Published in final edited form as:

J Psychosoc Oncol. 2008 ; 26(2): 1–16.

Informational needs of patients and perceived adequacy of information available before and after treatment of cancer

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Abstract

To examine the various concerns of patients after being diagnosed with cancer as well as the availability of information to address concerns from the time of diagnosis to the completion of treatment, we analyzed data from a longitudinal study of 731 adults recently diagnosed with cancer. Concerns about the effectiveness and side effects of treatment and family stress were most common after diagnosis. Information about the diagnosis and treatment plan was readily available to patients, but information addressing social, lifestyle, and financial concerns was less available. Significantly more information was desired regarding the long-term implications of treatment and disease.

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The findings and conclusions in this article are those of the authors and do not necessarily represent the views of the CDC.

Keywords

Patient education; Informational support; Cancer survivorship

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Introduction

Individuals are faced with a variety of challenges upon being diagnosed with cancer, and their quest for information to assist them becomes an important theme in their lives (Derdiarian, 1986; Hill, Amir, Muers, Connolly, & Round, 2003; Salminen, Vire, Poussa, & Knifssund, 2004; Squiers, Finney Rutten, Treiman, Bright, et al., 2005; Whelan, 2003). The extent to which a newly diagnosed patient's search for information is successful can have both short- and long-term implications for health and well-being. Having significant unmet needs for information has been associated with deleterious consequences (Booth, Beaver, Kitchener, O'Neill, & Farrell, 2005; Arora, Johnson, Gustafson, McTavish, Hawkins, et al., 2002), whereas receiving adequate informational support has been associated with lower depression and anxiety (Booth et al., 2005), greater quality of life (Templeton & Coates, 2004), and greater satisfaction with care (Templeton & Coates, 2004; Iconomou, Viha, Koutras, Koukourikou, Mega, et al., 2006). Furthermore, results from intervention studies suggest that, by increasing the availability of information to newly diagnosed cancer patients, it may be possible to improve mood and to reduce feelings of fear and anxiety (Gallant & Coutts, 2003; Allen, Shah, Nezu, Nezu, Ciambone, et al., 2002). In addition to these benefits, previous studies have found that most patients desire to be well-informed and will spend a significant amount of time looking for relevant information (Meredith, Symonds, Webster, Lamont, Pyper, et al., 1996; Whelan, Mohide, Willan, Arnold, Tew, et al., 1997; Blanchard, Labrecque, Ruckdeschel, & Blanchard, 1988; Davidson, Brundage, & Feldman-Stewart, 1999). Following from these findings, some experts suggest that access to informational support be recognized and implemented as an important and cost-effective component of standard patient care (McIllmurray, Thomas, Francis, Morris, Soothill, et al., 2001; Mossman, Boudioni, & Slevin, 1999; Bilodeau, 1996).

Evidence demonstrates the benefits of informational support for newly diagnosed cancer patients. However, research findings and practical constraints alike suggest that there are limits on the amount of information that can—and should (Friis, Elverdam, & Schmidt, 2003; Mohide, Whelan, Rath, Gafni, Willan, et al., 1996)—be offered to patients after a cancer diagnosis. It is, therefore, important to identify issues and concerns that may be addressed most effectively through informational support, to identify the most common concerns to patients after a diagnosis, and to identify the topics of concern for which resources are unavailable. Previous research has found that the issues of greatest concern to patients after a cancer diagnosis include learning more about their current illness, planning for the future, and cancer treatments (Derdiarian, 1986; Squiers et al., 2005; Booth et al., 2005; Meredith, et al., 1996; Whelan, et al., 1997; Friis, Elverdam & Schmidt, 2003; Beaver & Luker, 2005; Feldman-Stewart, Brundage, Hayter, Groome, Nickel, et al., 2000; Harrison-Woermke & Graydon, 1993). Other important topics of concern include treatment side effects, improving health, partner relationships, sexuality, and social or community support (Derdiarian, 1986; Squiers et al., 2005; Booth et al., 2005; Meredith, et al., 1996; Whelan, et al., 1997; Friis, Elverdam & Schmidt, 2003; Jonker-Pool, Hoekstra, van Imhoff, Sonneveld, Sleijfer, et al., 2004). Whereas many studies have aimed previously to identify the topics of greatest concern to patients around the time of treatment, fewer studies have examined the perceived adequacy of information that is available to patients at that time. Among the few studies that have examined this issue, the results have been inconclusive. Some studies (Soothill, Morris, Harman, Francis, Thomas, et al., 2001; Montgomery, Lydon, & Lloyd, 1999) have concluded that the majority of patients received enough information to

adequately address their concerns, while others (Jonker-Pool et al., 2004; Sahay, Gray, & Fitch, 2000; Sainio & Eriksson, 2003) have reported that the majority of patients were inadequately informed about their greatest concerns before and during cancer treatment. Such studies have begun to highlight the important problems that patients face in acquiring information before and during treatment of cancer. More work is required to confirm and to further examine these informational support issues using longitudinal studies of larger samples of cancer survivors.

This study had two main goals. Our first goal was to describe the content of the patients' informational needs and priorities just after a cancer diagnosis. Our second goal was to examine the perceived adequacy of information that is available to patients before and after treatment to address their many concerns. For the second goal, we wanted to highlight those concerns that patients considered to be important but also perceived as being unaddressed by the time treatment was completed. To avoid the potential for recall bias in asking patients who have already completed cancer treatment to remember their concerns at the time of diagnosis, we analyzed data that were collected prospectively from newly diagnosed cancer patients soon after diagnosis. To examine patient perceptions of the adequacy of information available to them from the time of diagnosis through the completion of treatment, data were collected from the same group of patients before and after undergoing treatment of cancer.

Methods

Data that were used in these analyses come from a larger longitudinal study of cancer patients who were undergoing chemotherapy or radiation therapy conducted by the University of Rochester Cancer Center (URCC) Community Clinical Oncology Program (CCOP) (Shields, Morrow, Griggs, et al., 2004; Yates, Mustian, Morrow, Gillies, Padmanaban, et al., 2005). Outpatients who were aged 18 years or older ($n = 1,004$) and had been diagnosed recently with cancer and treated at one of 17 community-based oncology practices located throughout the United States were recruited to participate in the study. The participating oncology practices were grantees of the National Cancer Institute's CCOP and were members of the URCC Research Base. Longitudinal data were collected from January 2001 through September 2002 to study the information needs of cancer patients. Baseline interviews were conducted with patients who had been diagnosed with breast, lung, genitourinary, hematologic, gastrointestinal, or head and neck cancer and whose treatment plan included chemotherapy or radiation therapy. Patients of any disease stage were eligible as long as their life expectancy was not less than 10 months. Baseline information, including demographic characteristics, concerns related to the cancer diagnosis, and a symptom inventory, was collected by personal interview. Pretreatment survey questionnaires were self-administered within 2 weeks before the start of treatment. Self-administered survey questionnaires were also completed within 2 weeks after the completion of treatment. At pretreatment and posttreatment, the patients were asked about their approaches to seeking information, the availability of information to address their concerns, and the adequacy of information that was available to address their concerns.

In this analysis, we examined the treatment, lifestyle, social, and financial concerns of the patient sample, as well as the perceived availability or unavailability of information related to these concerns. Twenty issues of potential concern to newly diagnosed cancer patients were identified a priori based on previous research and input from clinicians in the CCOP program. Patients were asked to describe their level of concern about each issue (shown in Table 2) using a Likert scale of 1 ("no concern") to 5 ("a great deal of concern"). We restricted the issue-specific analyses of perceived information availability to those patients who reported at baseline some degree of concern about the respective issue (e.g. "understanding the treatment plan"), excluding the reports of information availability from

those who reported no concern. Among the patients with concerns, we determined the cross-sectional proportions of those patients who reported that information was not available to address their concern at pretreatment and at posttreatment. We also determined the cross-sectional proportions of the patients who reported wanting additional information about that issue at pretreatment and posttreatment. All of the estimates are expressed as percentages.

Median age was used to define the dichotomous age groups 40–60 years and 61 years and older. We used *t*-tests to compare the proportions who endorsed various issues as concerns at baseline by sex and by age group, while using paired *t*-tests to compare the proportions of perceived information unavailability and the desire for additional information between pretreatment and posttreatment.

Results

Of the 1,004 patients who were recruited to the study, 974 (97%) completed the baseline assessment of current concerns and, of those, 731 (75%) completed and returned the pretreatment and posttreatment information questionnaires on perceived information unavailability and the desire for additional information. The median time between the initial cancer diagnosis and the baseline interview was 39 days.

As shown in Table 1, the patients were predominantly female (64.7%), white (92.8%), and married (70.4%). Ages ranged from 20 to 92 years, with a median age of 61 years. More than one half of all of the patients reported having at least some education beyond high school (54.8%). The most common diagnosis was cancer of the breast (46.9%), followed by genitourinary tract (e.g. prostate; 16.4%) and lung (13.8%).

Issues of concern

Of the 20 treatment, lifestyle, social, and financial issues shown, all were identified as being of some concern to at least some of the patients. Fifteen issues were identified as being of concern to more than half of the patients. The issues and the proportion of the patients who identified each of the issues as a concern at baseline are shown in Table 2. The five most commonly reported concerns were 1) knowing if my treatment will work (92.6%), 2) relieving side effects (89.6%), 3) easing my family's stress (83.7%), 4) being a burden to family and friends (77.1%), and 5) making long-term plans (76.5%). The least commonly reported concerns were maintaining my job (39.3%) and being able to have children (4.5%), although only 50.1% of the sample were in the labor force and only 21.7% were under age 50 years. Significant differences were found between the men and women in the proportions of each group who reported various issues as a concern. Specifically, significantly more women than men were concerned about being disfigured (56.3% vs. 38.8%; $p < 0.001$), eating right (73.8% vs. 64.5%; $p < 0.01$), and maintaining a job (43.2% vs. 32.4%; $p < 0.01$). In contrast, men more commonly expressed concern over having sexual relationships than women (54.2% vs. 44.0%; $p < 0.01$). Comparisons by age revealed that the patients who were 40–60 years of age were significantly more likely to express concerns about all of the issues than were those who were over age 60 years ($p < 0.01$ for all comparisons).

Information availability

Table 2 also shows the proportion of patients who reported that information was not available to address adequately their concerns regarding the 20 specified topics. During the pretreatment assessment, the highest proportion of patients reported a lack of information focusing on concerns regarding the following topics: becoming isolated (75.2%), paying for care not covered by insurance (68.2%), being a burden to family and friends (66.9%), and making long-term plans (65.0%). Conversely, the lowest proportion of patients reported

insufficient information dealing with concerns about understanding the treatment plan (7.8%) and understanding the diagnosis (9.5%). During the posttreatment assessment, the highest proportion of patients reported that information was not available for the following topics: paying for care not covered by insurance (63.2%), making long-term plans (60.8%), and becoming isolated (60.2%). Similar to the pretreatment assessment, the lowest proportion of patients reported insufficient information dealing with concerns about understanding the treatment plan (4.5%), understanding the diagnosis (7.1%), and relieving side effects (10.8%). Pretreatment to posttreatment comparisons revealed that significantly more information was available to patients for most topics after they had completed treatment (i.e. $p < 0.05$). However, perceived information availability did not change pretreatment to posttreatment for the following topics: knowing if my treatment will work, making long-term plans, understanding the diagnosis, understanding the treatment plan, and finding community services ($p > 0.09$ for each).

Desire for additional information

At pretreatment, the highest proportion of patients desired additional information about the following topics: knowing if my treatment will work (63.1%), being able to have children (62.5%), understanding the treatment plan (60.7%), understanding the diagnosis (60.3%), and paying for care not covered by insurance (59.2%). At posttreatment, the highest proportion of patients desired additional information about the following topics: knowing if my treatment will work (58.2%), understanding the diagnosis (54.5%), understanding the treatment plan (50.9%), being able to have children (50.0%), and relieving side effects (48.0%). Pretreatment to posttreatment comparisons revealed significant decreases ($p < 0.01$ for all comparisons) in the proportion of patients who desired additional information about each of the topics of concern.

Discussion

This study confirmed that cancer patients have many concerns and strongly desire a variety of information just after being diagnosed and treated for cancer. Each of the 20 specified issues were identified as being of concern to at least some patients, and 15 of the 20 issues were identified as being of concern to more than half of the patients. Comparisons by age revealed that patients 60 years of age and younger expressed a greater number of concerns than did those who were older than 60 years, which is consistent with previous research showing that older patients often have less desire for certain types of information (Derdiarian, 1986; Salminen et al., 2004; Friis, Elverdam, & Schmidt, 2003; Rutten, Arora, Bakos, Aziz, & Rowland, 2005), for taking an active role in their medical care (Meredith et al., 1996; Mossman, Boudioni, & Slevin, 1999), and are less likely to ask for support services (Squiers et al., 2005).

Soon after a cancer diagnosis, we found that the majority of patients were concerned with finding out more about treatment (e.g. relieving side effects). The most prevalent concerns, however, were about the long-term implications of cancer and treatment (e.g. knowing if my treatment will work and making long-term plans) and the consideration of social issues (e.g. easing my family's stress and being a burden to family and friends). These findings highlight the importance of exploring concerns on treatment effects as well as family and social context issues with patients across the different phases of cancer treatment.

We also observed differences in specific concerns by sex. Specifically, women were more concerned with disfigurement than were men, whereas men were more concerned with sexual dysfunction than were women. Such differences may be due to sex-linked cancer types and the treatments that are prescribed for them. For instance, women's heightened concerns with disfigurement may be due to surgical intervention for breast cancer, whereas

men's concerns about sexual dysfunction may be related to prostate cancer treatment-related side effects. Previous research has also noted differences in the content of patient concerns by sex. For instance, a review of inquiries made to the National Cancer Institute's telephone Cancer Information Service revealed that females were more likely to request information on support services and to discuss psychosocial issues, while males were more likely to seek information on treatment choices (Squiers et al., 2005).

With regard to questions about the availability of information to address specific concerns, we found a wide range of responses. While information addressing patients' clinically related concerns appeared to be readily available, information addressing the social and financial concerns of newly diagnosed patients was less available. More than one half of the patients reported that information on social and financial concerns was unavailable at the time of diagnosis and throughout the course of treatment. At posttreatment, a substantial proportion of the patients reported that information about their social and financial concerns was not available, with more than one half reporting that information about becoming isolated (60.2%) and paying for care not covered by insurance (63.2%) was not available to them. These findings suggest that the availability of information on changes in lifestyle, social interactions, and personal finances is often inadequate to meet the needs of cancer patients surrounding the time of diagnosis and treatment. Furthermore, our results are consistent with previous research that has found dissatisfaction among cancer patients regarding the types and amounts of information that is available to them (Jonker-Pool et al., 2004; Sahay, Gray, & Fitch, 2000; Shields et al., 2004).

At the completion of treatment, patients continued to want additional information on treatment, social, financial, and lifestyle considerations. Of interest, at posttreatment, patients frequently requested additional information on the topics that they reported previously as being readily available to them. For instance, a vast majority of patients expressed a desire for additional information on knowing if my treatment will work and understanding the diagnosis, even though they also reported that information on these issues had been readily available both before and after treatment. Conversely, at posttreatment, few patients desired to receive more information on making long-term plans and becoming isolated, even though they reported that information on these concerns had not been available. Finding a comparatively greater desire for information about treatment- and prognosis-related issues compared with social and emotional concerns is consistent with previous research (Derdiarian, 1986; Booth et al., 2005; Beaver & Luker, 2005; Harrison-Woermke & Graydon, 1993; Rutten et al., 2005; Grunfeld et al., 2006), but surprising, because this information was largely available from the time of diagnosis through the end of treatment. Perhaps the information available on these topics was general and the patients desired more specific information tailored to themselves (e.g. statistics versus individual risk). The desire for information addressing social and emotional concerns may have been lower due to a perception that an informational support approach is inadequate to address such concerns. For instance, a brochure on social isolation may not be seen as being helpful in alleviating concerns about becoming socially isolated. Future research could investigate this issue more closely to determine which types of information are perceived as being most helpful to address issue-specific concerns.

Although the data used in these analyses came from a national, multisite, community-based study, the study population consisted mostly of white patients with higher educational status, which limits generalizability. Patient concerns and perceptions by cancer stage at diagnosis could not be assessed because this information was not available from the study data. Disease prognosis may likely influence the issues of concern to cancer patients and their perceptions of the availability of relevant information. Additional limitations include not knowing the content and format of informational support that is actually received by the

patients throughout their diagnosis and treatment and only examining patients' concerns with 20 specified issues.

Conclusion

Addressing the concerns of cancer survivors is challenging because the concerns are unique to each individual and because the tools, training, and time needed to address these broader issues are often unavailable in current clinical settings. Most hospitals have social, case management and/or pastoral care services, but barriers, such as availability, the need for specialized training, and cost, often make these services inaccessible to the patients. This is especially true for cancer patients in the outpatient setting. Tools to help identify the patients' informational needs for the subsequent tailoring of information could be useful. For example, Crooks et al. (2004) demonstrated that an Individual Health Assessment form improved the documentation of patients' supportive care needs during their first visit to a cancer center.

Our study emphasizes that many cancer survivors report having lifestyle, social, and financial needs that are often addressed inadequately. Although it is unlikely that information alone may be sufficient to solve the complex challenges associated with the concerns that arise after a cancer diagnosis, information highlighting the prevalence of these concerns after diagnosis and suggesting strategies or resources for dealing with these problems would be useful to patients after a cancer diagnosis. In this vein, it is important to note that informational support, while helpful and highly effective in some domains of patient care, is not necessarily the best type of support for all types of patient concerns. Some concerns may be addressed more effectively through other types of services, such as support groups, financial assistance programs, and individual counseling services. However, in such circumstances, informational support would still be a useful tool to inform patients of services that are available for addressing their concerns.

Implications

In light of the differences that may exist in informational needs by patient characteristics and stage of cancer survivorship, informational support may be the most useful when it is tailored to address individual needs and needs that are specific to a patient's stage of care. Physicians must be trained and educated to recognize the multidimensional needs of patients and make appropriate referrals for additional support services. In addition to resources that may be available through medical groups and hospitals, there are many community and national programs that can offer tailored informational support to cancer survivors. For instance, the Lance Armstrong Foundation, local chapters of the American Cancer Society, the National Coalition of Cancer Survivors, and CancerCare all offer programs to help meet the needs of patients, their families, and caregivers after diagnosis and beyond the completion of treatment (Pollack, Greer, Rowland, Miller, Doneski, et al., 2005). How many cancer survivors are aware of and use such resources is currently unknown, but increasing physicians' and medical care teams' familiarity with such resources would likely lead to an increase in the number of individuals who are served by them. Although not all patient concerns will be amenable to the help offered by this type of informational support, the most effective strategy for addressing patient concerns will be one that involves adequate recognition, communication, and responsiveness to patient concerns and desires for information.

Acknowledgments

This work was supported in part by a supplement from the Division of Cancer Control and Population Sciences, NCI, to Public Health Service Grant U10 CA37420 and by Grant RSG-01-071-PBP from the American Cancer Society.

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Table 1

Community Clinical Oncology Program study population

Characteristic	% (n)
Age	
Median years	61
Sex	
Female	64.7% (630)
Male	35.3% (344)
Race/ethnicity	
White	92.8% (904)
African American	5.3% (52)
Hispanic	5.2% (5)
Asian	0.6% (6)
American Indian	0.4% (4)
Not reported	0.2% (2)
Marital status	
Married	70.4% (686)
Widowed	10.5% (102)
Divorced	9.2% (90)
Single	8.7% (85)
Separated	1.1% (11)
Educational level	
< High school	9.5% (93)
High school degree	35.6% (347)
Some college	24.0% (234)
College degree	30.8% (300)
Self-reported health	
Excellent	24.9% (243)
Very good	35.5% (346)
Good	27.7% (270)
Fair	8.8% (86)
Poor	3.0% (29)
Cancer diagnosis	
Breast	46.9% (457)
Genitourinary	16.4% (160)
Lung	13.8% (134)
Gastrointestinal	8.5% (83)
Hematologic	7.6% (74)
Gynecologic	5.3% (52)
Head and neck	1.4% (13)

Table 2

Patient concerns at baseline, perceived information unavailability at pretreatment and posttreatment, and desire for additional information at pretreatment and posttreatment

Patient concerns	Identified issue as a concern, % (n)		Reported that information was not available, % (n)		Wanted additional information, % (n)	
	Baseline		Pretreatment	Posttreatment	Pretreatment	Posttreatment
<i>Treatment</i>						
Knowing if my treatment will work	92.6% (901)		30.9% (268)		63.1% (531)	58.2% (396)
Relieving side effects	89.6% (871)		20.9% (176)		57.8% (470)	48.0% (314)
Understanding the treatment plan	70.6% (688)		7.8% (52)		60.7% (395)	50.9% (258)
Understanding the diagnosis	70.2% (684)		9.5% (62)		60.3% (389)	54.5% (277)
Being disfigured	50.2% (488)		49.5% (232)		43.1% (195)	33.0% (123)
<i>Lifestyle</i>						
Making long-term plans	76.5% (744)		65.0% (466)		51.9% (354)	37.3% (205)
Staying in control of myself	74.4% (724)		52.4% (366)		49.3% (328)	39.0% (209)
Exercising	70.9% (690)		43.4% (288)		51.3% (329)	41.5% (216)
Eating right	70.5% (686)		26.4% (175)		58.8% (377)	47.0% (242)
Having sexual relationships	47.6% (463)		51.7% (230)		43.6% (186)	39.0% (138)
Being able to have children	4.5% (44)		36.6% (15)		62.5% (25)	50.0% (14)
<i>Social</i>						
Easing my family's stress	83.7% (815)		57.6% (449)		50.8% (375)	36.0% (219)
Being a burden to family & friends	77.1% (751)		66.9% (482)		41.3% (281)	29.2% (161)
Relying on others for personal care	71.4% (695)		57.8% (387)		39.1% (247)	21.6% (109)
Caring for my family	63.5% (617)		58.7% (345)		39.0% (216)	26.9% (123)
Becoming isolated	51.6% (503)		75.2% (363)		40.3% (182)	29.4% (108)
Telling friends & family about my cancer	45.6% (444)		57.8% (242)		42.4% (169)	34.8% (109)
<i>Financial</i>						
Paying for care not covered by insurance	68.1% (663)		68.2% (435)		59.2% (359)	41.8% (209)
Finding community services	42.1% (410)		54.2% (212)		52.6% (200)	38.5% (114)
Maintaining my job	39.3% (382)		56.6% (209)		48.4% (170)	37.8% (110)

Note: Percentages representing unavailability of information and desire for additional information include only those who identified the respective issue as a concern. For example, we restricted the information assessment for the “Knowing if my treatment will work” issue to the 901 study participants who identified the issue as a concern.