Published in final edited form as:
Patient Educ Couns. 2012 November ; 89(2): 345–352. doi:10.1016/j.pec.2012.08.014.

Health information needs and health-related quality of life in a diverse population of long-term cancer survivors☆

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Abstract

Objective—To investigate health information needs and their association with health-related quality of life (HRQOL) in a diverse, population-based sample of long-term cancer survivors.

Methods—We analyzed health information needs from 1197 cancer survivors 4–14 years post-diagnosis drawn from two cancer registries in California. Multivariable regression models were used to identify factors associated with endorsement of total number and different categories of needs. The relationship between number of needs and HRQOL and effect modification by confidence for obtaining information was examined.

Results—Survivors reported a high prevalence of unmet information needs in the following categories: *side effects & symptoms:* 75.8%; *tests & treatment:* 71.5%; *health promotion:* 64.5%; *interpersonal & emotional:* 60.2%; *insurance:* 39.0%; and *sexual functioning & fertility:* 34.6%. Survivors who were younger, non-White, and did not receive but wanted a written treatment

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the National Cancer Institute or the National Institutes of Health. We confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.

summary reported a higher number of needs. Number of information needs was inversely related to mental well-being, particularly for those with low confidence for obtaining information ($P < 0.05$).

Conclusion—These patterns suggest disparities in access to important health information in long-term survivors and that affect HRQOL.

Practice Implications—Findings suggest a need for tailored interventions to equip survivors with comprehensive health information and to bolster skills for obtaining information.

Keywords

Cancer survivorship; Information needs; Self-efficacy; Quality of care; Health-related quality of life

1. Introduction

Cancer survivors encompass the population with a history of cancer from the point of diagnosis through the balance of life [1]. Meeting information needs among post-treatment cancer survivors is a vital component of quality survivorship care [2–4], yet most assessments of cancer survivors' information needs have focused on the treatment phase [5]. When assessed, survivors have reported higher unmet supportive care needs post-treatment than at completion of treatment [6]. While unmet information needs have been reported across different cancers and populations, disparities in information-seeking experiences have also been found, with low-income and African–American individuals indicating more problems in obtaining health information [7]. Survivors who are Non-Hispanic White and highly educated are more likely to seek information and utilize more sources [8]. Furthermore, low tangible social support has been linked to low health literacy among older adults [9], although whether this relationship holds for cancer survivors is unclear.

Unmet information needs not only reflect the level of need itself but also potentially reduced capacity to obtain information. Bandura's theory of self-efficacy suggests that expectations of effective performance (e.g., successful procurement of information) are likely to increase a behavior (e.g., information-seeking) to meet needs [10,11]. In addition, having more information about health has been linked to increases in healthy behaviors [12]. Survivors 2–5 years post-diagnosis with high levels of unmet needs have been shown to have poorer health-related quality of life (HRQOL)[13] and increased incidence of anxiety and depression [14]. Thus facilitating the confidence to obtain information may help survivors feel able to meet their own information needs, thereby reducing unmet needs and improving HRQOL.

The U.S. cancer survivor population is growing, and over half of survivors alive today are five or more years past their initial diagnosis [15]. Although many survivors reduce their use of regular follow-up care as time after completion of cancer treatment increases, attention to the late effects from cancer treatment among long-term survivors is rising [16]. Thus, it is important to document health information needs among these long-term survivors to inform them and their healthcare providers across the survivorship continuum. To extend previous work on health information needs in cancer survivors with more recent diagnoses [13], we analyzed information needs experienced by cancer survivors more than 4 years post-diagnosis drawn from a diverse population-based sample. Specifically, we (1) examined the relationship of survivors' information needs with their socio-demographics and key follow-up care related characteristics; (2) described the type unmet information needs in long-term cancer survivors (3) analyzed associations between information needs and survivors' HRQOL, investigating confidence to obtain information as a potential moderator of this relationship.

2. Methods

We analyzed data from the FOllow-up Care Use among Survivors (FOCUS) study, a population-based investigation of the follow-up care experiences among long-term cancer survivors (http://cancercontrol.cancer.gov/ocs/focus.html). We investigated health information needs among survivors of breast, prostate, colorectal, and gynecologic (endometrial and ovarian) cancer who were between 4 and 14 years past their initial diagnosis. We included a diverse racial/ethnic population from two Surveillance Epidemiology and End Results (SEER) cancer registries in California: the Los Angeles County Cancer Surveillance Program administered by University of Southern California (USC) and the Greater Bay Area Cancer Registry at the Cancer Prevention Institute of California (CPIC). The study was approved by the institutional review boards at CPIC and USC.

2.1. Patients

We collected data via self-reported questionnaires that were mailed to survivors between March 2005 and July 2006. A total of 6391 cases were sampled by the registries, and of those sampled 4981 were considered eligible for participation. Eligibility criteria included: age at diagnosis 21 and older, ability to read English, no physician refusal of permission to contact, and completion of active treatment. Of the eligible cases, 2977 were located; of those, 1666 completed and returned the survey. The overall participation rate based on eligible, located cases was 56%. Among eligible cases, non-respondents were more likely to be 65 and older, non-White, and with a longer time since diagnosis ($P < 0.05$). Breast cancer survivors were also more likely to respond than all other cancer survivors ($P < 0.05$). From the 1666 original respondents, a total of 332 had missing information with respect to health information needs and an additional 137 had missing information on study covariates of interest; these individuals were excluded from analyses, leaving a total of 1197 survivors in the analytic sample.

2.2. Measures

2.2.1. Health information needs—We asked survivors whether they currently needed information on several health-related topics. Twelve specific information needs were assessed in 6 needs categories: *tests & treatment, side effects & symptoms, health promotion, interpersonal & emotional, insurance, and sexual functioning & fertility* (see Supplementary material for exact wording of all items). Items were adapted from two previous studies conducted with cancer survivors [13,17]. The question wording was as follows: "Little is known about the information needs of long-term cancer survivors. At this time, would you like more information about any of the following health-related topics?" For each item, respondents were offered three response options: "yes," "no," and "not sure." Only a "yes" response was considered an endorsement of a specific need, and if respondents answered "yes" to any of the items in a given information needs category, the category was considered endorsed.

2.2.2. Confidence for obtaining information related to cancer—We measured confidence for obtaining health information with a single item adapted from the Health Information National Trends Survey (HINTS) that asked, "How confident are you at that you could get advice or information related to cancer if you needed it at this time?". Survivors' level of confidence was assessed on a 5-point response scale (not at all, a little, somewhat, very, and completely confident) [18]. For simplicity, we refer to this item as informational attainment confidence (IAC).

2.2.3. Sociodemographic characteristics—We collected data on several sociodemographic characteristics: age at survey (divided into four groups: <50, 50–64, 65–79, and >80), gender, race/ethnicity (determined by self-report or SEER registry data if left blank), annual household income, adequacy of financial resources (AFR) to meet daily family needs during the past 4 weeks, and health insurance status (private, private and public, public only, none/unknown). We chose AFR over annual household income in our models for the following reasons: (1) approximately 10.2% versus 2.5% of respondents had missing data on income and AFR respectively; (2) these variables were moderately correlated ($\rho = 0.29$); and (3) perceived financial stress may be more predictive of psychosocial needs than income [19].

2.2.4. Clinical characteristics—We included data on the following clinical variables: self-reported disease status (active or uncertain disease status, cancer free but experienced recurrence or subsequent cancers, cancer free with no recurrence or subsequent cancer), and number of comorbidities (based on the following 14 conditions: congestive heart failure, cardiomyopathy, heart attack, angina, hypertension, pericarditis, blood clots in the legs or lungs, stroke, chronic lung disease, lung fibrosis, liver disease, diabetes, arthritis, and depression/anxiety) [20].

2.2.5. Social support—We measured social support using a modified 12-item version of the Medical Outcomes Study Social Support Scale, which measures perceived instrumental, informational, and emotional support [21]. Survivors who endorsed >75% of the items were given an average social support score which was transformed to a 0–100 format to facilitate interpretation. A higher score indicated greater social support.

2.2.6. Follow-up care—We asked survivors several questions about the type, frequency, and quality of follow-up care they received over the past 2 years. They were asked who they considered to be their main follow-up care provider: oncologist, primary care physician, gynecologist, urologist, or other provider, and they were asked to rate the quality of the care they had received on a 5-point scale ('poor' to 'excellent'). We also asked survivors if they had received a written summary of their cancer treatment, and if not, would they have wanted one.

2.2.7. Health-related quality of life—We used the Short-Form (SF)-12® health status survey to measure physical and mental health over the past 4 weeks [22]. Responses to the items on the SF-12 were combined to generate two overall scores: a physical component summary score (PCS) and a mental component summary score (MCS). These scores were then normed to the 1999 U.S. general population by transforming them on a T-score metric such that a score of 50 represents the average score in the U.S. general population with a standard deviation of 10 [23]. Higher PCS and MCS scores indicated better physical and mental health respectively.

2.3. Statistical analysis

Analyses were conducted using the Statistical Analysis Software (SAS) callable version of SUDAAN 10.0 (RTI International, Research Triangle Park, NC). The prevalence of information needs across categories was first described for the whole population and across cancer types. We used multivariable modeling (linear and logistic regression) to test factors associated with (1) total number of health information needs (continuous), and (2) endorsement of each need category (dichotomous). Covariates associated with $P < 0.20$ in the bivariate analyses were included in final multivariable models of number of needs and categories of need.

For the models that examined whether number of health information needs was associated with mental and physical HRQOL, multivariable linear regression models were analyzed, with and without the presence of information attainment confidence (IAC) as an effect modifier. Both number of needs and IAC were centered on their grand mean, and an interaction term of the two centered variables was created. Potential confounders (age, sex, race/ethnicity, marital status, education, current health insurance status, adequate financial resources, cancer site, time since diagnosis, disease status, comorbidity burden, type of main follow-up care physician, receipt of a treatment summary, and self-rated quality of care) were modeled using backward elimination, with a 10–15% change in the coefficient for health information needs indicating confounding [24,25]. Final associations were deemed significant at $P < 0.05$. Spearman correlations of the independent variables were all low ($< |0.25|$).

3. Results

3.1. Sample description

Of the 1197 participants, there were 292 breast, 289 prostate, 305 colorectal, and 311 gynecologic cancer survivors. Table 1 describes the sample and presents bivariate associations between sample characteristics and mean number information needs. By design, approximately half (46%) of survivors were diagnosed at least 10 years prior to survey. Forty-two percent were Non-Hispanic White (NHW), 13% were Hispanic White (HW), 20.6% were African-American (AA), 22.3% were Asian-American/Pacific Islander (AAPI), and 1.6% were American Indian/Alaskan Native (AIAN). We suppressed output from AIAN survivors in our analytical models due to low numbers ($N = 19$).

3.2. Number of health information needs

The mean number of health information needs was 5.3 (95% CI: 5.0, 5.5). As shown in Table 2, after adjustment for all covariates in the model, number of needs varied by age at survey ($P < 0.001$), with younger survivors endorsing a significantly higher number of needs. Number of needs was also associated with cancer type ($P < 0.05$), with colorectal cancer survivors reporting lower number of needs than breast cancer survivors. Needs also varied significantly by race/ethnicity: NHWs had fewer information needs than all other racial/ethnic groups ($P < 0.001$). Of the followup care variables analyzed, number of needs differed only by reported receipt of a written treatment summary ($P < 0.05$); those who wanted but did not receive a treatment summary had a significantly higher number of information needs, and those who neither wanted nor received one had significantly lower number of needs.

3.3. Type of health information needs

Of the six information needs categories, more than half of survivors expressed a desire for more information about *side effects & symptoms* (75.8%), *tests & treatment* (71.5%), *health promotion* (64.5%), and interpersonal/emotional needs (60.2%) (Table 3). Needs were similar by cancer site, with the following exceptions: colorectal cancer survivors were less likely to report information needs related to *side effects & symptoms*, *health promotion*, and *interpersonal and emotional needs*. Prostate cancer survivors were more likely to report needs related to *sexual functioning & fertility*.

Multiple logistic variable regression models examined specific factors associated with each type of health information need category (models not shown). Predictors of endorsement of specific information needs varied greatly by category. African Americans [OR = 2.0 (1.1, 3.7)] and Asian American/Pacific Islanders [OR = 1.7 (1.1, 2.9)] as compared to non Hispanic Whites, those who reported less than excellent [OR = 1.9 (1.2, 3.1)] as compared to excellent follow-up care in the past 2 years, and those who wanted but did not receive a treatment summary [OR = 2.5 (1.5, 4.4)] as compared to those who did were more likely to report *side effects & symptoms* related information needs. Survivors diagnosed less than 10 years ago [OR = 1.8 (1.2, 2.8)] and Asian American/Pacific Islanders [OR = 1.7 (1.0–2.8)], were more likely to report *tests & treatment* information needs. In addition, those with active or uncertain disease status [OR = 3.6 (1.8, 7.0)] as compared to those who were cancer free, and those who wanted but did not receive a treatment summary [OR = 1.8 (1.0, 3.2)] were also more likely to report *tests & treatment*. Survivors who were under 50 at diagnosis [OR = 2.5 (1.0, 6.4)] as compared to 80 and over, those who were non-White [Hispanic OR = 2.1 (1.2, 3.8), African American OR = 1.9 (1.1, 3.4), Asian American/ Pacific Islander OR = 2.0 (1.2, 3.3)], reporting inadequate financial resources [OR = 2.8 (1.4, 5.6)], and with lower social support [OR = 0.99 (0.98, 1.00)] were more likely to report *health promotion* information needs. Younger survivors [under 50 OR = 5.6 (2.2, 14.6), 50–64 OR = 2.3 (1.2, 4.3)] and those less than 10 years since diagnosis [OR = 1.5, (1.0, 2.2)], were more likely to report *interpersonal & emotional* needs. In addition, non-White survivors [Hispanic OR = 3.0 (1.7, 5.3), African American OR = 2.2 (1.3, 3.8)] and those who wanted but did not receive a written treatment summary [OR = 1.6 (1.0, 2.7)] were more likely to report these needs. Younger survivors [under 50 OR = 6.8 (2.7, 16.8), 50–64

OR = 3.2 (1.7, 6.3)], African American [OR = 2.2 (1.3, 3.8)] and Asian American/Pacific Islanders [OR = 1.8 (1.1, 2.9)], those reporting inadequate financial resources [OR = 2.1 (1.1, 3.8)], and lower social support [OR = 0.99 (0.98, 1.00)] were more likely to report *insurance* related needs. Finally, younger survivors [under 50 OR = 10.1 (4.0, 25.6), 50–64 OR = 4.3 (2.0, 9.2), 65–79 OR = 2.1 (1.1, 4.4)] and those reporting inadequate financial resources [OR = 2.1 (1.1, 3.8)] were more likely to report *sexual functioning & fertility* information needs.

3.4. Number of information needs, HRQOL and information attainment confidence

Table 4 shows the adjusted regression parameter estimates of both the mental (MCS) and physical (PCS) component scales of the SF12, without (Model 1) and with (Model 2) an interaction term of confidence for obtaining information by number of needs. Both number of needs [$B = -0.4$ (-0.6, -0.2), $P < 0.001$] and IAC [$B = 1.2$ (0.4, 2.0), $P < 0.01$] were inversely associated with MCS. The interaction term was also significant [$B = 0.2$ (0.03, 0.5), $P < 0.02$], indicating that the relationship between number of health information needs and MCS differed by level of confidence. Fig. 1 shows the relationship between MCS and number of information needs by three categories of confidence: moderate (mean level), low, and high (±1 standard deviation). The negative slope steepens at lower levels of confidence, indicating that the inverse association between information needs and mental HRQOL is strongest among those with low confidence for obtaining information. Neither number of needs, confidence, nor the interaction term was associated with PCS.

4. Discussion and conclusion

4.1. Discussion

Many long-term survivors reported a diverse array of health information needs. Younger survivors, non-Whites, and those who did not receive but wanted a written summary of their cancer treatment reported a higher number of needs. Conversely, colorectal cancer survivors and those who did not want a treatment summary reported a lower number of needs. Information needs by category were highly endorsed in the areas of *tests & treatment, health promotion, side effects & symptoms*, and *interpersonal & emotional* issues.

As found in a previous study of survivors surveyed 2–5 years after diagnosis [13], non-White survivors reported a higher number of needs and significantly more *health promotion, interpersonal & emotional, side effects & symptoms*, and *insurance* needs. In addition, survivors reporting inadequate access to financial resources endorsed more *health promotion and insurance*, and *sexual functioning & fertility* information needs. Previous research has indicated that survivors of lower socioeconomic backgrounds report may need assistance and training in how to gain access to information and may benefit the most from training [7]. One recent patient/physician survey study found that income largely explained racial differences in patient/provider communication. The authors found that for African Americans reduced access to information such as cancer expert referrals persisted despite control for other factors, a finding that suggests the need for careful attention to systemic factors that inhibit information provision for non-White cancer survivors [26].

The main follow-up care variable associated with information needs in terms of both number and type was receipt of a treatment summary. Although 17.6% of our study sample indicated that they had received a one, providing treatment summaries to survivors as they transition off treatment was not common practice at the time when the participants of this study were finishing treatment [27]. A written summary may serve two purposes: as an information reference and as a reassurance that should questions arise in the future, there are resources to turn to. Although previous research in cancer survivors has shown that satisfaction with medical care predicts lower levels of unmet information needs [6], in this study less than excellent self-rated quality of care was only associated with higher likelihood of *side effects & symptom* information needs.

Our findings that number of information needs was inversely associated with perceived mental but not physical health replicates past work [13]. Our novel finding that confidence for obtaining information acts as a moderator of this relationship suggests a few possibilities. The inverse relationship between health information needs and MCS was strongest among those with low confidence for obtaining information. Thus, opportunities for improving HRQOL in the context of information needs are greatest among those with low confidence. These findings suggest a need to assess and meet current health information needs among survivors, as well as a need to equip survivors with skills, resources, and confidence to obtain information in the future.

In terms of how cancer survivors obtain health information, one study showed that most survivors consider their healthcare providers to be reputable sources of information but often turn instead to the Internet to answer questions [28]. This may reflect a lack of continuity of care, limited access to healthcare providers over time, or limited capacities of some providers to provide this type of comprehensive cancer care [29]. Although the Internet provides survivors with a multitude of information and support opportunities and has been shown to increase self-efficacy to obtain information [10], survivors are often wary of the quality or confused by the content of the information they find [5,7,30].

Confidence to obtain information may stem from both good patient-provider relationships and health literacy. A cross-sectional study of German cancer survivors found that a good patient-provider relationship was the strongest predictor of reporting fulfilled information needs [31]. Given high general population prevalence of low health literacy [32], and findings that low health literacy is associated with lower HRQOL in cancer survivors [33], efforts to improve health literacy may aid in both meeting information needs and improving mental well-being particularly among the less health literate. The open communication that often underlies good doctor-patient relationships may provide the ancillary benefit of equipping survivors with the tools and confidence to obtain information related to maintaining good health over the long term. Our findings suggest two opportunities for providers to meet information needs: at completion of treatment via a treatment summary, and throughout follow-up care by engaging in dialogue with survivors about emerging needs.

A strength of the current study is that it represents one of the few population-based surveys of survivors more than 5 years from diagnosis. However, it is limited by its cross-sectional design. Furthermore, while we oversampled racial/ethnic minorities to represent the diverse population of survivors, there are some limitations on generalizability. The two registries from which survivors were drawn cover predominantly urban/suburban regions of California with both comprehensive cancer centers and several community-based clinics. Non-responders were more likely to be older, diagnosed over 10 years ago, and diagnosed with colorectal cancer. Our findings may also have limited generalizability to survivors living in rural or geographically isolated areas, non-English speakers, or those for whom low levels of literacy hindered participation. Although the cancer sites included in the current analysis represent the most prevalent cancers among survivors in the US [34], results may differ by other cancer types, particularly those with shorter survival or higher treatment burden.

Only survivors who completed the entire health information needs section were included in analysis in order to avoid confusing non-response with a lack of endorsement of a particular need. However, a sensitivity analysis conducted on participants with at least 75% of the health information needs assessment completed yielded similar results to the final analysis. With regard to endorsement of health information needs, an alternative interpretation is that responding “yes” to an individual health information item may indicate interest in, rather than need for, health information in that category. However, this interpretation is less convincing for the following reasons: a prompt before the actual question stating that little is known about information needs of long-term cancer survivors was given; previous research which used similar items found very similar patterns in health information needs [13]; and the significant associations between higher endorsed health information needs and lower HRQOL. The use of a single-item measure of confidence to obtain information from the Health Information National Trends Survey [18], while informative, limits the depth of understanding of this construct. Future studies should expand upon this construct to examine its meaning and impact health outcomes. Finally, these data were collected in 2005–2006, and since that time increasing attention to the need for survivorship care planning in the US has occurred, including the American College of Surgeons Commission on Cancer decision to require evidence of systematic survivorship care planning as part of hospital certification, to take effect in 2015. Thus it is possible that we overestimate current health information needs among long-term cancer survivors. However, given the limited basis on which these documents are provided to date [35], we see no indications that that health information needs or associations between needs and HRQOL would have meaningfully changed.

4.2. Conclusions

Our findings suggest that that despite being years from diagnosis, many survivors have lingering questions about cancer survivorship. The pattern of needs endorsed by survivors suggests persistent health disparities in access to important health information. Findings also suggest the need for treatment summaries and possibly survivorship care plans to equip survivors with comprehensive health information, resources and instructions for obtaining info in the future, as well as tailored approaches for diverse survivor populations. Future research linking information needs, confidence for obtaining information from a variety of sources, and information seeking-behavior in the context of different models of cancer follow-up care and in diverse populations is needed to help improve cancer communication.

4.3. Practice implications

Since the publication of the Institute of Medicine's report *From Cancer Patient to Cancer Survivor: Lost in Transition* [36], there has been much discussion over the information that should be included in both a treatment summary and survivorship care plan, as well as who should be responsible for their development and delivery. Research on patient preferences regarding these documents indicates that survivors want a concise and easy-to-read plan, that contains diagnosis information, details of treatments received, clinical trial information, potential late effects of treatment, and a follow-up care plan [37]. Some of the barriers to providing survivorship care plans have included costs and fears about increasing patient anxiety (although recent evidence suggests the contrary [38,39]). Our finding that greater information needs were associated with poorer mental well-being also suggest that interventions such as care plans that address survivors' information needs are likely to reduce, not increase, patient anxiety.

In the US, although several models are currently being tested [40] there has not yet been comparative effectiveness research to generate an evidence base for the efficacy of survivorship care plans [41] despite the Commission on Cancer's upcoming requirement for implementation of survivorship care plans as part of their accreditation process [42]. As this research progresses, observing the experiences of implementing survivorship care planning in other countries like Canada [43] and the United Kingdom [44] as well as paying careful attention to the choice of evaluation outcome measures [45] will be critical for the US. If future intervention research confirms our findings, then educating survivors by providing them a SCP from diagnosis may serve to improve QOL, particularly for survivors who lack the confidence to seek out information themselves.

The current study supports the need for research to evaluate ways to provide survivors with comprehensive health information that (1) tailors to individual survivors with respect to information readiness, self-efficacy, and cultural sensitivity and (2) addresses numerous psychosocial needs that survivors express interest in, for example, information on nutrition and physical activity after cancer, managing recurrence anxiety, and understanding familial cancer risks. The majority of cancer patients in the US are 65 and older, survive 5 or more years after diagnosis and face potential increased physical and psychological sequelae [15]. Understanding the information needs of these survivors will better prepare the research and practice community to provide the tools survivors require to maintain good long-term health.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

This study was supported under NCI SEER contract numbers: N01-PC-35136, N01-PC-35139 (http://cancercontrol.cancer.gov/ocs/focus.html). The authors would like to acknowledge Ms. Gretchen Keel (Information Management Services, Inc., Rockville, MD) for her assistance with data analysis on this project. This study has been presented in part at a poster at the 2011 American Association of Cancer Research Science of Cancer Health Disparities Meeting, on September 19, 2011, in Washington, DC.

Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at http://dx.doi.org/10.1016/j.pec.2012.08.014.

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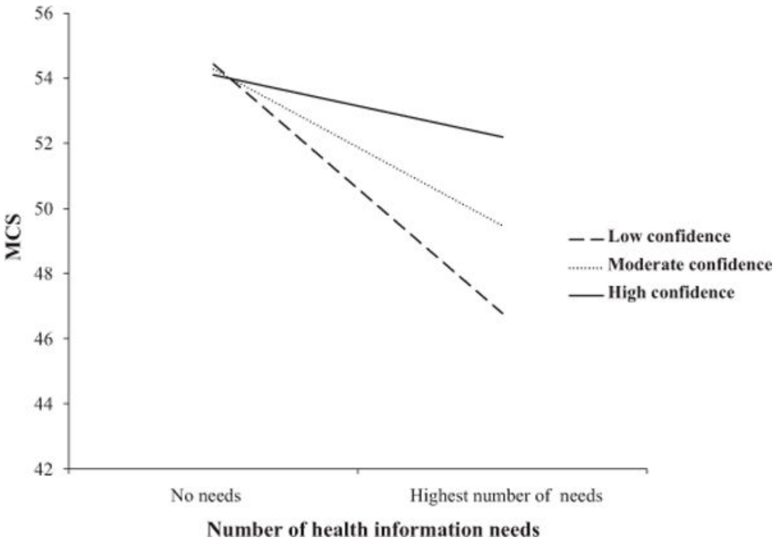

Fig. 1.

The association between mental health-related quality of life [the mental component scale (MCS) of the SF 12] and number of health information needs at low, moderate, and high levels of confidence to obtain information. Interaction significant at $P < 0.02$.

Table 1

Sample characteristics and bivariate associations with number of information needs.

		N	Sample % or mean (SD)	Mean number of information needs endorsed (SD) or bivariate correlation	***P****
Age at survey	80 and over	213	17.8	3.9 (3.6)	<0.0001
	65–79	550	45.9	5.0 (4.3)	
	50–64	354	29.6	6.2 (4.0)	
	Under 50	80	6.7	7.2 (4.2)	
	Age continuous		68.0 (11.4)	−0.32	<0.0001
Years since diagnosis	≥10	551	46	4.6 (4.2)	0.03
	<10	646	54	5.9 (4.1)	
	Time continuous		8.8 (3.2)	−0.07	0.02
Gender	Male	454	37.9	5.1 (4.3)	0.16
	Female	743	62.1	5.5 (4.1)	
Race/ethnicity	Non-Hispanic White	508	42.4	4.1 (4)	<0.0001
	Hispanic White	156	13	5.1 (4.2)	
	African-American	247	20.6	6.6 (4.3)	
	Asian-American/Pacific Islander	267	22.3	6.2 (3.8)	
	American Indian/Alaska Native	19	1.6	8.8 (0.5)	
Education	High school or less	288	24.1	5.1 (4.4)	0.02
	Some college	441	36.8	5.7 (4.2)	
	College graduate or higher	468	39.1	5.0 (3.9)	
Adequate financial resources	Yes	1065	89	5.1 (4.1)	<0.0001
	No	132	11	6.8 (4.4)	
Marital status	Married or living as married	746	62.3	5.2 (4.2)	0.39
	Never married	80	6.7	5.5 (4.2)	
	Divorced, separated, or widowed	371	31	5.6 (4.1)	
Health insurance status	Private or public/private	765	63.9	5.4 (4.1)	<0.0001
	Only public-sponsored	275	23	4.7 (4.3)	
	None/unknown	157	13.1	6.0 (4.3)	
Type of cancer	Breast	292	24.4	5.5 (4.1)	0.05
	Prostate	289	24.1	5.9 (4.4)	

		N	Sample % or mean (SD)	Mean number of information needs endorsed (SD) or bivariate correlation	*P**
	Colon or Rectum	305	25.5	4.7 (4.2)	
	Gynecologic	311	26	5.4 (4.0)	
Disease status	Cancer free, no recurrence/second cancer	907	75.8	4.9 (4.1)	0.003
	Currently cancer free, but reported recurrence/second cancer	145	12.1	5.9 (4.2)	
	Active or uncertain disease status	145	12.1	7.4 (4.0)	
Number of comorbidities	0	224	18.7	5.4 (4.0)	0.39
	1	307	25.6	5.2 (4.3)	
	2	284	23.7	5.1 (4.2)	
	3+	382	31.9	5.6 (4.1)	
	Number of comorbid conditions		1.7 (1.1)	−0.01	0.85
Quality of Care	Excellent	390	32.6	4.9 (4.1)	<0.0001
	Less than excellent care	462	38.6	6.6 (4.2)	
	No care in the past two years/unknown	345	28.8	4.2 (3.9)	
Type of main follow-up doctor	None/unknown	285	23.8	4.4 (4.1)	0.047
	PCP	148	12.4	5.5 (4.0)	
	Oncologist	491	41	5.7 (4.2)	
	Other specialist	273	22.8	5.5 (4.2)	
Receipt of treatment summary	Received	211	17.6	5.2 (4.3)	<0.0001
	Wanted but did not knowingly receive	749	62.6	6.0 (4.1)	
	Did not want and did not knowingly receive	237	19.8	3.4 (3.6)	
Total Social Support Scale Score	Mean (SD)		75.6 (21.5)		0.0001

[*] Unadjusted P-values given. $P < 0.20$ included in subsequent models.

Table 2

Multivariable regression model of number of information needs.[a]

		Total number of information needs (model adjusted $r^2 = 0.23$) *B* (SE) (95% CI)
Age at survey	80 and over	*Ref*
	65–79	0.2 (−0.5, 0.9)
	50–64	1.6 (0.7, 2.4)***
	Under 50	2.4 (1.2, 3.5)***
Years since diagnosis	≥10	
	<10	0.5 (0, 1.1)
Gender	Male	
	Female	−0.5 (−1.5, 0.6)
Race/ethnicity	Non-Hispanic White	*Ref*
	Hispanic White	1 (0.1, 1.8)*
	African-American	1.4 (0.6, 2.2)***
	Asian-American/Pacific Islander	1.2 (0.5, 1.9)**
Education	High school or less	*Ref*
	Some college	0.1 (−0.6, 0.8)
	College graduate or higher	0.1 (−0.7, 0.8)
Adequate financial resources	Yes	*Ref*
	No	0.9 (0, 1.9)
Health insurance status	Private or public/private	*Ref*
	Only public-sponsored	−0.6 (−1.3, 0.1)
	None/unknown	−0.7 (−1.6, 0.2)
Type of cancer	Breast	*Ref*
	Prostate	0.4 (−0.8, 1.7)
	Colon or Rectum	−1.1 (−1.9, 0.2)*
	Gynecologic	−0.3 (−1, 0.4)
Disease status	Cancer free, no recurrence/second cancer	*Ref*
	Currently cancer free, but reported recurrence/second cancer	0.7 (−0.1, 1.6)
	Active or uncertain disease status	0.8 (0, 1.6)
Quality of care	Excellent	*Ref*
	Less than excellent care	0.5 (−0.2, 1.1)
	No care in the past two years/unknown	−0.2 (−1.1, 0.7)
Type of main follow up doctor	None/unknown	−0.8 (−1.8, 0.2)
	PCP	*Ref*
	Oncologist	−0.1 (−1, 0.8)
	Other specialist	−0.5 (−1.6, 0.5)
Receipt of treatment summary	Received	*Ref*
	Wanted but did not knowingly receive	0.8 (0, 1.6)*
	Did not want and did not knowingly receive	−1 (−1.8, 0.1)*

		Total number of information needs (model adjusted $r^2 = 0.23$) *B* (SE) (95% CI)
Social support	Scale Score	−0.01 (−0.03, 0.00)

[a] Dependent variable ranged from 0 to 12, total number of needs.

* $P < 0.05$.

** $P < 0.01$.

*** $P < 0.001$.

Table 3

Information need category endorsements by cancer site

	Total (n = 1197) **% (95% CI)**	**Breast (n = 292)** **% (95% CI)**	**Prostate (n = 289)** **% (95% CI)**	**Colorectal (n = 305)** **% (95% CI)**	**Gynecologic (n = 311)** **% (95% CI)**
Side effects and symptoms	75.8 (72.1, 79.1)	77.2 (69.5, 83.4)	83.1 (76.8, 88.0)	61.9 (53.6, 69.6)[*]	76.1 (67.7, 82.8)
Tests and treatments	71.5 (67.5, 75.2)	71.7 (63.6, 78.5)	78.0 (70.2, 84.1)	60.8 (52.5, 68.5)	71.3 (62.7, 78.6)
Health promotion	64.5 (60.3, 68.4)	66.4 (58.3, 73.6)	72.4 (64.5, 79.1)	50.9 (43.0, 58.9)[*]	62.3 (53.1, 70.6)
Interpersonal and emotional	60.2 (56.0, 64.2)	63.6 (55.7, 70.9)	64.7 (56.5, 72.1)	46.0 (38.5, 53.8)[*]	64.2 (55.6, 72.0)
Insurance	39.0 (35.0, 43.1)	40.1 (33.0, 47.6)	44.0 (35.8, 52.5)	30.3 (23.9, 37.5)	38.0 (30.9, 45.6)
Sexual functioning and fertility	34.5 (30.6, 38.7)	22.1 (16.5, 29.0)[*]	54.7 (46.1, 63.0)[*]	22.5 (16.6, 29.8)[*]	23.7 (18.3, 30.2)[*]

[*] Significantly different from total ($P < 0.05$).

Table 4

SF-12 Parameter estimates of multivariable regression of health-related quality of life (mental and physical component scores) and information attainment confidence on number of health information needs (range 0–12).

Outcome	**Model 1** ***B* (95% CI)**	**Model 2** ***B* (95% CI)**
Mental Component Score (range: 0–100)[a]		
Number of needs	−0.4 (−0.6, −0.2)	−0.4 −0.6, −0.2)[***]
Information attainment confidence	1.2 (0.4, 2.0)	1.1 (0.4, 1.9)[**]
Interaction term	–	0.2 (0.03, 0.5)[*]
r^2	0.12	0.13
Physical Component Score (range: 0–100)[b]		
Number of needs	−0.03 (−0.27, 0.21)	−0.03 (−0.27, 0.21)
Information attainment confidence	0.6 (−0.2, 1.4)	0.6 (−0.2, 1.4)
Interaction term	–	−0.03 (−0.23, 0.17)
r^2	0.33	0.33

[a] Models adjusted for adequate financial resource.

[b] Models adjusted for time since diagnosis, age at diagnosis, race/ethnicity, educational attainment, marital status, adequate financial resources, cancer site, cancer status, number of comorbidities, and social support.

[*] $P < 0.05$.

[**] $P < 0.01$.

[***] $P < 0.001$.