study reported that people make the extra journey to receive cancer treatment and do not view missing treatment as an option.¹⁴ There is some evidence that geographic distance (i.e., travel time) has an inverse relationship to receiving specialized care when few such facilities are available.¹⁹ A study done in rural New Hampshire and Vermont found that patients who lived farther from a treatment center were more likely to receive surgery versus chemotherapy or radiation since it often requires a one-time visit versus multiple visits.²⁰ While rural dwellers may not view their proximity to a treatment center as a barrier, distance may affect their satisfaction with their treatment plan and its subsequent effect on their personal and professional life. In a literature review of the experience of rural women with breast cancer, rural women undergoing breast cancer treatment reported that traveling long distances for treatment affected family life and employment.¹⁵ Further exploration of the relationship between travel distance and satisfaction with treatment plan is needed.

There were several limitations to this study. While data was gathered on travel distance to receive treatment, geographic distribution of respondents and whether they lived in a

rural or frontier area of the state was not determined. If distance is a barrier to treatment, then residents from rural and frontier areas may have a higher cancer mortality rate, which would result in fewer responses from rural and frontier cancer survivors, thus potentially skewing the results. From 2003 to 2007, the average cancer mortality rate in South Dakota was 190.8 per 100,000, with significantly higher rates existing in five counties in western South Dakota and two in southeastern South Dakota.²¹

Findings from this study reflect the treatment and post-treatment needs of adult cancer survivors in South Dakota, a predominantly rural state. Results cannot be generalized to all cancer survivors. The sample was mainly Caucasian, thus limiting interpretation of findings across racial/ethnic groups. Compared to the demographics of new cancer cases in 2007, this sample had a higher number of females, and the age distribution was similar to that of the statewide distribution.²¹

Another limitation to this study is non-response bias. The response rate was 27 percent, which is typical for surveys that do not include reminders or incentives and are not from a well-known institution, but it does limit the validity and reliability of the findings. Those that responded to the survey may be different than those who did not respond.

These findings are useful in guiding practitioners and program developers as to what services and resources their cancer patients need, especially for underserved or rural populations. For example, incorporating counseling or support services and referrals that help cancer survivors cope with the many emotions they experience while transitioning to life after treatment may alleviate some of these concerns. Also, addressing the psychosocial and insidious needs, in addition to the physical and acute needs, would enhance the level of care patients receive. Future studies should also assess how these survivor needs change from year to year.

CONCLUSION

Health-related needs of cancer survivors living in a predominantly rural state include emotional, spiritual and broad health promotion concerns. Health care providers need to assess for these needs both during and post-treatment. Referral to community resources for meeting cancer survivor needs is a priority for rural communities. Future studies should examine how these needs evolve over time and also examine more closely the burden and effect of access to care issues.

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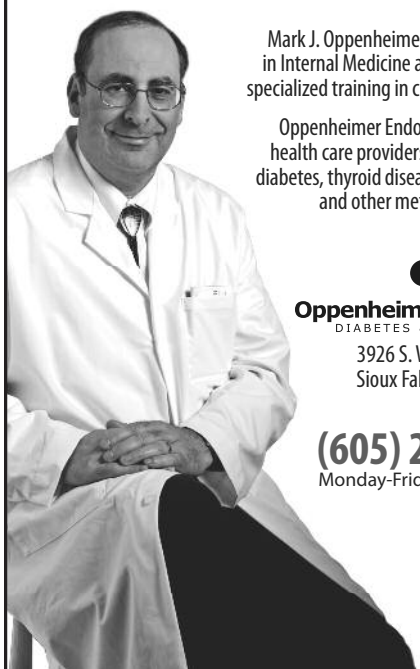
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REFERENCES

1. Rowland JH, Bellizzi KM. Cancer survivors and survivorship research: a reflection on today's successes and tomorrow's challenges. *Hematol Oncol Clin N.* 2008;22:181-200.
2. President's Cancer Panel: Report of the Chairman, 2000-2001. Voices of a broken system: real people, real problems. Bethesda, MD: National Cancer Institute; 2001.
3. Institute of Medicine. Unequal burden of cancer. Washington, DC: National Academy Press; 1999.
4. Institute of Medicine. Crossing the quality chasm: a new health system for the 21st century. Washington, DC: National Academy Press; 2001.
5. Stamm BH. Rural behavioral health care: an interdisciplinary guide. Washington, DC: American Psychological Association; 2003.
6. Wagenfeld MO. A snapshot of rural and frontier America. In Stamm BH, ed. Rural behavioral healthcare: an interdisciplinary guide. Washington, DC: American Psychological Association; 2003: 33-40.
7. Thewes B, Butow P, Girgis A, Pendlebury S. The psychosocial needs of breast cancer survivors: a qualitative study of the shared and unique needs of younger versus older survivors. *Psycho-Oncol.* 2004;13(3):177-189.
8. Cappiello M, Cunningham RS, Knopf MT, Erdos D. Breast cancer survivors: information and support after treatment. *Clin Nurs Res.* 2007;16(4):278-293.
9. Duke JM, Treloar CJ, Byles JE. Evaluation of a revised instrument to assess the needs of men diagnosed with prostate cancer. *Support Care Cancer.* 2005;13(11):895-903.

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