# UCSF UC San Francisco Previously Published Works

# Title

Rural cancer survivors' health information needs post-treatment

# Permalink

https://escholarship.org/uc/item/25t4z0nk

## Journal

Patient Education and Counseling, 103(8)

# **ISSN**

0738-3991

# Authors

Palmer, Nynikka R Avis, Nancy E Fino, Nora F <u>et al.</u>

# **Publication Date**

2020-08-01

# DOI

10.1016/j.pec.2020.02.034

Peer reviewed



# **HHS Public Access**

Patient Educ Couns. Author manuscript; available in PMC 2021 August 01.

Published in final edited form as:

Author manuscript

Patient Educ Couns. 2020 August ; 103(8): 1606–1614. doi:10.1016/j.pec.2020.02.034.

# Rural Cancer Survivors' Health Information Needs Post-Treatment

Nynikka R. Palmer<sup>a</sup>, Nancy E. Avis<sup>b</sup>, Nora F. Fino<sup>c</sup>, Janet A. Tooze<sup>c</sup>, Kathryn E. Weaver<sup>b</sup>

<sup>a</sup>Department of Medicine, University of California San Francisco, San Francisco, California, USA

<sup>b</sup>Department of Social Sciences and Health Policy, Wake Forest School of Medicine, Winston-Salem, North Carolina, USA

<sup>c</sup>Department of Biostatistical Sciences, Wake Forest School of Medicine, Winston-Salem, North Carolina, USA

## Abstract

**Objective:** This study describes the most common cancer-related health information needs among rural cancer survivors and characteristics associated with reporting more information needs.

**Methods:** Rural breast, prostate, and colorectal cancer survivors, two to five years post-diagnosis, identified from an institutional cancer registry, completed a mailed/telephone-administered survey. Respondents were asked about 23 health information needs in eight domains (tests and treatment, side effects and symptoms, health promotion, fertility, interpersonal, occupational, emotional, and insurance). Poisson regression models were used to assess relationships between number of health information needs and demographic and cancer characteristics.

**Results:** Participants (n=170) reported an average of four health information needs, with the most common domains being: side effects and symptoms (58%), health promotion (54%), and tests and treatment (41%). Participants who were younger (compared to 5-year increase, rate ratio [RR]=1.11, 95% CI=1.02–1.21), ethnic minority (RR=1.89, 95% CI=1.17–3.06), less educated (RR=1.49, 95% CI=1.00–2.23), and financially stressed (RR=1.87, 95% CI=1.25–2.81) had a greater number of information needs.

**Conclusions:** Younger, ethnic minority, less educated, and financially strained rural survivors have the greatest need for informational support.

**Practice Implications:** The provision of health information for rural cancer survivors should consider type of cancer, treatments received, and sociocultural differences to tailor information provided.

Declarations of interest: None

Corresponding author at: Nynikka R. Palmer, Department of Medicine, Division of General Internal Medicine, University of California, San Francisco, Building 10, 3<sup>rd</sup> Floor, UCSF Box 1364, San Francisco, CA 94143, USA, Phone: 628-206-4334; Fax: 628-206-5586; nynikka.palmer@ucsf.edu.

**Publisher's Disclaimer:** This is a PDF file of an unedited manuscript that has been accepted for publication. As a service to our customers we are providing this early version of the manuscript. The manuscript will undergo copyediting, typesetting, and review of the resulting proof before it is published in its final form. Please note that during the production process errors may be discovered which could affect the content, and all legal disclaimers that apply to the journal pertain.

cancer survivorship; rural; health information needs; posttreatment

## 1. Introduction

Cancer survivors are living longer after diagnosis due to early detection and improved treatments [1]. However, survivors are at risk for poor health and well-being due to the long-term and late effects of cancer and its treatment [1,2]. Many cancer survivors experience physical (e.g., fatigue, heart damage), psychosocial (e.g., emotional distress, fear of recurrence), and financial sequelae that persists or arise over time [1]. It is essential to fulfill survivors' health-related information needs as this leads to increased patient engagement and activation [3], enhanced knowledge and satisfaction with care [4], less anxiety [5], adherence to care [6,7], involvement in health care decision-making [8,9], and better health outcomes [6–8,10]. In prior studies, cancer survivors who are younger or non-White, reported greater unmet health information need and/or greater difficulties obtaining cancer information [10–12].

Rural cancer survivors are a particularly vulnerable population that make up approximately 21% of the cancer survivor population [1,13]. Compared to their urban counterparts, rural survivors experience poorer health outcomes [13] – including poorer self-reported health [13,14]; more non-cancer comorbidities [13]; greater anxiety and distress [13,15]; higher prevalence of negative health behaviors [14]; and higher mortality for several cancers [16–18]. Cancer disparities are particularly pronounced within the Appalachian Region, a geographic area along the Appalachian Mountain range in the Eastern United States (US) that is home to approximately 25 million people [19], and is characterized by a large rural population, high poverty rates, and increased cancer burden [19–21]. Rural Appalachian residents have higher cancer incidence and lower 3- and 5-year cancer survival compared to their urban and non-Appalachian counterparts [20].

Rural residents tend to be older, poorer, and less educated than their urban counterparts [22–25] and these factors are related to cancer knowledge [26,27]. Thus, having greater cancerrelated health information needs may be an obstacle to optimal post-treatment care for rural cancer survivors. Persons residing in rural areas may be under informed about cancer screening and follow-up care [28–31], have unmet cancer information [32,33], and may be unfamiliar with services provided by national cancer organizations [32]. Compared to urban survivors, rural cancer survivors are also more likely to report difficulty understanding cancer-related information [34].

Although studies have assessed cancer survivors' health information needs across the cancer continuum [8,35,36], few studies have focused on survivors during the post-treatment period [10,37,38], and even less is known about rural cancer survivors post-treatment [35,39]. To address these gaps, the present study assessed health-related information needs among Appalachian rural cancer survivors treated for the three most prevalent cancers among US survivors (breast, prostate, and colorectal cancers) [1]. Further, identifying subgroups within this vulnerable population of survivors will guide the development of tailored education and

resources to empower survivors and will help guide health care professionals in patientcentered communication and care.

## 2. Methods

#### 2.1. Sample

We conducted a cross-sectional study with breast, prostate, and colorectal cancer survivors identified through the cancer registry of the Wake Forest Baptist Comprehensive Cancer Center (WFBCCC). The medical center is located in a county designated as Appalachian, and most of the recruited survivors also resided in Appalachian counties [19]. Survivors were included if they: 1) resided in a rural area – defined according to ZIP code-based ruralurban commuting area (RUCA) codes as micropolitan, small town, or rural area with less than 30% commuting to an urban area [40], 2) were at least 40 years old and two to five years post-diagnosis (to ensure patients were at least 1 year post-treatment), and 3) received treatment at WFBCCC. We focused on cancer survivors age 40 and older as adolescent and young adult cancer survivors (age 15-39) are less likely to develop breast, prostate, and colorectal cancers and they face different issues compared to older survivors [41,42]. Survivors were excluded if they: 1) were diagnosed with a recurrence or new primary cancer, 2) had multiple cancers, 3) reported receipt of treatment (excluding maintenance hormonal therapy) in the past 12 months, 4) were a male breast cancer survivor, 5) had metastatic cancer (stage IV), or 6) did not read English. We excluded male breast cancer cases and survivors who did not speak English because they comprise very small proportions of our rural survivor population. This study was approved by the Wake Forest School of Medicine Institutional Review Board.

#### 2.2. Data Collection Procedures

Treating physicians were notified of our intent to contact their eligible patients and could decline any patient's participation (n=2 were declined by a physician). Eligible patients were mailed an initial survey packet that included an introductory letter, the survey, a reply-paid envelope, and information to complete the survey by telephone if preferred. Three weeks after the initial mailing, non-responders were sent a reminder letter. Non-respondents to both mailings were called by study staff and encouraged to complete the survey by telephone at that time. Study participants received a \$20 gift card for completing the survey and a thank you letter with information about cancer support services. We reviewed questionnaires for completeness and attempted to re-contact participants with missing items.

#### 2.3. Measures

**2.3.1. Cancer-related health information needs**—Study participants were asked if they need more information (yes/no) about 23 different cancer-related follow-up care topics in 8 domains: tests and treatment, side effects and symptoms, health promotion, fertility, interpersonal, occupational, emotional, and insurance. Sixteen of these items were drawn from a previous National Cancer Institute (NCI) study on health information needs in adult cancer survivors [37]. Based on findings from previous studies of unmet needs of cancer survivors in general and rural cancer survivors specifically [13,14,34,43–45], seven questions were added assessing smoking cessation, fatigue, memory problems, return to

work, losing weight or maintaining a healthy weight, finding a counselor/psychologist, and finding a support group.

**2.3.2. Demographic and cancer characteristics**—We collected data on age, gender, race and ethnicity (categorized as non-Hispanic White vs other), education (categorized as college graduate: yes or no), adequate income, and rural residence. Adequate income was assessed using a single item that asked participants if they had enough money to meet their daily needs during the past month (yes/no). We chose this alternate measure as an indicator of a person's perception of financial need versus income alone, as perceived financial stress may be more predictive of needs than income level [10,46]. Rural residence was determined by rural-urban commuting area (RUCA) codes [40] for ZIP code provided by participants. Urban was defined as cities with a population of 50,000 or greater and their associated suburban areas with more than 30% commuting rates – RUCA Codes 1.0–3.0, 4.1, 5.1, 7.1, 8.1, and 10.1 [47]. All other areas were designated as rural. We further divided rural areas into large rural towns and cities with populations of 10,000–50,000 and small/isolated rural areas with populations under 10,000. This categorization captures greater variation in the degree of rurality [48], and has been used in several studies of rural health [49,50].

Cancer registry data was used to determine cancer site, date of diagnosis, and cancer stage and to supplement socio-demographic data when necessary. In order to address known limitations with registry data, we ascertained receipt of the following treatment modalities, defined as yes/no for surgery, chemotherapy, radiation, and maintenance hormonal therapy, by confirming data from the cancer registry with self-reported patient data. Receipt of cancer-related follow-up care in the past 12 months (yes/no) was self-reported.

#### 2.4. Statistical Methods

Categorical demographic (gender, race/ethnicity, rurality) and cancer characteristics (site, stage) of responders were compared to those that declined or did not respond using chi-square tests; age and time since diagnosis were compared using t-tests. Participant characteristics were summarized overall and by cancer site using frequencies for categorical variables and means  $\pm$  standard deviations for continuous variables. Differences in characteristics by cancer site were compared using ANOVA for continuous variables and chi-square tests for categorical variables.

To identify the most common health information needs, we calculated the frequency of each need overall and by cancer site and education status. Additionally, we calculated the proportion of individuals who reported at least one need in each of the domain areas, and the mean number of information needs and domains identified. Differences in prevalence of information needs by cancer site were evaluated using chi-square tests; differences in the mean number of needs and domains reported were compared using ANOVA. We also calculated the prevalence of information needs for a subset of 16 items that were reported in prior studies of cancer survivors to facilitate comparison with other studies [10,37].

We fit univariate Poisson regression models using each participant's number of needs as the outcome to determine which factors were associated with more health information needs. To address potential confounding in the univariate models, we fit a multivariable regression

model adjusted for age, gender (male vs. female), race/ethnicity (non-Hispanic White vs. other), education status ( bachelor's degree vs. < bachelor's degree), adequate income (yes vs. no), receipt of cancer-related follow-up care in the past year (yes vs. no), and RUCA degree of rurality (large rural city/town vs. small and isolated rural town). All analyses were performed in SAS Version 9.3 (SAS Institute, Cary, NC). All hypothesis testing was two-sided and performed at the alpha=0.05 significance level.

## 3. Results

#### 3.1. Characteristics of Respondents

Of the 345 participants who met the eligibility criteria, had a valid address (mail was not returned) or phone number (not disconnected), 173 (50%) responded to the survey, with the highest proportion of respondents among women with breast cancer (N=71/128, 55%), followed by prostate (N=74/145, 51%) and colorectal cancers (N=28/72, 39%). Those that actively declined the survey (N=79) or did not respond (N=93), did not differ from those that responded by age (p=0.62), gender (p=0.96), cancer stage (p=0.26), cancer site (p=0.08), time since diagnosis (p=0.60), or degree of rurality (p=0.66), but did differ in terms of race (p=0.001), with racial/ethnic minorities more likely to refuse (53.7% of non-Hispanic Whites completed the survey compared to 28.6% of Hispanics and non-Whites). Three participants were excluded from the analysis because they were missing questions about cancer care in the past year, resulting in a final sample size of 170 for this analysis.

Demographic and cancer-related characteristics are summarized in Table 1. Participants were mostly White, non-Hispanic (92%), had less than a bachelor's degree (67%), had adequate income (86%), and resided in a large rural city/town (69%). Breast cancer survivors were on average younger than the prostate and colorectal cancer survivors (p=0.001). The type of cancer treatments received and cancer stage differed significantly by cancer site. All breast and colorectal cancer survivors had surgery compared to 69% of prostate cancer survivors. Fewer prostate cancer survivors had radiation (19%), compared to breast (62%) and colorectal (33%) survivors; hormonal therapy was more common among breast cancer survivors (64%) compared to prostate (12%) and colorectal (7%) cancer survivors.

#### 3.2. Health Information Needs by Cancer Site

Survivors reported an average of 4.0 needs in 2.1 domain areas. The number of needs and domain areas did not differ by cancer site (Table 2). *Side effects and symptoms* was the most common domain in which needs were reported (58%). Over 25% of participants reported needing more information about symptoms that should prompt a call to his or her doctor, what late and long-term side effects to expect, and dealing with fatigue after cancer. Respondents also commonly reported needs in the health promotion domain (54%). Decreasing the risk of having cancer again (36%), nutrition and diet (30%), losing weight or maintaining a healthy weight (26%), and staying physically fit (25%) were the most commonly reported needs in this domain.

There were also cancer site-specific differences in needs relating to sexual problems (p=0.01), with prostate cancer survivors most likely to report this need (31%) compared to breast (13%) and colorectal cancer survivors (8%). Survivors also reported significant differences in the need for decreasing the risk of having cancer again (p=0.05), with prostate cancer survivors reporting lower rates (25%) compared to breast (46%) and colorectal cancer (41%). The need regarding cancer risk for family members also differed by site (p=0.01), with fewer prostate cancer survivors reporting this need (14%), compared to colorectal (40%) and breast cancer survivors (32%).

Using the 16-item subset from Beckjord and colleagues [37], the prevalence of needs in each domain was: side effects and symptoms (50%), health promotion (49%), tests and treatment (41%), interpersonal and emotion (33%), sexual function and fertility (20%), and insurance (19%). The mean number of domains reported was 2.0 (SD=1.9), and the mean number of needs was 3.1 (SD=3.5) (see Table 2).

#### 3.3. Univariate and Multivariate Models of Information Needs

Results from the Poisson regression models are shown in Table 3. In the univariate analysis, a five-year increase in age was associated with a 10% reduction in the number of information needs reported (Rate Ratio [RR]=0.90, 95% CI=0.83-0.98). Compared to non-Hispanic Whites, racial/ethnic minorities were more likely to report more needs (RR=1.89, 95% CI=1.17–3.06). Survivors with less education than a bachelor's degree reported 49% more needs compared to survivors with a bachelor's degree or higher (RR=1.49, 95% CI=1.00-2.23). Individuals without adequate income reported 87% more needs (RR=1.87, 95% CI=1.25–2.81) than individuals with adequate income. Type of cancer, stage, time since diagnosis, type of treatment, gender, receipt of follow-up care in the past year, and degree of rurality were not significantly associated with the number of information needs. In the multivariable model, a five-year increase in age remained significantly associated with decreased information needs (RR=0.91, 95% CI=0.84-1.00), and individuals without a bachelor's degree reported more needs than those with a bachelor's degree (RR=1.54, 95% CI=1.02–2.34), after adjusting for other factors. There were no significant differences in univariate or multivariate models between survivors who resided in large vs small rural towns.

#### 3.4. Health Information Needs by Educational Attainment

We identified that education was a significant predictor of the number of information needs in the Poisson regression, therefore, we explored whether domains of health information needs varied by educational attainment (bachelor's degree vs < a bachelor's degree). In addition to reporting needs in significantly fewer domain categories (mean = 1.6 vs. 2.3, p=0.02), participants with a bachelor's degree reported an average of 1.5 fewer information needs compared to individuals with less education (mean = 3.0 vs. 4.4, p=0.05) (see Supplementary Table). Those without a college degree were more likely to report at least one need in tests and treatment (46.9% vs. 27.8%; p=0.02), health promotion (59.1% vs. 40.4%; p=0.03), and emotional domains (28.0% vs. 7.3%; p=0.002) than individuals with a degree. Additionally, those with less education were significantly more likely to report needs related to fatigue after cancer (31.1% vs. 15.1%; p=0.03), nutrition and diet (34.3% vs.

18.9%; p=0.04), managing fears about recurrence (23.0% vs. 7.3%; p=0.01), and getting or keeping insurance after cancer (23.5% vs. 7.3%; p=0.01).

## 4. Discussion and Conclusion

#### 4.1. Discussion

Health information needs were common among rural breast, prostate, and colorectal cancer survivors two to five years post-diagnosis, suggesting the need for ongoing educational efforts years into survivorship care. Survivors reported an average of four information needs; the most common health information need domains included *side effects and symptoms* (58%), *health promotion* (54%), and *tests and treatment* (41%). Health information needs were generally similar by type of cancer, with two exceptions; information needs regarding *dealing with sexual problems* were more prevalent among prostate cancer survivors. Underserved rural survivors (racial/ethnic minorities, less educated and lower income) and younger rural survivors reported more health information needs than their counterparts; highlighting the need to consider health equity within the population of rural survivors.

The three most common domains for information needs – side effects and symptoms, health promotion, and tests and treatment – have traditionally been a focus of cancer follow-up care and/or survivorship care; yet, more than 40% of our rural survivors report continued needs in these areas. This suggests that specific educational efforts may be needed during survivorship. Although the overall number of informational needs and the most common domains did not vary across cancer sites, survivorship educational efforts should consider symptoms/informational needs more common in certain cancer sites or treatment regimens. For example, sexual dysfunction is one of the most prevalent and distressing consequences of prostate cancer treatment [51,52], heightening the importance of information on *dealing* with sexual problems for these male survivors. Almost a third of rural prostate cancer survivors reported continued information needs about dealing with this symptom, even two to five years post-treatment. In addition, rural colorectal cancer survivors were significantly more likely to report information needs regarding *cancer risks to your family*, which may be associated with gender and/or hereditary cancer syndromes. A study by Tan and colleagues examined the same three cancers and also found that female colon cancer survivors tend to seek more information about how to reduce the risk of family members getting colon cancer or a different cancer [53].

Our results also support the need to consider which subgroups of rural cancer survivors may require specific attention to address informational needs. Consistent with the broader literature on disparities in unmet and information needs among cancer survivors [8,10,18,37,53,54], rural survivors who were younger, racial/ethnic minorities, less educated, and had inadequate income reported more health information needs in univariate analyses. Two systematic reviews noted similar patient characteristics associated with more information needs, including women, younger age, low income, advanced disease, and rural locality/remote areas [8,35]. Additionally, while James et al reported that rural populations experience more health problems, they underscore the importance of disaggregating racial/ ethnic minority population data and assessing the interaction of race/ethnicity, age, and

socioeconomic status within rural communities [55]. They noted that rural racial/ethnic minorities tend to be younger than non-Hispanic Whites, and rural African Americans, Hispanics/Latinos, and American Indian/Alaska Natives tend to be poorer and have lower educational attainment [55].

We also found age and education remained statistically significant in multivariate analyses. Importantly, nearly two-thirds of our sample reported less than a bachelor's level of educational attainment. Lower education is associated with limited health literacy [56], which has been linked with less perceived information provision [57]. These findings highlight the need to examine factors associated with education and literacy, such as information finding skills, self-efficacy, environmental resources, and understanding [34]. To meet the needs of rural cancer survivors who may have lower education and health literacy, educational materials for survivors should use language appropriate for low literacy populations, which is often preferred by adequate literacy populations as well [58].

Beckjord and colleagues conducted a similar study of survivors of non-Hodgkin's lymphoma, leukemia, bladder, and colorectal cancers, two to five years post diagnosis in California (rurality not assessed) [37]. For the subset addressed in both studies, rural survivors in this study reported an average of 3.1 health information needs (compared to 3.3 needs in Beckjord et al); the most common need domains were the same in both samples, but Beckford et al. reported slightly higher domain endorsements (*tests and treatments*: 70.8%, *health promotion*: 67.8%, and *side effects and symptoms*: 63.3%). Kent and colleagues also assessed health-related information needs among long-term (4–14 years post-diagnosis) survivors of breast, prostate, colorectal, endometrial, and ovarian cancers in California (rurality not assessed) [10]. Again, the most common need domains were the same: *side effects and symptoms* (75.8%), *tests and treatment* (71.5%) and *health promotion* (64.5%); they reported an average number of 5.3 needs. Both Beckjord and colleagues [37] and Kent and colleagues [10] identified small, but significant differences in the number of needs by cancer site; however, we did not find significant differences, potentially due to our exclusive focus on rural cancer survivors or our smaller total sample size.

This cross-sectional study has some limitations associated with design and population. First, the generalizability of our findings are limited by recruitment at a single academic medical center in North Carolina. Although there are few other hospitals in this region, it is possible that rural survivors who seek care at an academic cancer center are different. Second, our sample size was insufficient to fully explore differences by race/ethnicity, type of cancer and gender, as compared to similar studies that did not include information on rural residence [10,37]. Third, our response rate was 50%, which is on the lower end compared to reported response rates for similar mailed surveys among cancer survivors that ranged from 49.2% to 64% [8,10,37,53,59,60], but comparable to survey studies assessed in a systematic review of cancer patients' information needs [8]. Our low response rate of minorities is similar to other mailed surveys [61,62]; literacy and language may have been barriers to participation. Given these factors, it is possible that we underestimated the prevalence of information needs in this population of rural cancer survivors. Lastly, we did not measure health literacy, although it is reported to be lower in rural populations [63]. Future intervention and observational

research with rural survivors should directly consider limited health literacy in both the design of assessments, as well as intervention materials.

Despite our study's limitations, this analysis adds substantially to the very limited research on rural cancer survivors' health information needs post-treatment, and is one of the largest studies of rural survivors to date. We used questions from larger population-based studies that permitted cross-study comparisons [10,37]. Additionally, the questions we added on side effects and symptoms and health promotion domains (managing continuing side effects, fatigue, memory, reducing cancer risk, weight maintenance) were endorsed by a substantial proportion of survivors (20–30%), suggesting these items have value in identifying information needs in other populations of cancer survivors in future studies.

#### 4.2. Conclusion

A majority of rural cancer survivors report cancer-related health information needs relating to side effects and symptoms and health promotion activities, even several years post-treatment. General resources for post-treatment rural survivors should address common needs, such as monitoring symptoms, late and long-term effects, health promotion, and fatigue. Tailoring to address cancer site, treatment-specific, and age-related concerns may be valuable. Furthermore, educational resources to address rural survivors' health information needs should be appropriate for low education and limited health literacy populations.

#### 4.3. Practice Implications

Information provision, including assessment of needs and confirmation of understanding, is fundamental to high-quality patient-centered cancer care. Meeting survivors' health information needs can help enhance their self-management skills and psychological adjustment, inform health promotion lifestyle changes, and reduce anxiety about future health problems [5], [64]. Further research is needed to identify the best methods to systematically assess and address health information needs among rural cancer survivors from diagnosis through survivorship and further consider the commonalities and differences within and between rural populations. Intervention development efforts should draw on existing survivorship educational materials (e.g., Facing Forward Series, Springboard Beyond Cancer, and Macmillan Cancer Support) [65–67] and consider new ways to tailor and deliver content that is culturally congruent to rural cancer survivors, particularly those who are younger, racial/ethnic minorities, and less educated.

Strategies that do not require in-person contact, especially outside of regular medical appointments, may be especially important for this population which often experiences challenges with access to care. Rural cancer survivors have limited access to interventions and survivorship resources beyond their healthcare providers, and typically have to travel great distances to receive cancer care [16,68–71]. eHealth technologies (e.g., telemedicine, telehealth, mHealth, eMedicine, and patient portals) could be viable options to facilitate and geographically link resources and information to cancer survivors in rural communities [72–76]. Carefully designed internet-based resources may be helpful in addressing health information needs [72,77] and improving health promotion awareness and activities among rural cancer survivors [78,79]. Patient portals could be used to assess health information

needs and symptoms, offering an opportunity to tailor survivors' information needs and provide information electronically [80]. Many, but not all rural counties have internet access [72], and various subgroups (e.g., racial/ethnic minorities, older, unemployed, less educated, and rural residents) are less likely to ever access the Internet, highlighting the persistent digital divide [81]. While technology can decrease patients' burden by providing information resources and supportive communication in their homes, at their convenience, targeted interventions are needed to increase access to, awareness of, and utilization of health information resources, particularly among vulnerable populations.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

## Acknowledgements:

The authors wish to acknowledge the support of the Biostatistics Shared Resources of the Comprehensive Cancer Center of Wake Forest University. We would like to acknowledge the UCSF K Scholars Program for their feedback during Nynikka R. Palmer's works-in-progress presentations. Nora F. Fino is now affiliated with the Department of Internal Medicine, Division of Epidemiology at the University of Utah in Salt Lake City, Utah.

**Funding:** This research was supported by the National Cancer Institute (NCI) of the National Institutes of Health under award number R03CA157211 and the NCI Cancer Center Support Grant P30 CA012197. Dr. Palmer was supported by the National Cancer Institute of the National Institutes of Health under award number R25CA122061 during this study. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The funders had no role in the design or conduct of the study, collection, management, analysis, or interpretation of data, nor the preparation, review, or approval of the manuscript.

## REFERENCES

- American Cancer Society, Cancer Treatment & Survivorship Facts& Figures 2019–2021. American Cancer Society, Atlanta, Georgia, 2019 No. 865019.
- [2]. Miller KD, Siegel RL, Lin CC, Mariotto AB, Kramer JL, Rowland JH, Stein KD, Alteri R, and Jemal A, Cancer treatment and survivorship statistics, 2016, CA. Cancer J. Clin, 66 (2016) 271– 89. 10.3322/caac.21349. [PubMed: 27253694]
- [3]. Odisho AY and Gore JL, Patient-centered approaches to creating understandable health information, Urol. Oncol, 35 (2017) 559–63. 10.1016/j.urolonc.2017.06.055. [PubMed: 28736251]
- [4]. Gaston CM and Mitchell G, Information giving and decision-making in patients with advanced cancer: A systematic review, Soc. Sci. Med, 61 (2005) 2252–64. 10.1016/ j.socscimed.2005.04.015. [PubMed: 15922501]
- [5]. Husson O, Mols F, and van de Poll-Franse LV, The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review, Ann. Oncol, 22 (2011) 761–72. 10.1093/annonc/mdq413. [PubMed: 20870912]
- [6]. Venetis MK, Staples S, Robinson JD, and Kearney T, Provider Information Provision and Breast Cancer Patient Well-Being, Health Commun, 34 (2019) 1032–42. 10.1080/10410236.2018.1454254. [PubMed: 29583022]
- [7]. Heisig SR, Shedden-Mora MC, von Blanckenburg P, Schuricht F, Rief W, Albert US, and Nestoriuc Y, Informing women with breast cancer about endocrine therapy: effects on knowledge and adherence, Psychooncology., 24 (2015) 130–7. 10.1002/pon.3611. [PubMed: 24953538]
- [8]. Rutten LJF, Arora NK, Bakos AD, Aziz N, and Rowland J, Information needs and sources of information among cancer patients: a systematic review of research (1980–2003), Patient Educ. Couns, 57 (2005) 250–61. 10.1016/j.pec.2004.06.006. [PubMed: 15893206]

- [9]. Schoenberger YM, Benz R, McNees P, and Meneses K, Patient-centered outcome evaluation of the Rural Breast Cancer Survivors Intervention, Support. Care Cancer, 24 (2016) 1841–8. 10.1007/ s00520-015-2974-4. [PubMed: 26452487]
- [10]. Kent EE, Arora NK, Rowland JH, Bellizzi KM, Forsythe LP, Hamilton AS, Oakley-Girvan I, Beckjord EB, and Aziz NM, Health information needs and health-related quality of life in a diverse population of long-term cancer survivors, Patient Educ. Couns, 89 (2012) 345–52. 10.1016/j.pec.2012.08.014. [PubMed: 23021856]
- [11]. McInness DK, Cleary PD, Stein KD, Ding L, Mehta CC, Ayanian JZ, Perceptions of cancerrelated information among cancer survivors: a report from the American Cancer Society's studies of cancer survivors, Cancer, 113 (2008) 1471–9. 10.1002/cncr.23713. [PubMed: 18666212]
- [12]. Lisy K, Langdon L, Piper A, Jefford M, Identifying the most prevalent unmet needs of cancer survivors in Australia: a systematic review, Asia Pac. J. Clin. Oncol, 15 (2019) e68–e78. 10.1111/ ajco.13176. [PubMed: 31215167]
- [13]. Weaver KE, Geiger AM, Lu L, and Case LD, Rural-urban disparities in health status among US cancer survivors, Cancer 119 (2013) 1050–7. 10.1002/cncr.27840. [PubMed: 23096263]
- [14]. Weaver KE, Palmer N, Lu L, Case LD, and Geiger AM, Rural-urban differences in health behaviors and implications for health status among US cancer survivors, Cancer Causes Control 24 (2013) 1481–90. 10.1007/s10552-013-0225-x. [PubMed: 23677333]
- [15]. Burris JL and Andrykowski M, Disparities in mental health between rural and nonrural cancer survivors: a preliminary study, Psychooncology 19 (2010) 637–45. 10.1002/pon.1600. [PubMed: 19582800]
- [16]. Singh GK, Williams SD, Siahpush M, and Mulhollen A, Socioeconomic, Rural-Urban, and Racial Inequalities in US Cancer Mortality: Part I-All Cancers and Lung Cancer and Part II-Colorectal, Prostate, Breast, and Cervical Cancers, J. Cancer Epidemiol 2011 (2011) 107497 10.1155/2011/107497. [PubMed: 22496688]
- [17]. Hines RB and Markossian TW, Differences in late-stage diagnosis, treatment, and colorectal cancer-related death between rural and urban African Americans and whites in Georgia, J. Rural Health 28 (2012) 296–305. 10.1111/j.1748-0361.2011.00390.x. [PubMed: 22757954]
- [18]. Blake KD, Moss JL, Gaysynsky A, Srinivasan S, and Croyle RT, Making the Case for Investment in Rural Cancer Control: An Analysis of Rural Cancer Incidence, Mortality, and Funding Trends, Cancer Epidemiol. Biomark. Prev 26 (2017) 992–7. 10.1158/1055-9965.EPI-17-0092.
- [19]. Appalachian Regional Commission, The Appalachian Region. https://www.arc.gov/ appalachian\_region/TheAppalachianRegion.asp. (accessed 26 April 2019).
- [20]. Yao N, Alcala HE, Anderson R, Balkrishnan R, Cancer disparities in rural Appalachia: incidence, early detection, and survivorship, J. Rural Health, 33 (2017) 375–381. 10.1111/jrh.12213.
   [PubMed: 27602545]
- [21]. Wilson RJ, Ryerson AB, Singh SD, King JB, Cancer incidence in Appalachia 2004–2011, Cancer Epidemiol. Biomark. Prev, 25 (2016) 250–8. 10.1158/1055-9965.EPI-15-0946.
- [22]. Probst JC, Laditka SB, Moore CG, Harun N, Powell MP, and Baxley EG, Rural-urban differences in depression prevalence: implications for family medicine, Fam. Med, 38 (2006) 653–60. https:// www.ncbi.nlm.nih.gov/pubmed/17009190. [PubMed: 17009190]
- [23]. Muskie School of Public Services, Kaiser Commission on Medicaid and the Uninsured, Health Insurance Coverage in Rural America. Published 9 29, 2003 https://www.kff.org/uninsured/ report/health-insurance-coverage-in-rural-america/. (accessed 26 October 2016).
- [24]. Glover S, Moore CG, Samuels ME, and Probst JC, Disparities in access to care among rural working-age adults, J. Rural Health, 20 (2004) 193–205. https://www.ncbi.nlm.nih.gov/pubmed/ 15298093. [PubMed: 15298093]
- [25]. Laditka JN, Laditka SB, and Probst JC, Health care access in rural areas: evidence that hospitalization for ambulatory care-sensitive conditions in the United States may increase with the level of rurality, Health Place, 15 (2009) 731–40. 10.1016/j.healthplace.2008.12.007. [PubMed: 19211295]
- [26]. Lukwago SN, Kreuter MW, Holt CL, Steger-May K, Bucholtz DC, and Skinner CS, Sociocultural correlates of breast cancer knowledge and screening in urban African American women, Am. J. Public Health, 93 (2003) 1271–4. 10.2105/ajph.93.8.1271. [PubMed: 12893610]

- [27]. Viswanath K, Breen N, Meissner H, Moser RP, Hesse B, Steele WR, and Rakowski W, Cancer knowledge and disparities in the information age, J. Health Commun, 11 (2006) 1–17. 10.1080/10810730600977517. [PubMed: 16641071]
- [28]. Schootman M, Homan S, Weaver KE, Jeffe DB, and Yun S, The health and welfare of rural and urban cancer survivors in Missouri, Prev. Chronic. Dis, 10 (2013) E152 10.5888/pcd10.130052. [PubMed: 24028832]
- [29]. Tessaro I, Mangone C, Parkar I, and Pawar V, Knowledge, barriers, and predictors of colorectal cancer screening in an Appalachian church population, Prev. Chronic. Dis, 3 (2006) A123 https:// www.ncbi.nlm.nih.gov/pubmed/16978498. [PubMed: 16978498]
- [30]. Paskett ED, Tatum C, Rushing J, Michielutte R, Bell R, Foley KL, Bittoni M, and Dickinson S, Racial differences in knowledge, attitudes, and cancer screening practices among a triracial rural population, Cancer, 101 (2004) 2650–9. 10.1002/cncr.20671. [PubMed: 15505784]
- [31]. Jones AR, Shipp M, Thompson CJ, and Davis MK, Prostate cancer knowledge and beliefs among Black and White older men in rural and urban counties, J. Cancer Educ, 20 (2005) 96–102. 10.1207/s15430154jce2002\_10. [PubMed: 16083373]
- [32]. Engelman KK, Perpich DL, Peterson SL, Hall MA, Ellerbeck EF, and Stanton AL, Cancer information needs in rural areas, J. Health Commun, 10 (2005) 199–208. 10.1080/10810730590934217. [PubMed: 16036728]
- [33]. Bernardes CM, Diaz A, Valery PC, Sabesan S, Baxi S, Aoun S, Thompson SC, Lashbrook M, Garvey G, Unmet supportive care needs among indigenous cancer patients across Australia, Rural Remote Health, 19 (2019) 4660 10.22605/RRH4660. [PubMed: 31521102]
- [34]. Katz ML, Reiter PL, Corbin S, de Moor JS, Paskett ED, and Shapiro CL, Are rural Ohio Appalachia cancer survivors needs different than urban cancer survivors?, J. Cancer Surviv, 4 (2010) 140–8. 10.1007/s11764-010-0115-0. [PubMed: 20099044]
- [35]. Harrison JD, Young JM, Price MA, Butow PN, and Solomon MJ, What are the unmet supportive care needs of people with cancer? A systematic review, Support. Care Cancer 17 (2009) 1117– 28. 10.1007/s00520-009-0615-5. [PubMed: 19319577]
- [36]. Puts MTE, Papoutsis A, Springall E, and Tourangeau AE, A systematic review of unmet needs of newly diagnosed older cancer patients undergoing active cancer treatment, Support. Care Cancer, 20 (2012) 1377–94. 10.1007/s00520-012-1450-7. [PubMed: 22476399]
- [37]. Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton AS, and Hesse BW, Healthrelated information needs in a large and diverse sample of adult cancer survivors: implications for cancer care, J. Cancer Surviv, 2 (2008) 179–89. 10.1007/s11764-008-0055-0. [PubMed: 18792791]
- [38]. Playdon M, Ferrucci LM, McCorkle R, Stein KD, Cannady R, Sanft T, and Cartmel B, Health information needs and preferences in relation to survivorship care plans of long-term cancer survivors in the American Cancer Society's Study of Cancer Survivors-I, J. Cancer Surviv, 10 (2016) 674–85. 10.1007/s11764-015-0513-4. [PubMed: 26744339]
- [39]. Tzelepis F, Clinton-McHarg T, Paul CL, Sanson-Fisher RW, Joshua D, and Carey ML, Quality of Patient-Centered Care Provided to Patients Attending Hematological Cancer Treatment Centers, Int. J. Environ. Res. Public. Health, 15 (2018) E549 10.3390/ijerph15030549. [PubMed: 29562704]
- [40]. United States Department of Agriculture, Economic Research Service, Rural-Urban Community Area (RUCA) Codes. https://www.ers.usda.gov/data-products/rural-urban-commuting-areacodes.aspx#.U1wZD\_RDt8E, 2019 (accessed 02 June 2014).
- [41]. Nass SJ, Beaupin LK, Demark-Wahnefried W, Fasciano K, Ganz PA, Hayes-Lattin B, Hudson MM, Nevidjon B, Oeffinger KC, Rechis R, Richardson LC, Seibel NL, and Smith AW, Identifying and addressing the needs of adolescents and young adults with cancer: summary of an Institute of Medicine workshop, The Oncologist, 20 (2015) 186–95. 10.1634/ theoncologist.2014-0265. [PubMed: 25568146]
- [42]. Zebrack B, Information and service needs for young adult cancer survivors, Support. Care Cancer, 17 (2009) 349–57. 10.1007/s00520-008-0469-2. [PubMed: 18543006]
- [43]. Armes J, Crowe M, Colbourne L, Morgan H, Murrells T, Oakley C, Palmer N, Ream E, Young A, and Richardson A, Patients' supportive care needs beyond the end of cancer treatment: a

prospective, longitudinal survey, J. Clin. Oncol, 27 (2009) 6172–9. 10.1200/JCO.2009.22.5151. [PubMed: 19884548]

- [44]. White KJ, Roydhouse JK, D'Abrew NK, Katris P, O'Connor M, Emery L, Unmet psychological and practical needs of patients with cancer in rural and remote areas of Western Australia, Rural Remote Health, 11 (2011) 1784 https://www.ncbi.nlm.nih.gov/pubmed/21848359. [PubMed: 21848359]
- [45]. Grimison P, Phillips F, Butow P, White K, Yip D, Sardelic F, Underhill C, Tse R, Simes R, Turkey K, Raymond C, Goldstein D, Are visiting oncologists enough? A qualitative study of the needs of Australian rural and regional cancer patients, carers and health professionals, Asia Pac. J. Clin. Oncol, 9 (2013) 226–38. 10.1111/ajco.12014. [PubMed: 22989350]
- [46]. Gage E, Examining the most relevant conceptualization of the socioeconomic status construct for cancer research, Cancer Nurs., 33 (2010) E1–9. 10.1097/NCC.0b013e3181c29583.
- [47]. The WWAMI Rural Health Research Center, RUCA Data: Using RUCA data. 2010 http:// depts.washington.edu/uwruca/ruca-uses.php. (accessed 26 April 2014).
- [48]. Hall SA, Kaufman JS, and Ricketts TC, Defining urban and rural areas in U.S. epidemiologic studies, J. Urban Health, 83 (2006) 162–75. 10.1007/s11524-005-9016-3. [PubMed: 16736366]
- [49]. Axelrod DA, Guidinger MK, Finlayson S, Schaubel DE, Goodman DC, Chobanian M, and Merion RM, Rates of solid-organ wait-listing, transplantation, and survival among residents of rural and urban areas, JAMA, 299 (2008) 202–7. 10.1001/jama.2007.50. [PubMed: 18182602]
- [50]. O'Hare AM, Johansen KL, and Rodriguez RA, Dialysis and kidney transplantation among patients living in rural areas of the United States, Kidney Int, 69 (2006) 343–9. 10.1038/ sj.ki.5000044. [PubMed: 16408125]
- [51]. Kerleau C, Guizard AV, Daubisse-Marliac L, Heuttle N, Mercier M, Grosclaude P, Joly F, and French Network of Cancer Registries, Long-term quality of life among localised prostate cancer survivors: QALIPRO population-based study, Eur. J. Cancer, 63 (2016) 143–53. 10.1016/ j.ejca.2016.05.020. [PubMed: 27318002]
- [52]. Litwin MS, Flanders SC, Pasta DJ, Stoddard ML, Lubeck DP, and Henning JM, Sexual function and bother after radical prostatectomy or radiation for prostate cancer: multivariate quality-of-life analysis from CaPSURE. Cancer of the Prostate Strategic Urologic Research Endeavor, Urology, 54 (1999) 503–8. 10.1016/s0090-4295(99)00172-7. [PubMed: 10475362]
- [53]. Tan ASL, Nagler RH, Hornik RC, and DeMichele A, Evolving Information Needs among Colon, Breast, and Prostate Cancer Survivors: Results from a Longitudinal Mixed-Effects Analysis, Cancer Epidemiol. Biomark. Prev, 24 (2015) 1071–8. 10.1158/1055-9965.EPI-15-0041.
- [54]. Hubbard G, Venning C, Walker A, Scanlon K, Kyle RG, Supportive care needs of women with breast cancer in rural Scotland, 23 (2015) 1523–32. 10.1007/s00520-2501-z.
- [55]. James CV, Moonesinghe R, Wilson-Frederick SM, Hall JE, Penman-Aguilar A, and Bouye K, Racial/Ethnic Health Disparities Among Rural Adults - United States, 2012–2015, Morb. Mortal. Wkly. Rep. Surveill. Summ, 66 (2017) 1–9. 10.15585/mmwr.ss6623a1.
- [56]. Nutbeam D, Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century, Health Promot. Int, 15 (2000) 259– 67. 10.1093/heapro/15.3.259.
- [57]. Verkissen MN, Ezendam NP, Fransen MP, Essink-Bot ML, Aarts MJ, Nicolaije KA, Vos MC, and Husson O, The role of health literacy in perceived information provision and satisfaction among women with ovarian tumors: a study from the population-based PROFILES registry, Patient Educ. Couns, 95 (2014) 421–8. 10.1016/j.pec.2014.03.008. [PubMed: 24698535]
- [58]. Gaglio B, Glasgow RE, and Bull SS, Do patient preferences for health information vary by health literacy or numeracy? A qualitative assessment, J. Health Commun, 17 (2012) 109–21. 10.1080/10810730.2012.712616. [PubMed: 23030565]
- [59]. Shea-Budgell MA, Kostaras X, Myhill KP, and Hagen NA, Information needs and sources of information for patients during cancer follow-up, Curr. Oncol, 21 (2014) 165–73. 10.3747/ co.21.1932. [PubMed: 25089098]
- [60]. Søndergaard EG, Grøne BH, Wulff CN, Larsen PV, and Søndergaard J, A survey of cancer patients' unmet information and coordination needs in handovers–a cross-sectional study, BMC Res. Notes, 6 (2013) 378 10.1186/1756-0500-6-378. [PubMed: 24066725]

- [61]. Evans BR, Peterson BL, Demark-Wahnefried W, No difference in response rate to a mailed survey among prostate cancer survivors using conditional versus unconditional incentives, Cancer Epidemiol. Biomarkers Prev, 13 (2004) 277–8. 10.1158/1055-9965.epi-03-0065. [PubMed: 14973100]
- [62]. Bulkey JE, O'Keeffe-Rosetti M, Wendel CS, Davis JV, Danforth KN, Harrison TN, Kwan ML, Munneke J, Brooks N, Grant M, Leo MC, Banegas M, Weinmann S, McMullen CK, The effect of multiple recruitment contacts on response rates and patterns of missing data in a survey of bladder cancer survivors 6 months after cystectomy, Qual. Life Res, (2019). 10.1007/ s11136-019-02379-3.
- [63]. Zahnd WE, Scaife SL, Francis ML, Am. J. Health Behav, 33 (2009) 550–7. 10.5993/ajhb.33.5.8.
   [PubMed: 19296745]
- [64]. Lie HC, Loge JH, Fossa SD, Hamre HM, Hess SL, Mellblom AV, Ruud E, and Finset A, Providing information about late effects after childhood cancer: lymphoma survivors' preferences for what, how and when, Patient Educ. Couns, 98 (2015) 604–11. 10.1016/j.pec.2015.01.016. [PubMed: 25704291]
- [65]. National Cancer Institute, Office of Cancer Survivorship, Facing Forward Series. http:// www.cancercontrol.gov/ocs/resources/ffseries.html, 2019 (accessed 31 January 2020).
- [66]. National Cancer Institute and the American Cancer Society, Springboard Beyond Cancer. http:// www.survivorship.cancer.gov, 2019 (accessed 31 January 2020).
- [67]. Macmillan Cancer Support, Cancer information and support. http://www.macmillan.org.uk/ cancer-information-and-support,2020. (accessed 31 January 2020).
- [68]. Wilson SE, Andersen MR, and Meischke H, Meeting the needs of rural breast cancer survivors: what still needs to be done?, J. Womens Health Gend. Based Med, 9 (2000) 667–77. 10.1089/15246090050118198. [PubMed: 10957755]
- [69]. Fuchsia Howard A, Smillie K, Turnbull K, Zirul C, Munroe D, Ward A, Tobin P, Kazanjian A, and Olson R, Access to medical and supportive care for rural and remote cancer survivors in northern British Columbia, J. Rural Health, 30 (2014) 311–21. 10.1111/jrh.12064. [PubMed: 24483272]
- [70]. Tzelepis F, Paul CL, Sanson-Fisher RW, Campbell HS, Bradstock K, Carey ML, Williamson A, Unmet supportive care need of haematological cancer survivors: rural versus urban residents, Ann. Hematol, 97 (2018) 1283–1292. 10.1007/s00277-018-3285-x. [PubMed: 29525897]
- [71]. Loughery J, Woodgate RL, Supportive care needs of rural individuals living with cancer: a literature review, Can. Oncol. Nurse J, 25 (2015) 157–78. 10.5737/23688076252157166.
- [72]. Fennell KM, Turnbull DA, Bidargaddi N, McWha JL, Davies M, and Olver I, The consumerdriven development and acceptability testing of a website designed to connect rural cancer patients and their families, carers and health professionals with appropriate information and psychosocial support, Eur. J. Cancer Care, 26 (2017) e12533 10.1111/ecc.12533.
- [73]. Haozous E, Doorenbos AZ, Demiris G, Eaton LH, Towle C, Kundu A, and Buchwald D, Role of telehealth/videoconferencing in managing cancer pain in rural American Indian communities, Psychooncology, 21 (2012) 219–23. 10.1002/pon.1887. [PubMed: 22271543]
- [74]. Doorenbos AZ, Eaton LH, Haozous E, Towle C, Revels L, and Buchwald D, Satisfaction with telehealth for cancer support groups in rural American Indian and Alaska Native communities, Clin. J. Oncol. Nurs, 14 (2010) 765–70. 10.1188/10.CJON.765-770. [PubMed: 21112853]
- [75]. Pisu M, Meneses K, Azuero A, Benz R, Su X, and McNees P, Variation in resources needed to implement psychosocial support interventions for rural breast cancer survivors, J. Cancer Surviv, 10 (2016) 375–83. 10.1007/s11764-015-0483-6. [PubMed: 26341349]
- [76]. Scurrey S, Garland SN, Thomas J, Laing K, Evaluating the experience of rural individuals with prostate cancer breast cancer participating in research via telehealth, Rural Remote Health, 19 (2019) 5269 10.22605/RRH5269. [PubMed: 31412701]
- [77]. Vollmer Dahlke D, Kellstedt D, and Weinberg AD, Developing NaviCanPlan: A Mobile Web Resource Locator for Cancer Providers and Survivors, J. Cancer Educ, 30 (2015) 670–6. 10.1007/s13187-014-0768-x. [PubMed: 25519250]
- [78]. Frensham LJ, Zarnowiecki DM, Parfitt G, King S, and Dollman J, The experiences of participants in an innovative online resource designed to increase regular walking among rural

cancer survivors: a qualitative pilot feasibility study, Support. Care Cancer, 22 (2014) 1923–9. 10.1007/s00520-014-2177-4. [PubMed: 24573604]

- [79]. Frensham LJ, Zarnowiechki DM, Parfitt G, King S, Dollman J, The experiences of participants in an innovative online resource designed to increase regular walking among rural cancer survivors: a qualitative pilot feasibility study, Support. Care Cancer, 22 (2014) 1923–9. 10.1007/ s00520-014-2177-4. [PubMed: 24573604]
- [80]. Rodriguez ES, Using Patient Portals to Increase Engagement in Patients with Cancer, Semin. Oncol. Nurs, 34 (2018) 177–83. 10.1016/j.soncn.2018.03.009. [PubMed: 29625803]
- [81]. Nguyen A, Mosadeghi S, and Almario CV, Persistent digital divide in access to and use of the Internet as a resource for health information: Results from a California population-based study, Int. J. Med. Inf, 103 (2017) 49–54. 10.1016/j.ijmedinf.2017.04.008.

## Highlights

- Rural cancer survivors report health information needs 2–5 years postdiagnosis.
- Most common needs include side effects/symptoms and health promotion activities.
- Information tailored to younger, minority, and less educated survivors is needed.

#### Table 1.

Sociodemographic and Cancer Characteristics of Rural Breast, Prostate, and Colorectal Cancer Survivors (N=170)

Characteristic	Total N=170 Breast		t N=69 Prostat		e N=74	Colorectal N=27		p-value <sup>*</sup>	
	Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Age (mean ± SD)	66.2	10.3	62.7	10.1	68.0	9.0	70.0	11.6	0.001
Gender (n, %)	Ν	%	Ν	%	Ν	%	Ν	%	
Male	90	52.9	0	0.0	74	100.0	16	59.3	< 0.0001
Female	80	47.1	69	100.0	0	0.0	11	40.7	
Race/ethnicity (n, %)									
White, non-Hispanic	156	91.8	67	97.1	66	89.2	23	85.2	0.00
Other	14	8.2	2	2.9	8	10.8	4	14.8	0.09
Education (n, %)									
< Bacholor's Degree	112	66.7	47	68.1	45	62.5	20	74.1	0.52
Bachelor's Degree	$56^{\text{F}}$	33.3	22	31.9	27	37.5	7	25.9	
Adequate income to meet needs (n. %)									
No	23	13.7	9	13.2	7	9.6	7	25.9	
		0.5.0	-	0.5.0		00.4	20		0.11
Yes	145	86.3	59	86.8	66	90.4	20	/4.1	
Cancer Treatments Received (n, % yes)	1.47	965	60	100.0	51	69.0	27	100.0	-0.0001
Surgery	147	86.5	69	100.0	51	18.0	27	22.2	<0.0001
Radiation	42	38.8	43	62.3	14	18.9	9	33.3 49.2	<0.0001
Chemotherapy	43	25.5	29	42.0	1	1.4	15	48.2	<0.0001
Hormonai Nana ( matal-fail maiting	33 10	52.4	44	03.8	9	12.2	2	7.4	<0.0001
None/ watchill waiting	Moon	13.5 SD	- Moon	-	Moon	15.5 SD	- Moon	- 6D	-
Time since concer diagnosis years (mean + SD)	4 2	0.0	4 2	1.0	4 1	0.8	4 2	0.0	0.67
Concer store $(n, \%)$	4.2 N	0.9 0/	4.2 N	1.0 0/	4.1 N	0.8 0/2	4.2 N	0.9	0.07
Cancel stage (II, 70)	n €	/0	19	/0	19	/0	1	/0	
0/I	62 <sup>C</sup>	37.4	50	73.5	0	0.0	12	48	0.0001
II	88	53.0	14	20.6	67	91.8	7	28	<0.0001
III	16	9.6	4	5.9	6	8.2	6	24	
Received cancer-related									
follow-up care in the past year									0.12
(n, % yes)	147	86.5	64	92.8	60	81.1	23	85.2	
Degree of Rurality									
Large Rural City / Town	117	68.8	50	72.5	51	68.9	16	59.3	
Small and Isolated Rural Town	53	31.2	19	27.5	23	31.1	11	40.7	0.45

Note: Degree of Rurality was defined by Rural-Urban Commuting Area (RUCA) codes

\* p-value for comparison by cancer site by ANOVA or chi-square test.

 ${}^{\not{E}}$ Education missing for 2 prostate cancer respondents.

<sup>\$</sup>Missing for 2 respondents (1 breast, 1 prostate).

# € Missing for 4 respondents (1 breast, 1 prostate, 2 colorectal)

## Table 2.

## Health-Related Information Needs of Rural Cancer Survivors by Cancer Type

Information Need	Total (N=170) % yes	Breast (n=69) % yes	Prostate (n=74) % yes	Colorectal (n=27) % yes	p-value for comparison by site <sup>*</sup>
I. Tests and Treatment	40.9	45.0	35.7	45.8	0.49
Cancer related follow-up tests/procedures that you should have $\stackrel{F}{=}$	19.6	23.0	14.1	26.1	0.32
Complementary and alternative treatments <sup><math>F</math></sup>	10.8	7.8	14.5	8.3	0.42
Medical advances in cancer treatment $\neq$	31.8	37.1	29.6	25.0	0.48
II. Side Effects and Symptoms	57.6	59.7	50.0	73.1	0.11
Symptoms that should prompt you to call your doctor $\not\models$	32.0	34.4	23.9	48.0	0.08
What late and long-term side effects of cancer treatment to expect $\not$	30.5	39.3	21.2	33.3	0.08
Dealing with continuing side effects of cancer treatment $\stackrel{ \not\models}{}$	22.5	17.2	20.3	40.0	0.06
Dealing with fatigue after cancer	26.0	30.3	20.6	29.2	0.41
Dealing with sexual problems $ i$	20.0	12.5	31.0	8.0	0.01
Dealing with memory problems after cancer	23.3	31.3	15.5	25.0	0.09
III. Health Promotion	53.5	57.1	47.1	61.5	0.34
Losing weight or maintaining a healthy weight	26.3	27.9	20.6	38.5	0.19
Staying physically fit $\stackrel{J}{\leftarrow}$	24.5	29.0	21.1	23.1	0.56
Nutrition and diet ${}^{\not\!$	30.1	28.1	26.4	44.4	0.20
Quitting smoking	9.2	7.6	10.0	11.1	0.83
Decreasing the risk of having cancer again ${}^{\not\!$	36.0	45.9	25.4	40.9	0.05
IV. Fertility	0.6	0	1.4	0	0.52
Having children after cancer treatment ${}^{\not\!$	0.6	0	1.4	0	0.52
V. Interpersonal	28.8	33.9	19.7	41.7	0.06
Cancer risks to your family ${}$	25.6	32.3	14.3	40.0	0.01
Talking about your cancer experience with family, friends, or $ \mathcal{L} $					
coworkers	8.5	4.6	12.2	8.0	0.27
Dealing with people who may avoid you $\neq$	2.4	0	2.7	7.7	0.09
VI. Occupational	1.2	0	2.8	0	0.26
Returning to work after cancer	1.2	0	2.8	0	0.26
VII. Emotional	21.7	24.2	17.0	29.2	0.37
Managing your fears about recurrence <sup>¥</sup>	18.5	21.0	15.5	20.8	0.68
Finding a counselor, psychologist, or doctor to talk to about your feelings	7.6	7.9	7.0	8.0	0.98
Finding a support group for people with cancer	7.9	4.5	9.7	12.0	0.37
VIII. Insurance	18.9	19.4	20.8	12.0	0.62
Getting or keeping health, life, or disability insurance after cancer $\not\!$	18.9	19.4	20.8	12.0	0.62

Information Need	Total (N=170) % yes	Breast (n=69) % yes	Prostate (n=74) % yes	Colorectal (n=27) % yes	p-value for comparison by site <sup>*</sup>
Mean Number of Needs Reported, Mean $\pm$ SD	$4.0\pm4.5$	$4.2\pm4.8$	$3.6\pm4.3$	$4.7\pm4.6$	0.95
Mean Number of Domains Reported, Mean $\pm$ SD	2.1 ± 2.0	$2.2 \pm 2.1$	$1.9 \pm 2.0$	2.4 ±1.7	0.98
Beckjord et al 16-Items <sup>¥</sup>					
Mean Number of Needs Reported, Mean $\pm$ SD	$3.1\pm3.5$	$3.2\pm3.7$	$2.8\pm3.4$	$3.5\pm3.3$	0.57
Mean Number of Domains Reported, Mean $\pm$ SD	2.0 ± 1.9	$2.0 \pm 2.0$	$1.8 \pm 2.0 \; 1$	2.3 ± 1.7	0.41

\* P values derived from chi-square test for prevalence of information needs and ANOVA for mean number of needs and domains reported.

¥ Beckjord et al [37] 16-Items

#### Table 3.

Predictors of Total Health-related Information Needs among Rural Cancer Survivors using Poisson Regression (N=170)

Predictor		Total Information Needs					
		Univariate	М	lultivariable <sup>*</sup>			
	Rate Ratio	95% Confidence Interval	Rate Ratio	95% Confidence Interval			
Cancer Type							
Breast	1.00						
Prostate	0.85	0.58 to 1.24					
Colorectal	1.10	0.68 to 1.78					
Age (Five year Increase)	0.90	0.83 to 0.98	0.91	0.84 to 1.00			
Gender							
Male	1.00		1.00				
Female	1.23	0.87 to 1.74	1.18	0.82 to 1.70			
Race/ethnicity							
White, non-Hispanic	1.00		1.00				
Other	1.89	1.17 to 3.06	1.51	0.84 to 2.71			
Education (n=168)							
Bachelor's Degree	1.00		1.00				
< Bacholor's Degree	1.49	1.00 to 2.23	1.54	1.02 to 2.34			
Adequate income to meet needs (n=168)							
Yes	1.00		1.00				
No	1.87	1.25 to 2.81	1.42	0.92 to 2.18			
Cancer Treatments Received [yes vs no (ref) for each]							
Surgery	1.10	0.65 to 1.85					
Radiation	1.20	0.85 to 1.70					
Chemotherapy	1.42	0.99 to 2.05					
Hormonal	0.89	0.61 to 1.30					
Time since cancer diagnosis (years, mean, std) Cancer stage (n=166)	1.02	0.84 to 1.23					
0/I	1.00						
II / III	0.90	0.63 to 1.28					
Received cancer-related follow-up care in the past year [vs. no (ref)]	0.88	0.54 to 1.42	0.82	0.51 to 1.32			
Degree of Rurality							
Large Rural City / Town	1.00		1.00				
Small and Isolated Rural Town	1.21	0.85 to 1.74	1.32	0.92 to 1.89			

Note: Degree of Rurality was defined by Rural-Urban Commuting Area (RUCA) codes

adjusted for all variables listed.

\*