

Review

Information needs and sources of information among cancer patients: a systematic review of research (1980–2003)

Lila J. Finney Rutten^{a,b,*}, Neeraj K. Arora^b, Alexis D. Bakos^c,
Noreen Aziz^b, Julia Rowland^b

^a*Cancer Prevention Fellow, Cancer Prevention Fellowship Program, Division of Cancer Prevention, National Cancer Institute, 6130 Executive Blvd., EPN 4051A, MSC 7365, Bethesda, MD 20892, USA*

^b*Division of Cancer Control and Population Sciences, National Cancer Institute, 6130 Executive Blvd., Bethesda, MD, USA*

^c*National Institute of Nursing Research, 6701 Democracy Blvd., Bethesda, MD, USA*

Received 5 March 2004; received in revised form 12 April 2004; accepted 5 June 2004

Abstract

Understanding what cancer patients need to know and from whom they receive information during the course of care is essential to ensuring quality care. We reviewed 112 articles published from 1980 to 2003 and developed a typology summarizing cancer patients' information needs and the sources from which they receive information. The majority of articles focused on information needs and sources during the diagnosis and treatment phase. Thus, the most frequent information need was treatment-related (38.1%). The most frequent information source was health professionals (27.3%). We examined patients' information needs and sources along the continuum of care and found that during diagnosis and treatment, information needs about the stage of disease, treatment options, and side-effects of treatment were prominent; during post-treatment, patients continued to need information about treatment, and information about recovery was also important. Future research should examine cancer patients' information needs and sources throughout their cancer journey.

© 2004 Elsevier Ireland Ltd. All rights reserved.

Keywords: Cancer; Information needs; Information sources

1. Introduction

A vast body of research identifying cancer patients' information needs and the sources from which they receive cancer-relevant information has emerged; our study provides a comprehensive review of this literature [1–112]. The benefits of information for cancer patients include increased patient involvement in decision-making and greater satisfaction with treatment choices [20,60]; improved ability to cope during the diagnosis, treatment, and post-treatment phases [63,113,114]; reductions in anxiety and mood disturbances [96,115]; and improved communication with family members [116–118]. Information seeking has been demonstrated to play a critical role in individuals' efforts to cope with the disruption of quality of life associated with cancer diagnosis

and treatment [119]. Because effective communication is known to be key to optimal health outcomes, understanding *what* patients need to know, *when* during the course of care, and from *whom* they receive this information becomes vital to ensuring the delivery of quality cancer care. To date, most studies of patients' information needs have been conducted in distinct sets of patients at limited periods during their care. Furthermore, many of the existing reviews of this literature have limited to specific cancers (e.g. [120,121]). To our knowledge, no comprehensive attempt has been made to synthesize findings from previous investigations to provide a broad overview of cancer patients' information needs over time.

Our review of the literature aims to synthesize this body of research to discern cancer patients' information needs and the sources from which they receive cancer-relevant information throughout their cancer journey. Specifically, this review seeks to address the following objectives: (1) identify cancer patients' information needs during their cancer journey, (2)

* Corresponding author. Tel.: +1 301 435 2842

E-mail address: finneyl@mail.nih.gov (L.J.F. Rutten).

identify the sources cancer patients use to obtain cancer-relevant information, and (3) examine whether, and to what extent needs and information sources sought vary by phase of the cancer care continuum (diagnosis, treatment, post-treatment/survivorship, relapse/recurrence, and end-of-life).

2. Methods

A review of the literature published over the past 20 years was conducted using the following databases: Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Social Science Citation Index (SSCI), and PsychINFO. The search was limited to articles published in English between January 1, 1980 and July 31, 2003, involving adult samples. To be comprehensive, we conducted a fairly broad search using the following search terms in conjunction with the term cancer: information needs, information resources, information support, information seeking, information sources, patient concerns, patient satisfaction, patient communication, patient experience, patient education, and patient knowledge.

This initial search resulted in a total of 3401 hits. We reviewed the abstracts for each of these articles and determined that many of the articles were not relevant to the topic of our review and were more broadly related to cancer, including health care providers' descriptions of patients' cancer experiences, clinical guidelines for cancer care, and research describing cancer information services, cancer screening utilization, cancer mortality, and patient needs other than information needs. We identified 217 articles that appeared relevant to our focus on cancer information needs and sources. Detailed examination of these 217 resulted in the selection of 112 articles that explicitly assessed cancer patients' information needs and/or information sources. Specifically, articles focusing on patients' cancer educational concerns, cancer-relevant information needs, and sources of informational support were included in our review. To maintain a refined and specific focus on the information needs and sources of cancer patients, the following were excluded: (1) articles focusing on information needs and/or information sources for family members of cancer patients, (2) articles focusing on cancer-related information needs or sources for individuals with no cancer history, (3) articles limited to the description of survey instrument development, (4) articles describing the evaluation of interventions aimed at improving information support without explicit assessment of patient information needs and/or sources, (5) articles focusing exclusively on cancer patients' knowledge, and (6) articles that reviewed the literature.

3. Results

3.1. Sample characteristics

Characteristics of the samples described in the articles were coded and summarized (Table 1). In the majority of

Table 1
Characteristics of literature included in review

	N	%
Cancer continuum phase of patient		
Diagnosis/treatment	38	33.9
Post-treatment/survivorship	36	32.1
Multiple stages	38	33.9
Cancer sites		
Multiple sites	52	46.4
Breast	25	22.3
Prostate	16	14.3
Other site specific	19	17.0
Sample country		
USA	35	31.3
Canada	31	27.7
UK	21	18.8
Other European nations	15	13.4
Australia	8	7.1
Other	2	1.8
Study design		
Concurrent	52	46.4
Prospective/longitudinal	7	6.3
Retrospective	42	37.5
Other (mixed designs)	11	9.8
Data collection method		
Original questionnaire/survey	53	47.3
Existing questionnaire/survey	22	19.6
Interview	24	21.4
Focus groups	5	4.5
Other	13	11.6
Theory		
Discussed	22	19.6
Not discussed	90	80.4
Publication date		
1980–1984	2	1.8
1985–1989	7	6.3
1990–1994	15	13.4
1995–1999	46	41.1
2000–July 2003	42	37.5

articles reviewed, samples included patients with a variety of cancer diagnoses (52%); samples focusing exclusively on breast cancer patients (25%) or patients with prostate cancer (16%) were also common. The average sample size was $n = 352$, ranging from ($n = 1$) [80] to ($n = 13,136$) [24]. Since the search was limited to articles published in English, it is not surprising that the majority of samples were drawn from populations in the United States (31.3%), Canada (27.7%), and the United Kingdom (18.8%). Although our literature search included articles published from 1980 to July 2003, the overwhelming majority of articles (92.0%) were published since 1990. More than half of the articles included in the review assessed both information needs and sources (52.9%), while 39.2% of the articles assessed only needs and 7.8% assessed only sources. Patient samples were drawn from across the cancer care continuum: 34% of articles assessed patients who were at the diagnosis and/or treatment phase; 32% of articles assessed patients during

post-treatment; and the remaining articles included patients from multiple phases of the cancer care continuum (33.9%).

3.2. Methodological characteristics

Methodological characteristics of the articles reviewed were coded and summarized (Table 1). Most investigations employed either a concurrent (46.4%) or retrospective (37.5%) design. Studies employed a range of data collection approaches including original surveys (47.3%), previously developed surveys (19.6%) and interviews (21.4%). Original and previously developed surveys were administered via telephone, by in-person interview, and through pencil and paper measures. Commonly used survey instruments included the Krantz Health Opinion Survey (KHOS) [122], instruments derived from the nine information needs identified and initially tested by Luker et al. [20] and by Bilodeau and Degner [13] and their colleagues, the Toronto Information Needs Questionnaire (TINQ-BC) [15], the Cancer Needs Questionnaire (CNQ) [123], and the Information Needs Questionnaire-Breast Cancer (INQ-BC) [124]. Approximately 20% of the articles discussed their work in terms of a theoretical framework; Lazarus' [125] model of stress and coping was most commonly used, with an emphasis on the important role that information seeking plays in helping cancer patients cope with the demands of their illness [8,13,26,40,61,63,67,92,123].

3.3. Information needs

We created a typology of information needs containing 10 information need categories with 64 subcategories as a classification scheme for information needs (Table 2). The 10 information need categories were as follows: *cancer-specific information*, *treatment-related information*, *prognosis information*, *rehabilitation information*, *surveillance and health information*, *copmg information*, *interpersonal information*, *financial/legal information*, *medical system information*, and *body image/sexuality information*. These categories were identified and refined throughout the review process to reflect prominent themes in the studies reviewed. We examined the 91 articles assessing patient needs to discern and classify patients' information needs; citations for these articles by category of need and the associated 64 subcategories are shown in Table 2.

We report the frequency with which different types of information needs are mentioned in the literature in two ways. First, we summarized the relative percentage of needs discussed across the entire body of literature reviewed that belonged to each of the 10 information need categories. We also provide information on the percentage of articles that discussed each of the 10 information need categories. For example, 96% of the articles mentioned patients' need for *treatment-related information*, and 65% mentioned a need for *cancer-specific information*. The significance of examining needs and sources as both a percentage of total unique

needs identified in the literature and as a percentage of articles that mention a specific need is that this provides a fuller, more in-depth picture of cancer patients' information needs and sources. Furthermore, the consistency in the content identified through these two means provides some reassurance that the content of our typology is a valid reflection of the current literature.

The 64 distinct subcategory needs were identified across the literature for a total of 795 times. Note, since the majority of articles mentioned more than one information need, any given article could therefore, be classified into multiple categories. We determined the percentage of needs belonging to each category by dividing the frequency of occurrence of subcategory needs within each category by 795. For example, the nine subcategories of needs within the *cancer-specific information* category were mentioned for a total of 102 times in the literature. Thus, 12.8% (102/795) of the information needs discussed in the literature were related to cancer-specific concerns. Percentages for the 10 categories thus sum to 100%.

In addition to presenting the distribution of information needs in the literature across the 10 categories, we also summarized the relative percentage of needs for each individual subcategory. Since needs identified in a given article could be classified into more than one subcategory, we determined the percentage of needs in each subcategory by dividing the number of unique occurrences of each subcategory need by the sum of all subcategory needs within each category. For example, within the category *cancer-specific information* the nine distinct subcategories occur a total of 102 times; therefore, to determine the percentage for each subcategory of needs within diagnosis, the frequency for each of the nine subcategories was divided by 102. Subcategory percentages within each category thus sum to 100%.

Table 2 summarizes the percentage of total needs for each need category and for each corresponding subcategory. The most frequently cited category was *treatment-related information* (38.1%). Within the *treatment-related information* category, the most frequent subcategories were *available treatments and treatment options* (17.2%) and *side effects of treatment/risks and benefits of treatment* (20.5%). Other prominent categories were *cancer-specific information* (12.8%) and *rehabilitation information* (12.2%). The most common subcategory need mentioned in the *cancer-specific information* category was *type of cancer/nature of disease* (27.5%), and the most common subcategory in the *rehabilitation information* category was *self-care issues/home care during recovery* (30.9%).

3.4. Information sources

We also created a typology of cancer patients' information sources containing five source categories and 19 distinct subcategories (Table 3). The five information source categories were as follows: *health care professionals*, *printed*

Table 2
Typology of cancer patients' information needs (*n* = 91 articles, 795 needs)

Category (%) ^a	Subcategory (%) ^b	References
Cancer-specific information (12.8%)	Type of cancer/nature of disease (27.5%)	[8–13,15,17,18,20,21,23–29,31,33,34,36,37,42,
	Etiology and course of disease (15.7%)	45,48,50–58,61–64,66,68,76,79,82,84,86,93–96,
	Physical effects of disease (14.7%)	98–100,102,103,106,109,110,112]
	Specific diagnosis information (12.7%)	(65% of articles, <i>n</i> = 59)
	Stage of disease (9.8%)	
	Symptoms of cancer/management of symptoms (7.8%)	
	Where to get information about specific cancer diagnosis (6.9%)	
	Seeking second opinions (2.9%)	
Treatment-related information (38.1%)	Disease information (2.0%)	
	Side effects of treatment/risks and benefits of treatment (20.5%)	[5,8–34,36,37,42,44,45,59,46–70,76,78,79,82,84,
	Available treatments/treatment options (17.2%)	85,87–89,91–96,98–103,105,106,108–112]
	Treatment plan, treatment description, or logistical information (10.2%)	(96% of articles, <i>n</i> = 87)
	Tests and procedures involved in treatment (8.6%)	
	Reducing side effects of treatment (8.3%)	
	Alternative or complimentary treatments (7.3%)	
	How treatment works (4.6%)	
	Physical effects of treatment (4.3%)	
	Progress during treatment (3.0%)	
	Medications (3.0%)	
	Treatment success (2.6%)	
	Physical limitations during treatment (2.3%)	
	Clinical trials (2.0%)	
	Purpose of treatment (2.0%)	
	Other patients' experiences or choices about treatment (2.0%)	
Prognosis information (10.8%)	Referrals for treatment (1.3%)	
	Where to get information about treatment (0.7%)	
	Effects of missing treatment (0.3%)	
	Chance of cure (24.4%)	[8–10,13,14,16,18,20,21,23,25,26,28,31–33,37,
	Life span or survival rate (20.9%)	42,45,47,48,50,51,54,55,57–59,61,62,64,67,69,
	Recurrence of cancer (17.4%)	80,96,99,100–103,106,108–112]
	Spread of disease or metastasis (12.8%)	(51% of articles, <i>n</i> = 46)
	Expectations for future health condition (8.1%)	
Effect on life plan or long term goals (7.0%)		
Rehabilitation information (12.2%)	Outcome of no treatment or delayed treatment (5.8%)	
	Options if initial treatment fails (3.5%)	
	Chance of cure (24.4%)	
	Self care issues or home care during recovery (30.9%)	[5,13,14,16–18,20,21,23,25–31,33,34,36,37,42,
	Nutrition during recovery (21.6%)	47–49,53,54,57–60,64–70,79,82,85–89,91,92,94,
	Immediate post-treatment follow-up care (16.5%)	95,98–101,103,106,108,111,112]
Surveillance and health information (3.4%)	Long-term side effects of cancer or treatment (12.4%)	(63% of articles, <i>n</i> = 57)
	Recognizing or preventing complications following treatment (6.2%)	
	Recovery time (6.2%)	
	Where to get medical supplies or medical equipment (6.2%)	
Coping information (8.8%)	Maintaining physical health or physical activity (37.0%)	[8,9,15,18,19,28,29,33,44,48,54,62,78,79,85,87,
	Prevention and early detection (29.6%)	89,92,94,100,110,112] (24% of articles, <i>n</i> = 22)
	Maintaining psychological health (22.2%)	
	Health behavior and promotion (11.1%)	
Interpersonal/social information (6.0%)	Emotional reactions, emotional support, coping with cancer (45.7%)	[5,9,11–13,15–19,25,27,29,33,34,36,48,51,53,54,
	Community counseling or support (24.3%)	56,57,63–69,78,79,82,84,89,91,92,95,98,105,
	Support groups (17.1%)	108,112] (45% of articles, <i>n</i> = 41)
	Support from other patients (8.6%)	
Financial/legal information (2.0%)	Spiritual support (4.3%)	
	Effect on family, friends, or caregivers (35.4%)	[8,9,13,14,17,20,21,23,26,28,37,53,57,59,63,67,
	Effect on social life or leisure (29.2%)	69,79,80,84,86,87,94,98–100,102,103,108,112]
	Risk of disease for family members (22.9%)	(33% of articles, <i>n</i> = 30)
Financial/legal information (2.0%)	Effect on employment or work life (12.5%)	
	Cost of treatment, insurance coverage, or other financial issues (75.0%)	[54,56,99,112] (4% of articles, <i>n</i> = 4)
Financial/legal information (2.0%)	Advanced directives or writing a will (25.04%)	

Table 2 (Continued)

Category (%) ^a	Subcategory (%) ^b	References
Medical system information (1.9%)	Interactions with health care providers (26.7%)	[25,28,29,33,64,79,99,100] (9% of articles, <i>n</i> = 8)
	Experience or qualifications of physician and medical staff (20.0%)	
	Quality of medical equipment and supplies (20.0%)	
	Health care systems (20.0%)	
	Available research (13.3%)	
Body image/sexuality information (3.9%)	Sexuality (64.5%)	[13,14,20,21,23,25,26,28,30,35,48,53,56,64,69,86,90,91,98,100,106,109,111] (25% of articles, <i>n</i> = 23)
	Physical appearance/physical attractiveness (35.5%)	

^a The percentage of total needs assessed within each category was determined by dividing the frequency of needs within each category by the 795 unique occurrences of the 64 distinct subcategory needs that were identified.

^b The percentage of needs in each subcategory was determined by dividing the number unique occurrences of subcategory needs by the sum of all subcategory needs within each category.

material, media, interpersonal, organizational and scientific resources. These categories were developed and refined throughout the review process to reflect prominent information sources identified by cancer patients in the studies reviewed. We examined the 45 articles assessing patient sources to discern and classify patients' information sources; citations for these articles by source category are shown in Table 3.

We determined the frequency of sources in the five broad information source categories in the same manner previously described for information needs; the number of

unique occurrences of specific subcategory sources was counted. We identified 260 total occurrences of the 19 distinct subcategories. We determined the percentage of total sources for each source category by dividing the frequency of sources within each category by 260. Thus, the percentages for the five categories sum to 100%. We calculated the percentage of sources for each subcategory by dividing the number of unique occurrences of a particular subcategory source by the sum of subcategory sources within each category. For example, within the category *health professionals*, the four distinct subcategory sources

Table 3

Typology of cancer patients' information sources (*n* = 45 articles, 260 sources)

Category (%) ^a	Subcategory (%) ^b	References
Health professionals (27.3%)	Physician (e.g. general practitioner, surgeon, oncologist) (43.7%)	[1,2,6,7,13,21,22,31,32,35,40–43,58,60,71–76,80,81,83,87,15,99,101,104–108,111,112] (80% of articles, <i>n</i> = 36)
	Nurse (28.2%)	
	Other health care professional or health care professionals in general (25.4%)	
	Other health-related professionals (e.g. lawyers, financial planners) (2.8%)	
Printed materials (26.2%)	Books (25.0%)	[1,2,4,5–7,12,13,21,22,31,32,38,40–43,49,58,60,71–73,75,77,80,87,89,97,104–108,111,112] (80% of articles, <i>n</i> = 36)
	Libraries/unspecified readings (23.5%)	
	Brochures (22.1%)	
	Magazines and newspapers (22.1%)	
	Materials from physician (7.4%)	
Media (13.5%)	TV, radio, or videos (62.9%)	[2,3,4,6,7,13,21,31,38,40,41,43,49,71,75,77,80,87,89,97,104–108,111,112] (60% of articles, <i>n</i> = 27)
	Internet (37.1%)	
Interpersonal (18.8%)	Friends and/or family (42.9%)	[2,3,5,6,12,13,21,22,32,38,40–43,58,60,71,72,75–77,80,81,83,87,89,99,101,104–108,111,112] (78% of articles, <i>n</i> = 35)
	Counseling, support groups, or support services (30.6%)	
	Other patients (20.4%)	
	Clergy, church, synagogue, or other place of worship (6.1%)	
Organizational and scientific resources (14.2%)	Telephone information services (e.g. Cancer Information Service) (37.8%)	[1,3–5,12,13,21,22,31,32,38,41–43,49,40,60,71,75–77,81,83,87,89,104,106,108] (62% of articles, <i>n</i> = 28)
	Charitable or professional organizations (e.g. American Cancer Society) (35.1%)	
	Medical journals or books (21.6%)	
	Health care organizations (5.4%)	

^a The percentage of total sources assessed within each category was determined by dividing the frequency of sources within each category by the 260 unique occurrences of the 19 distinct subcategory sources that were identified.

^b The percentage of sources in each subcategory was determined by dividing the number unique occurrences of subcategory sources by the sum of all subcategory sources within each category.

Table 4
Comparing information needs and sources at diagnosis and treatment to post-treatment

Information needs	Phase in cancer care continuum		
	Diagnosis/treatment	Post-treatment	
Occurrences of subcategory needs	176	80	
Number of articles	24	9	
Need category ^a	%	%	<i>P</i> value ^c
Cancer-specific	15.3	6.3	.047
Treatment-related	43.8	35.0	.232
Prognosis	10.8	7.5	.307
Rehabilitation	5.7	22.5	.001
Surveillance and health	4.5	6.3	.393
Coping	6.3	7.5	.457
Interpersonal/social	7.4	6.3	.494
Financial/legal	1.7	3.8	.286
Medical system	0.6	2.5	.236
Body image/sexuality	4.0	2.5	.436
Information sources	Diagnosis/treatment	Post-treatment	
Total occurrences of sources	26	32	
Total number of articles	7	5	
Source category ^b	%	%	<i>P</i> value ^c
Health professionals	26.9	40.6	.309
Printed materials	34.6	21.9	.299
Media	19.2	15.6	.513
Interpersonal	11.5	25.0	.230
Organizational/scientific	7.7	12.5	.464

^a Percentages determined by dividing the frequency of needs within each category by the unique occurrences of the distinct subcategory needs.

^b Percentages determined by dividing the frequency of needs within each category by the unique occurrences of the distinct subcategory needs.

^c Fisher's Exact Test.

were mentioned for a total of 71 times; therefore, the frequencies for each of the four subcategories in the category *health professionals* were divided by 71 to determine the percentage belonging to each particular subcategory. Thus, subcategory percentages within each category sum to 100%.

Table 3 summarizes the percentage of total sources for each source category and corresponding subcategories. The most frequent information source category was *health professionals* (27.3%), with the most prominent subcategory being *physicians* (43.7%). *Printed materials* (26.2%) was also a frequently mentioned category; the most frequent subcategory in this category was *books* (25.0%). Table 3 also provides information on the percentage of articles that discussed each of the 10 information source categories. For example, 80% of the articles mentioned health professionals as a source, and 80% mentioned printed materials as an information source.

3.5. Needs and sources across the cancer care continuum

Our initial intention for this review was to summarize key information needs and sources for cancer patients within each of the phases of the cancer care continuum. To this end, we hoped to characterize and compare patients' needs and sources during the diagnosis, treatment, and post-treatment phases. Patients in the studies reviewed were roughly evenly

distributed across the cancer care continuum. However, while the majority of patients in the diagnosis and treatment phase were asked about their current information needs (68.4%), the majority of patients in the post-treatment phase (72.2%) were asked to consider their needs retrospectively. Regardless of where patients were along the cancer care continuum, they were most often asked to discuss information needs and sources at the time of diagnosis and during treatment. Thus, overall this body of literature primarily addresses patients' information needs and sources during diagnosis and treatment. Therefore, it became clear that our original plan to organize this review of literature as a comparison of patient needs and sources across the cancer care continuum would have to be limited to a comparison of those studies wherein patients at different phases in the continuum were asked to consider their information needs and sources concurrently.

To examine the issue of changing needs and sources over time, we identified a subset of articles that concurrently assessed patients' needs and/or sources during diagnosis and treatment ($n = 26$) as well as a subset of articles that concurrently assessed patients' needs and/or sources post-treatment ($n = 9$). The previously discussed categories and subcategories of needs and sources were used to summarize the percentage of the total unique occurrences of needs and sources in this subset of articles. These percentages were determined within categories and subcategories in the same

manner previously described. The percentages of total needs and the percentages of total sources in each of the categories during the diagnosis and treatment phase of the cancer care continuum and during the post-treatment phase are shown in Table 4.

3.5.1. Information needs

As might be expected, the most frequently cited needs during the diagnosis and treatment phase were in the *cancer-specific information* (15.3%) and the *treatment-related information* (43.8%) categories. Within the *treatment-related information* category, the most frequently cited subcategory needs were *available treatments/treatment options* (18.2%) and *side effects of treatment* (18.2%). The subcategories most frequently mentioned within the *cancer-specific information* category were *stage of disease* (18.5%) and *specific diagnosis information* (18.5%).

The most frequently cited post-treatment information needs were in the *treatment-related* (35%) and *rehabilitation information* (22%) categories. During the post-treatment phase, information about *available treatments/treatment options* was frequently mentioned, with 21.4% of needs in this subcategory. Another prominent subcategory need during post-treatment was the *side effects of treatment* (17.9%). Within the *rehabilitation information* category, the following subcategories were cited most often: *self-care issues/home care* (22.2%), *follow-up care and treatment* (22.2%), and *long-term side effects* (22.2%).

3.5.2. Information sources

The most prominent information sources used during the diagnosis and treatment phase were *printed materials* (34.6%) and *health professionals* (26.9%). *Brochures* (33.3%) and *libraries/unspecified readings* (33.3%) were the most frequently mentioned subcategories within the *printed materials* category. *Physicians* (42.9%) were most often cited within the *health professionals* category. Post-treatment survivors identified *health professionals* (40.6%) and *interpersonal* (25.0%) contacts as key information sources. During the post-treatment phase, *physicians*, *nurses*, and *other health care professionals* were cited as sources of information equally often, with 30.8% of the total sources in each of these subcategories.

3.5.3. Comparison of diagnosis and treatment phase to post-treatment phase

We used Fisher's exact test to compare the proportion of information needs and sources in each category during the diagnosis and treatment phase of the cancer continuum to the proportion of needs and sources during the post-treatment phase. As would have been expected, a significantly greater proportion of needs fell into the *cancer-specific information* category during the diagnosis and treatment phase than during the post-treatment phase ($P < .05$), while a significantly greater proportion of needs fell into the *rehabilitation information* category during the post-treatment phase than

during the diagnosis and treatment phase ($P < .01$). No significant differences were detected in the proportion of information sources cited by phase of the cancer care continuum.

3.6. Sociodemographic factors and information needs and sources

Several broad conclusions about cancer patients' information needs and sources can be drawn from the literature reviewed. In general, younger patients tend to seek more information than older patients [6,10,11,15,39,45,61,65]. Additionally, the range of sources from which individuals seek information appears to be broader in the younger patients than in older patients. Furthermore, older patients demonstrate greater reliance on information provided by the cancer specialist or physician than younger patients [6]. Several studies also suggest that women seek more information than men [5,12,25]. In general, there do not appear to be dramatic differences in information needs or sources based on racial/ethnic differences [7]. However, evidence for differences among socioeconomic groups suggests that information needs and sources are influenced by economic class; greater amounts of information are sought from more diverse sources among those from higher socioeconomic strata. Patients with higher educational attainment were also more likely to seek information from a greater range of sources [3]. Although a few differences in information needs and sources for patients living in urban versus rural locations have been documented [16], in the majority of investigations the informational needs and common sources of information used by rural patients have not been found to differ dramatically from those of urban patients [43,84,88,101].

4. Methodological critique of studies

There is a great deal of consistency in the content of information needs and sources reported across diverse samples and varied methodologies, which provides a cohesive picture of cancer patients' information needs and sources. However, there are several conceptual, measurement, and design limitations of this literature that are worth noting.

4.1. Conceptual refinement

Only a minority of investigations reported use of a theoretical or conceptual framework [7,11,13,15,22,26,40,46,51,61,63,67,79,84,86,88,92]. In many of the investigations that reported use of a theoretical model, the theories underpinned research questions and guided instrument development [7,11,13,15,22,26,40,46,63,79,85,88,92]. Other investigations employed theoretical models to explain or organize their research findings [51,61,67,84,86]. Specifically, the use of theoretical models, such as Lazarus' [125] model of stress and coping, provided a rationale for examining

cancer patients' information needs and clarified the importance of information from trusted sources for cancer patients. Both of these approaches served to clarify the conceptual context of the research, and to provide a more comprehensive, and theory-grounded understanding of patients' information needs and sources. Theoretical frameworks and models can guide approaches to assessing cancer patients' information needs and sources and provide a framework for summarizing them. Use of theoretical models to provide a rationale for investigating information needs and sources as well as to derive hypotheses and explain findings would provide a more coherent picture of patients' information needs, and the sources from which they seek information.

4.2. Measurement

Several of studies in the review assessed needs and sources with instruments that had not been previously validated [2,3,5–7,28,35,37,38,40,41,43,46,48,51,55–58,60,65–67,71–73,75,76,82,83,112]. Only a minority of studies used previously validated instruments rendering comparisons across studies more difficult and potentially limiting the validity of the findings [14,21,26,61–63,70]. An advantage of developing original survey instruments is that it allows investigators to tailor the questions to their unique patient population; however, use of previously existing instruments allows for more ready comparisons between patient populations. Future efforts to assess cancer patients' information needs and sources should strive for continuity with previous research while advancing the quality of available instruments.

4.3. Study design

A limitation of many of the studies was the predominant use of cross-sectional and retrospective designs [3,6,14,15,29,47,53,59,68,79,90,95,96]. Very few investigations utilized longitudinal study designs [21,52,67,102]. Among those who did, investigators suggest that the information needs of cancer patients change throughout the clinical course of cancer. For example, Luker and coworkers [21,22] found that the relative importance of information among women with breast cancer changed from the time of diagnosis to 21 months following diagnosis with greater concerns regarding the risk of breast cancer among family members emerging at the 21-month follow-up. Understanding the evolution of cancer patients' information needs and preferred sources of information as they progress through their cancer journey is a vital first step in meeting patients' needs. Few longitudinal investigations have examined cancer patients' needs and sources; thus, it is difficult to assess from the bulk of this literature, how patients' needs and sources many change over time.

4.4. Sampling

Several studies reported small (less than $n = 25$) sample sizes [32,42,47,67,74,80,81,98,102,111]. Therefore, results

from these studies may not be representative of the wider population of cancer patients, and must be interpreted with caution. Many of the patient samples were homogenous with regard to factors such as race, socioeconomic status, and age [3,37,66,72,90], thereby limiting the extent to which findings from these samples can be generalized to under-represented individuals, including people of color, older adults, and individuals with lower socioeconomic standing. Response rates reported in many studies were low (often below 50%) [5,11,16,27,34,36,40,43,51,55,60,66,75,68,86,95], or in few cases, not reported [5,8,26,41,72,112]. Low response rates, coupled with lack of information about the characteristics of patients who chose not to participate may undermine the generalizability of the results.

5. Conclusions

Our review provides a better understanding of the relative focus of this expanding body of literature through summary of both the number of articles addressing a particular category of information need and/or information source as well as the total number of occurrences of a particular category of need or source in the entire literature. The use of qualitative and quantitative approaches to analyzing these reports provides greater understanding of patients' needs and the sources of information used by patients. More than a third of the articles reviewed were published since 2000, suggesting that research attention to the informational needs and sources of cancer patients is growing.

Although the samples included patients from across the cancer care continuum, patients were most often asked about their needs during diagnosis and treatment. Given the emphasis in this literature on assessment of needs and sources during diagnosis and treatment, the finding that patients' most frequently sought cancer-specific and treatment-related information is not surprising. During the diagnosis and treatment phase, patients were primarily interested in finding out their specific diagnosis including the stage of disease, and in exploring their treatment options and understanding the side effects associated with those options. Patients during the post-treatment phase demonstrated a continued need for information about the treatment that they had undergone and its side effects; during this phase, information about rehabilitation was also prominent.

The finding that health professionals are the most frequently cited information source emphasizes the crucial role that physicians, nurses, and other health care professionals play in meeting patients' information needs. During the diagnosis and treatment phase, patients rely heavily upon brochures and their physicians for information about their illness. Physicians remain an important source of information during post-treatment; however, nurses and other health care professionals become equally important sources of information during this time.

Although health care professionals consistently emerge as important sources of health information, continued evaluation of the sources from which cancer patients seek information is necessary to track potential shifts in sources of information used by cancer patients in a climate of increasing information access. For example, the rapid growth in health information on the World Wide Web (WWW) and the development of technology-based health resources and consumer health informatics systems which improve access to and ease of use of such information, has begun to influence the sources of health information used by cancer patients. Recent investigations suggest that cancer patients are interested in Web-based resources [126] and that they may benefit from the use of consumer health informatics systems [127].

5.1. Practice implications

Our typology offers a comprehensive review of the existing literature published to date on cancer patients' information needs and sources. Although several methodological limitations of this body of research have been identified, our typology provides a snapshot of the state of this research and suggests important recommendations for advancing assessment and methodology in this important area of research and for improving our understanding of cancer patients' information needs and sources. The typology of information needs and information sources developed in our review provides a structure for summarizing this significant and expanding body of research.

Organizing patients' needs and sources into this typology has allowed us to identify important strengths and limitations of this area of research. Future investigations should be guided by both the strengths and limitations of prior research. A key strength of this research resides in the consistency with which the content of patients' information needs and sources emerges from varied patient samples, methodological approaches, and assessment tools. Continued evaluation in this direction through a variety of methodological approaches will contribute to our understanding of patients' needs and the sources from which they seek information. The typology developed in this review may serve as a framework for crafting more comprehensive and standardized assessment tools for evaluating cancer patients' information needs and sources.

The methodological limitations identified in this research and the insufficient number of investigations focusing on patients' information needs and sources post-treatment illuminated through the development of our typology offer fertile ground for making recommendations for advancing research on cancer patients' information needs and sources. Future research should address the limitations identified in past research by assessing the information needs and sources of large, representative, and diverse samples of cancer patients, including those with rare cancer diagnoses. To capture a fuller understanding of the dynamic nature of

patients' information needs, future research efforts should be mindful that patients' information needs and sources change over the course of their cancer journey. Thus, assessment of needs and sources should occur with clear reference to the point in the cancer care continuum that a patient is currently experiencing. Efforts to conduct longitudinal evaluations of patients' needs and sources are encouraged. Future investigations should initiate assessment of patients' needs at the time of diagnosis and follow patients through their cancer journey to ascertain important changes in information needs and sources over time.

Previous research focuses almost exclusively on understanding patients' needs and sources during the diagnosis and treatment phase; thus, greater attention to the informational needs and sources of cancer patients during recovery, survivorship, and end of life is also needed to address this gap. Such research, combined with the findings from existing studies, which have largely focused on the active phase of care, would inform evidence-based interventions to address the information needs of cancer patients across the cancer care continuum.

In addition to serving as a template for a more comprehensive assessment tool for researchers, this typology also provides a tool for health care practitioners to familiarize themselves with and assess common information needs of cancer patients throughout their cancer journey. Understanding cancer patients' information needs is the crucial first step in designing interventions to meet the needs of cancer patients. The typology of information needs and sources created in this review provides a resource to guide the development of interventions to address the information needs of cancer patients across the cancer care continuum.

References

- [1] Loehrer Sr PJ, Greger HA, Weinberger M, Musick B, Miller M, Nichols C et al., Knowledge and beliefs about cancer in a socioeconomically disadvantaged population. *Cancer* 1991;68:1665–71.
- [2] Hinds C, Streater A, Mood D. Functions and preferred methods of receiving information related to radiotherapy. Perceptions of patients with cancer. *Cancer Nurs* 1995;18:374–84.
- [3] Eakin EG, Strycker LA. Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: patient and provider perspectives. *Psychooncology* 2001;10:103–13.
- [4] Slevin ML, Nichols SE, Downer SM, Wilson P, Lister TA, Arnott S et al., Emotional support for cancer patients: what do patients really want? *Br J Cancer* 1996;74:1275–9.
- [5] Manfredi C, Czaja R, Price J, Buis M, Derk D. Patient use of treatment-related information received from the cancer information service. *Cancer* 1993;71:1326–37.
- [6] Silliman RA, Dukes KA, Sullivan LM, Kaplan SH. Breast cancer care in older women: sources of information, social support, and emotional health outcomes. *Cancer* 1998;83:706–11.
- [7] Guidry JJ, Aday LA, Zhang D, Winn RJ. Information sources and barriers to cancer treatment by racial/ethnic minority status of patients. *J Cancer Educ* 1998;13:43–8.

- [8] Derdarian AK. Informational needs of recently diagnosed cancer patients. *Nurs Res* 1986;35:276–81.
- [9] Derdarian AK. Informational needs of recently diagnosed cancer patients. Part II. Method description. *Cancer Nurs* 1987;10:156–163.
- [10] Jenkins V, Fallowfield L, Saul J. Information needs of patients with cancer: results from a large study in UK cancer centres. *Br J Cancer* 2001;84:48–51.
- [11] McIlmurray MB, Thomas C, Francis B, Morris S, Soothill K, Al Hamad A. The psychosocial needs of cancer patients: findings from an observational study. *Eur J Cancer Care* 2001;10:261–9.
- [12] Manfredi C, Czaja R, Price J, Buis M, Janiszewski R. Cancer patients' search for information. *J Natl Cancer Inst Monogr* 1993;14:93–104.
- [13] Bilodeau BA, Degner LF. Information needs, sources of information, and decisional roles in women with breast cancer. *Oncol Nurs Forum* 1996;23:691–6.
- [14] Degner LF, Kristjanson LJ, Bowman D, Sloan JA, Carriere KC, O'Neil J et al., Information needs and decisional preferences in women with breast cancer. *JAMA* 1997;277:1485–92.
- [15] Galloway S, Graydon J, Harrison D, Evans-Boyden B, Palmer-Wickham S, Burlein-Hall S et al., Informational needs of women with a recent diagnosis of breast cancer: development and initial testing of a tool. *J Adv Nurs* 1997;25:1175–83.
- [16] Girgis A, Boyes A, Sanson-Fisher RW, Burrows S. Perceived needs of women diagnosed with breast cancer: rural versus urban location. *Aust N Z J Pub Health* 2000;24:166–73.
- [17] Gray RE, Greenberg M, Fitch M, Sawka C, Hampson A, Labrecque M et al., Information needs of women with metastatic breast cancer. *Cancer Prev Control* 1998;2:57–62.
- [18] Gustafson DH, Taylor JO, Thompson S, Chesney P. Assessing the needs of breast cancer patients and their families. *Qual Manag Health Care* 1993;2:6–17.
- [19] Lindop E, Cannon S. Evaluating the self-assessed support needs of women with breast cancer. *J Adv Nurs* 2001;34:760–71.
- [20] Luker KA, Beaver K, Leinster SJ, Owens RG, Degner LF, Sloan JA. The information needs of women newly diagnosed with breast cancer. *J Adv Nurs* 1995;22:134–41.
- [21] Luker KA, Beaver K, Leinster SJ, Owens RG. Information needs and sources of information for women with breast cancer: a follow-up study. *J Adv Nurs* 1996;23:487–95.
- [22] Rees CE, Bath PA. Information-seeking behaviors of women with breast cancer. *Oncol Nurs Forum* 2001;28:899–907.
- [23] Wallberg B, Michelson H, Nystedt M, Bolund C, Degner LF, Wilking N. Information needs and preferences for participation in treatment decisions among Swedish breast cancer patients. *Acta Oncol* 2000;39:467–76.
- [24] Veronesi U, von Kleist S, Redmond K, Costa A, Delvaux N, Freilich G et al., Caring About Women and Cancer (CAWAC): a European survey of the perspectives and experiences of women with female cancers. *Eur J Cancer* 1999;35:1667–75.
- [25] Boudioni M, McPherson K, Moynihan C, Melia J, Boulton M, Leydon G et al., Do men with prostate or colorectal cancer seek different information and support from women with cancer? *Br J Cancer* 2001;85:641–8.
- [26] Davison BJ, Degner LF, Morgan TR. Information and decision-making preference of men with prostate cancer. *Oncol Nurs Forum* 1995;22:1401–8.
- [27] Fitch MI, Johnson B, Gray R, Franssen E. Survivors' perspectives on the impact of prostate cancer: implications for oncology nurses. *Can Oncol Nurs J* 1999;9:23–34.
- [28] Feldman-Stewart D, Brundage MD, Hayter C, Groome P, Nickel JC, Downes H et al., What questions do patients with curable prostate cancer want answered? *Med Decision Making* 2000;20:7–19.
- [29] Gulavita S, Sinnott C, Setliff AE, Sellick SM. Short report: what do men with prostate cancer want to know? *Can Fam Physician* 2000;46:1769–71.
- [30] Moore KN, Estey A. The early post-operative concerns of men after radical prostatectomy. *J Adv Nurs* 1999;29:1121–9.
- [31] Wong F, Stewart DE, Dancy J, Meana M, McAndrews MP, Bunston T et al., Men with prostate cancer: influence of psychological factors on informational needs and decision making. *J Psychosom Res* 2000;49:13–9.
- [32] Carlsson ME, Strang PM. How patients with gynecological cancer experience the information process. *J Psychosom Obstet Gynaecol* 1998;19:192–201.
- [33] Carlsson ME, Strang PM, Nygren U. Qualitative analysis of the questions raised by patients with gynecologic cancers and their relatives in an educational support group. *J Cancer Educ* 1999;14:41–6.
- [34] Fitch MI, Gray RE, Franssen E. Perspectives on living with ovarian cancer: older women's views. *Oncol Nurs Forum* 2001;28:1433–42.
- [35] Fox S, Collins M, Haney L, Qualitza B. Male genitourinary cancer sexuality questionnaire. *Urol Nurs* 1999;19:101–7.
- [36] Fitch MI, Gray RE, Franssen E. Women's perspectives regarding the impact of ovarian cancer: implications for nursing. *Cancer Nurs* 2000;23:359–66.
- [37] Stewart DE, Wong F, Cheung AM, Dancy J, Meana M, Cameron JI et al., Information needs and decisional preferences among women with ovarian cancer. *Gynecol Oncol* 2000;77:357–61.
- [38] Carlsson M. Cancer patients seeking information from sources outside the health care system. *Support Care Cancer* 2000;8:453–7.
- [39] Turk-Charles S, Meyerowitz BE, Gatz M. Age differences in information-seeking among cancer patients. *Int J Aging Human Dev* 1997;45:85–98.
- [40] Hopkins MB. Information-seeking and adaptational outcomes in women receiving chemotherapy for breast cancer. *Cancer Nurs* 1986;9:256–62.
- [41] Chen X, Siu LL. Impact of the media and the internet on oncology: survey of cancer patients and oncologists in Canada. *J Clin Oncol* 2001;19:4291–7.
- [42] Mills ME, Sullivan K. Patients with operable oesophageal cancer: their experience of information-giving in a regional thoracic unit. *J Clin Nurs* 2000;9:236–46.
- [43] Nelson L, O'Brien PJ, Ashikaga T, Bosompra K. Education about lymphedema prevention and management: a needs assessment of breast cancer survivors in a rural U.S. state. *Int Q Commun Health Educ* 2000;19:229–39.
- [44] Campbell-Forsyth L. Patients' perceived knowledge and learning needs concerning radiation therapy. *Cancer Nurs* 1990;13:81–9.
- [45] Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med* 1980;92:832–6.
- [46] Fieler VK, Wlasowicz GS, Mitchell ML, Jones LS, Johnson JE. Information preferences of patients undergoing radiation therapy. *Oncol Nurs Forum* 1996;23:1603–8.
- [47] Gamble K. Communication and information: the experience of radiotherapy patients. *Eur J Cancer Care Engl* 1998;7:153–61.
- [48] McLoughlin HA, Oosthuizen BL. The information needs of cancer patients in the Pretoria and Witwatersrand area. *Curatationis* 1996;19:31–5.
- [49] Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. Supportive Care Review Group. *Cancer* 2000;88:226–37.
- [50] Tamburini M, Gangeri L, Brunelli C, Beltrami E, Boeri P, Borreani C et al., Assessment of hospitalised cancer patients' needs by the Needs Evaluation Questionnaire. *Ann Oncol* 2000;11:31–7.
- [51] Borgers R, Mullen PD, Meertens R, Rijken M, Eussen G, Plagge I et al., The information-seeking behavior of cancer outpatients: a description of the situation. *Patient Educ Couns* 1993;22:35–46.
- [52] Eardley A. Radiotherapy: what are patients' needs? *Eur J Surg Oncol* 1985;11:353–5.
- [53] Grahn G, Johnson J. Learning to cope and living with cancer. Learning-needs assessment in cancer patient education. *Scand J Caring Sci* 1990;4:173–81.

- [54] Kutner JS, Foehner K, Steiner JF. Evaluation of the impact of a pre-visit questionnaire for addressing cancer patients' information needs. *J Cancer Educ* 1999;14:248–53.
- [55] Griffiths M, Leek C. Patient education needs: opinions of oncology nurses and their patients. *Oncol Nurs Forum* 1995;22:139–44.
- [56] Jany L. Active living with cancer results of a group support program for cancer patients and their families. *Onkologie* 1995;18:468–72.
- [57] Lauer P, Murphy SP, Powers MJ. Learning needs of cancer patients: a comparison of nurse and patient perceptions. *Nurs Res* 1982;31:11–6.
- [58] Newall DJ, Gadd EM, Priestman TJ. Presentation of information to cancer patients: a comparison of two centres in the UK and USA. *Br J Med Psychol* 1987;60:127–31.
- [59] Beaver K, Bogg J, Luker KA. Decision-making role preferences and information needs: a comparison of colorectal and breast cancer. *Health Expect* 1999;2:266–76.
- [60] Cawley M, Kostic J, Cappello C. Informational and psychosocial needs of women choosing conservative surgery/primary radiation for early stage breast cancer. *Cancer Nurs* 1990;13:90–4.
- [61] Graydon J, Galloway S, Palmer-Wickham S, Harrison D, Rich-van der Bij L, West P et al., Information needs of women during early treatment for breast cancer. *J Adv Nurs* 1997;26:59–64.
- [62] Harrison DE, Galloway S, Graydon JE, Palmer-Wickham S, Rich-van der Bij L. Information needs and preference for information of women with breast cancer over a first course of radiation therapy. *Patient Educ Couns* 1999;38:217–25.
- [63] Harrison-Woermke DE, Graydon JE. Perceived informational needs of breast cancer patients receiving radiation therapy after excisional biopsy and axillary node dissection. *Cancer Nurs* 1993;16:449–55.
- [64] Feldman-Stewart D, Brundage MD, Nickel JC, MacKillop WJ. The information required by patients with early-stage prostate cancer in choosing their treatment. *BJU Int* 2001;87:218–23.
- [65] Meredith P, Emberton M, Wood C, Smith J. Comparison of patients' needs for information on prostate surgery with printed materials provided by surgeons. *Qual Health Care* 1995;4:18–23.
- [66] Gray RE, Klotz LH, Iscoe NA, Fitch MI, Franssen E, Johnson BJ. Results of a survey of Canadian men with prostate cancer. *Can J Urol* 1997;4:359–65.
- [67] Davidson JR, Brundage MD, Feldman-Stewart D. Lung cancer treatment decisions: patients' desires for participation and information. *Psychooncology* 1999;8:511–20.
- [68] Fitch MI, Gray RE, DePetrillo D, Franssen E, Howell D. Canadian women's perspectives on ovarian cancer. *Cancer Prev Control* 1999;3:52–60.
- [69] Knowles G, Tierney A, Jodrell D, Cull A. The perceived information needs of patients receiving adjuvant chemotherapy for surgically resected colorectal cancer. *Eur J Oncol Nurs* 1999;3:208–22.
- [70] Bonevski B, Sanson-Fisher R, Hersey P, Paul C, Foot G. Assessing the perceived needs of patients attending an outpatient melanoma clinic. *J Psychosoc Oncol* 1999;17:101–18.
- [71] Benedict S, Cole DJ, Baron L, Baron P. Factors influencing choice between mastectomy and lumpectomy for women in the Carolinas. *J Surg Oncol* 2001;76:6–12.
- [72] Nair MG, Hickok JT, Roscoe JA, Morrow GR. Sources of information used by patients to learn about chemotherapy side effects. *J Cancer Educ* 2000;15:19–22.
- [73] Perez DJ, Allan SG, Humm GP, Wynne CJ. The information needs of patients with breast cancer. *Aust N Z J Med* 1995;25:521–2.
- [74] Sahay TB, Gray RE, Fitch M. A qualitative study of patient perspectives on colorectal cancer. *Cancer Pract* 2000;8:38–44.
- [75] Schapira MM, Meade CD, McAuliffe TL, Lawrence WF, Nattinger AB. Information sources and professional consultations sought by men newly diagnosed as having prostate cancer. *J Cancer Educ* 1999;14:243–7.
- [76] Ashbury FD, Findlay H, Reynolds B, McKerracher K. A Canadian survey of cancer patients' experiences: are their needs being met? *J Pain Symptom Manage* 1998;16:298–306.
- [77] Muha C, Smith KS, Baum S, Ter Maat J, Ward JA. The use and selection of sources in information seeking: the Cancer Information Service experience. Part 8. *J Health Commun* 1998;3:109–20.
- [78] Whelan TJ, Mohide EA, Willan AR, Arnold A, Tew M, Sellick S et al., The supportive care needs of newly diagnosed cancer patients attending a regional cancer center. *Cancer* 1997;80:1518–24.
- [79] Hughes LC, Hodgson NA, Muller P, Robinson LA, McCorkle R. Information needs of elderly postsurgical cancer patients during the transition from hospital to home. *J Nurs Scholarsh* 2000;32:25–30.
- [80] van der MB. Relating information-needs to the cancer experience. 1. Jenny's story: a cancer narrative. *Eur J Cancer Care Engl* 2000;9:41–7.
- [81] van der MB. Relating information needs to the cancer experience. 2. Themes from six cancer narratives. *Eur J Cancer Care Engl* 2000;9:48–54.
- [82] van Hartevelde JT, Mistiaen PJ, Dukkens van Emden DM. Home visits by community nurses for cancer patients after discharge from hospital: an evaluation study of the continuity visit. *Cancer Nurs* 1997;20:105–14.
- [83] Stalker MZ, Johnson PS, Cimma C. Supportive activities requested by survivors of cancer. *J Psychosoc Oncol* 1989;7:21–31.
- [84] Sullivan T, Weinert C, Fulton RD. Living with cancer: self-identified needs of rural dwellers. *Fam Commun Health* 1993;16:41–9.
- [85] Boman L, Andersson JU, Bjorvell H. Needs as expressed by women after breast cancer surgery in the setting of a short hospital stay. *Scand J Caring Sci* 1997;11:25–32.
- [86] Feather BL, Wainstock JM, Remington A, Ringenberg QS. Post-mastectomy educational needs and social support. *J Cancer Educ* 1988;3:135–44.
- [87] Gray RE, Fitch M, Greenberg M, Hampson A, Doherty M, Labrecque M. The information needs of well, longer-term survivors of breast cancer. *Patient Educ Couns* 1998;33:245–55.
- [88] Wilson SE, Andersen MR, Meischke H. Meeting the needs of rural breast cancer survivors: what still needs to be done? *J Womens Health Gender-Based Med* 2000;9:667–77.
- [89] Steginga SK, Occhipinti S, Dunn J, Gardiner RA, Heathcote P, Yaxley J. The supportive care needs of men with prostate cancer. *Psychooncology* 2001;10:66–75.
- [90] Corney RH, Crowther ME, Everett H, Howells A, Shepherd JH. Psychosexual dysfunction in women with gynaecological cancer following radical pelvic surgery. *Br J Obstet Gynaecol* 1993;100:73–8.
- [91] Corney RH, Everett H, Howells A, Crowther ME. The care of patients undergoing surgery for gynaecological cancer: the need for information, emotional support and counseling. *J Adv Nurs* 1992;17:667–71.
- [92] Galloway SC, Graydon JE. Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer Nurs* 1996;19:112–7.
- [93] Johansson S, Steineck G, Hursti T, Fredrikson M, Furst CJ, Peterson C. Aspects of patient care. Interviews with relapse-free testicular cancer patients in Stockholm. *Cancer Nurs* 1992;15:54–60.
- [94] Galloway SC, Bubela N, McKibbin A, McCay E, Ross E. Perceived information needs and affect of symptoms on activities after surgery for lung cancer. *Can Oncol Nurs J* 1993;3:116–9.
- [95] Fitch MI, Gray R, Franssen E, Johnson B. Men's perspectives on the impact of prostate cancer: implications for oncology nurses. *Oncol Nurs Forum* 2000;27:1255–63.
- [96] Meredith C, Symonds P, Webster L, Lamont D, Pyper E, Gillis CR et al., Information needs of cancer patients in west Scotland: cross sectional survey of patients' views. *BMJ* 1996;313:724–6.
- [97] Hammick M, Tutt A, Tait DM. Knowledge and perception regarding radiotherapy and radiation in patients receiving radiotherapy: a qualitative study. *Eur J Cancer Care Engl* 1998;7:103–12.
- [98] Brandt B. Informational needs and selected variables in patients receiving brachytherapy. *Oncol Nurs Forum* 1991;18:1221–7.

- [99] Kutner JS, Steiner JF, Corbett KK, Jahnigen DW, Barton PL. Information needs in terminal illness. *Soc Sci Med* 1999;48:1341–52.
- [100] Boberg EW, Gustafson DH, Hawkins RP, Offord KP, Koch C, Wen KY, Kreutz K, Salner A. Assessing the unmet information, support and care delivery needs of men with prostate cancer. *Patient Educ Couns* 2003;49:223–42.
- [101] Davis C, Williams P, Redman S, White K, King E. Assessing the practical and psychosocial needs of rural women with early breast cancer in Australia. *Soc Work Health Care* 2003;36:25–36.
- [102] Friis LS, Elverdam B, Schmidt KG. The patient's perspective: a qualitative study of acute myeloid leukaemia patients' need for information and their information-seeking behavior. *Support Care Cancer* 2003;11:162–70.
- [103] Iconomou G, Viha A, Koutras A, Vagenakis AG, Kalofonos HP. Information needs and awareness of diagnosis in patients with cancer receiving chemotherapy: a report from Greece. *Palliative Med* 2002;16:315–21.
- [104] Kakai H, Maskarinec G, Shumay DM, Tatumura Y. Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: an exploratory study with correspondence analysis. *Soc Sci Med* 2003;56:851–62.
- [105] Lock KK, Willson B. Information needs of cancer patients receiving chemotherapy in an ambulatory-care setting. *CJNR* 2002;34:83–93.
- [106] Maly R, Leake B, Silliman RA. Health care disparities in older patients with breast carcinoma: informational support from physicians. *Cancer* 2003;87:1517–27.
- [107] Mills ME, Davidson R. Cancer patients' sources of information: use and quality issues. *Psycho-Oncology* 2002;11:371–8.
- [108] Raupach JCA, Hiller JE. Information and support for women following the primary treatment of breast cancer. *Health Expect* 2002;5:289–301.
- [109] Tamburini M, Gangeri L, Brunelli C, Boeri P, Borreani C, Bosisio M, Karmann CF, Greco M, Miccinesi G, Murru L, Trimigno P. Cancer patients' needs during hospitalisation: a quantitative and qualitative study. *BMC Cancer* 2003;3:12.
- [110] Templeton H, Coates V. Informational needs of men with prostate cancer on hormonal manipulation therapy. *Patient Educ Couns* 2002;49:243–56.
- [111] Thewes B, Meiser B, Rickard J, Friedlander M. The fertility- and menopause-related information needs of younger women with a diagnosis of breast cancer: a qualitative study. *Psycho-Oncology* 2003;12:500–11.
- [112] Wong RKS, Franssen E, Szumacher E, Connolly R, Evans M, Page B, Chow E, Hayter C, Harth T, Andersson L, Pope J, Danjoux C. What do patients living with advanced cancer and their carers want to know?—a needs assessment. *Support Care Cancer* 2002;10:408–15.
- [113] Damian D, Tattersall MH. Letters to patients: improving communication in cancer care. *Lancet* 1991;338:923–92.
- [114] Johnson JE, Nail LM, Lauver D, King KB, Keys H. Reducing the negative impact of radiation therapy on functional status. *Cancer* 1988;61:46–51.
- [115] Rainey LC. Effects of preparatory patient education for radiation oncology patients. *Cancer* 1985;56:1056–61.
- [116] Hogben B, Fallowfield L. Getting it taped: the “bad news” consultation with cancer patients. *Br J Hosp Med* 1989;41:330–3.
- [117] Johnson IA, Adelstein DJ. The use of recorded interviews to enhance physician-patient communication. *J Cancer Educ* 1991;6:99–102.
- [118] Reynolds PM, Sanson-Fisher RW, Poole AD, Harker J, Byrne MJ. Cancer and communication: information-giving in an oncology clinic. *Br Med J Clin Res Ed* 1998;282:1449–51.
- [119] Arora NK, Johnson P, Gustafson DH, McTavish F, Hawkins RP, Pingree S. Barriers to information access, perceived health competence, and psychosocial health outcomes: test of a mediation model in a breast cancer sample. *Patient Educ Couns* 2002;47:37–46.
- [120] Rees CE, Bath PA. The information needs and source preferences of women with breast cancer and their family members: a review of the literature published between 1988 and 1998. *Cancer Nurs* 2000;31:833–41.
- [121] Echlin KN, Rees CE. Information needs and information seeking behaviors of men with prostate cancer and their partners: a review of literature. *Cancer Nurs* 2002;25:35–41.
- [122] Krantz DS, Baum A, Wideman M. Assessment of preferences for self-treatment and information in health care. *J Pers Soc Psychol* 1980;39:977–90.
- [123] Foot G, Sanson-Fisher R. Measuring the unmet needs of people living with cancer. *Cancer Forum* 1995;19:131–5.
- [124] Chalmers KI, Luker KA, Leinster SJ, Ellis I, Booth K. Information and support needs of women with primary relatives with breast cancer: development of the Information and Support Needs Questionnaire. *J Adv Nurs* 2001;35:497–507.
- [125] Lazarus RS. Coping with the stress of illness. *WHO Regul Publ Eur Ser* 1992;44:11–31.
- [126] James C, James N, Davies D, Harvey P, Tweddle S. Preferences for different sources of information about cancer. *Patient Educ Couns* 1999;37:273–82.
- [127] Gustafson DH, Hawkins RP, Boberg EW, McTavish F, Owens B, Wise M et al., CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved. *Int J Med Inf* 2002;65:169–77.