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Patient education about treatment in cancer care: an overview of the literature on older patients' needs.

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ABSTRACT

Major issue

An increasing number of older people are treated for cancer. Several factors, such as co-morbidity and sensory deficits occur more frequently in older patients than in younger patients. In addition, their life circumstances, values and preferences may differ. These factors ask for tailored nurse-older patient communication. This paper reviews recent literature on the specific needs of older cancer patients in the treatment phase of the disease.

Findings

No studies addressed treatment related needs of older patients specifically. The seventeen studies that controlled for age showed that many older patients want as much information about disease and treatment as possible, but they are less interested in details than younger patients. Furthermore, older patients reported less need for information about sexual consequences and psychosocial support. The results remain difficult to interpret because of variation in study designs and questionnaires. Moreover, none of the studies controlled for age related variables.

Conclusion

Studies that illuminate the unique needs of older patients with cancer in the treatment phase of the disease are strikingly limited given the demographics of

cancer in our society. Research is needed that explicitly investigates these needs and the influence of age-related changes in cognitive, physical and psychosocial functioning.

INTRODUCTION

Cancer is primarily a disease of older people with approximately 60% of all cancer related deaths occurring in individuals aged 65 and over. As the world population is aging it is estimated that there will be an increasing number of older cancer patients in the years ahead (1). Most of these patients receive treatment at some time during their disease. Although the older patient population is highly heterogeneous, a large number of them also suffer from physical and psychosocial conditions such as co-morbidity and cognitive decline that can influence (the side effects of) treatment (2). A better understanding of age related needs of older individuals during communication about cancer treatment is critical for providing high quality care, and may prevent the risk of under-treatment in this highly vulnerable patient group (3).

Patient education is important to prepare older cancer patients for the treatment and to help them to deal with side effects. In addition, the recent shift to outpatient and home-based treatment (4;5) has increased the necessity of good patient education, as most patients and their caregivers now have to deal with treatment-related problems and side effects at home. This may be even more challenging if those who care for older patients at home are older themselves. In addition, providing cancer patients with tailored information has been found to improve their ability to cope with treatment, to reduce anxiety, increase satisfaction with treatment, and improve communication with family (see Hack et al., (6) for an overview). Nurses have an important role in providing cancer patients with information and support regarding treatment (7). Tailored patient education, i.e. education which corresponds to patients' needs, values, wishes and psychosocial circumstances, is likely to be most effective (8), as it increases the chance that the information is correctly understood, remembered and used by the patient (9).

Needs can be conceptualized in a variety of ways. According to Hack et al (6), the communication needs of patients are inextricably linked to their communication goals which are primarily related to optimal management of the cancer (e.g. knowing what the side effects of treatment are) and optimal attention to the patient's psychosocial response to the experience of having cancer (e.g. discussing emotional functioning or daily activities). It is likely that needs will vary according to the age of a patient at the time of diagnosis and treatment. A 35 year old mother of two with cancer will probably struggle with different problems than a widow aged 75. When the current cohort of older patients was younger, people rarely spoke about cancer openly, treatments were more harsh and patients were often hospitalized to receive treatment. Although today's mortality rate for cancer has reduced and new methods of treatment have been developed, it is likely that many older individuals have maintained the early perceptions about cancer (3). Green et al. furthermore argue that older patients may have different expectations of their own role and the role of the health care professional in the medical encounter. In addition to differences in attitudes, there is a greater possibility of the presence of cognitive impairment, loss of vision and/or hearing loss in older patients compared with younger patients which affects their ability to process and remember information (3;10). Also, older patients are likely to have lower education and make less use of the internet. As a result, they may have more difficulties with medical jargon and are not as aware of the different types of cancers and new treatments as younger patients. On the other hand, studies suggest that older patients succeed better at coping with their disease compared to their younger counterparts (3;11) and are less insecure about for example their prognosis and treatment (12).

How do these factors influence the educational needs of older patients? A recent review by Rutten et al. (13) showed that, in general, younger patients have a higher need for information than older patients. Older patients do, however, wish to know their diagnosis and to be kept informed about their treatment progress, but often do not wish to be told about progression of their illness and length of their survival (11). Studies also showed that older patients felt that they did not receive adequate assistance to cope with the side effects of treatment (10) and experienced less contact, engagement and concern from doctors and nurses (14). To our knowledge, no attempt has been made to provide an overview of the specific needs of older cancer patients in the treatment phase of their disease.

The aim of this paper is to assess what aspects nurses have to consider when educating older patients about the treatment for cancer, by reviewing recent literature on this topic. More specifically, the following questions were asked:

1. *How much* information and support do older patients need during patient education about cancer treatment?
2. *What kind of* information and support do older patients need during patient education about cancer treatment?

METHODS

Selection of studies

The present review focused on studies evaluating the needs of older cancer patients when they communicate with doctors and nurses about their treatment for cancer. Initial exploration revealed no relevant studies that were concerned exclusively with older patients needs. Therefore, the search was expanded to include patients of all ages and consecutively assessed the presence of age as a variable within these articles. Searches were conducted on Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE, PsychLIT and CINAHL from January 1990 to April 2005, using the following search terms: patient, cancer, need, communication, patient education, information, professional-patient relations, and treatment or therapy. Both free text words and related MeSH terms were used.

Inclusion and exclusion criteria

Type of studies

Both qualitative and quantitative studies were included. Individual case reports and articles that reviewed the literature were excluded.

Type of participants

Studies had to involve patients diagnosed with cancer in consultation with doctors and nurses about any treatment for cancer in any clinical setting. Studies focusing on other clinicians (e.g. dentists) were excluded as were studies on complementary cancer treatments. Ideally, this review would have included studies with an a priori purpose of studying the needs of older cancer patients (i.e. 65 years or over) surrounding treatment. However, no studies of this type were found. Therefore, to avoid excluding potentially useful data, studies were included in which the relation between age and needs of patients was investigated, although not necessarily as a primary focus of the research.

Type of needs

Only studies on patients' need for information or support after the treatment decision had been made were included. To retain a specific focus, studies that only assessed patients' needs related to decision making about a treatment plan were excluded.

Inclusion procedure

A first selection for inclusion was performed by the first author (author1). Based on the titles and abstracts, all studies that clearly did not meet one of the inclusion criteria were

excluded from the review. If there was any doubt about meeting the inclusion criteria, the full article was examined. A second selection was made by two reviewers independently (author1, author2). Based on the full articles, studies were checked against the criteria for inclusion. Disagreements regarding inclusion were resolved by discussion, if necessary a third reviewer (author3) was asked for advice. No relevant foreign (non-English) papers were identified.

Description of the results

The type and amount of information and support patients want may depend on the type of cancer, the extent of disease progression, the type of treatment they receive (6) and changes in the course of their cancer journey (13). These and other characteristics of the studies were coded and summarized if the information was available (see Table 1). The most common features are described in the result section of this article.

The two research questions guided the organization of the review findings. Studies are summarized under the categories preferences for amount of information and preferences for type of information. The latter category was, guided by the results, divided in psychosocial needs and needs related to sexuality and physical attractiveness. Under each subcategory, results related to needs for information are discussed first, followed by studies on needs for support. Studies that addressed more than one of the topics of interest were listed under each relevant category, along with the results specific to that category.

[TABLE 1]

RESULTS

The initial search of the literature resulted in a total of 1978 hits. Of these, 247 duplicates were identified and eliminated, leaving 1731 papers for further consideration. Reviews of these articles determined that 1455 studies were not relevant to the topic of this review but were more broadly related to cancer including biological aspects of cancer and clinical issues related to treatment, and general communication issues. The remaining 276 articles appeared relevant to the focus on older patients needs concerning communication about cancer therapy. Detailed examination of these, showed that 17 papers met all the inclusion criteria. The other 259 studies were excluded for one or more of the following reasons (in order of most frequent reason for exclusion): (1) studies that did not focus on cancer patients' needs related to treatment, (2) studies that did not discuss the older patients' needs, (3) studies evaluating the professionals' needs rather than the patients' needs, (4) studies that reviewed the literature or studies limited to describing an individual case, (5) studies focusing on clinicians other than doctors or nurses, (6) studies focusing on the needs of individuals with no cancer history, (7) studies focusing on patients under 18 only, (8) age effect not discussed, (9) article not available. Figure 1 provides an overview of the inclusion process.

[FIGURE 1]

Study characteristics

Sample characteristics

Several studies utilized fairly heterogeneous patient samples regarding type of cancer, type of treatment and phase of the disease. Many of the studies examined the patients' needs in various, non-specific, phases of their illness (47%). About one third of the studies (29%)

involved patients with a variety of cancer diagnosis and another third (29%) focused exclusively on breast cancer patients. The prognosis of the patients in the different studies varied (59%) or was not specified (41%). Many studies focused on a variety of treatments, including surgery, chemotherapy or a combination of these (47%) or did not specify the type of treatment involved (29%). In more than half of the studies, treatment intent (e.g. curative or palliative) was not mentioned (53%). Most studies were conducted either in the UK (41%) or in Canada (35%) (see Tables 1 and 2).

Study method

The majority of articles reviewed used a quantitative data collection approach solely (77%). Commonly used survey instruments included instruments based on the ones originally developed by Cassileth et al. (29%) (12), the Toronto Information Needs Questionnaire (TINQ-BC) (12%) (7) and the Supportive Care Needs Survey (SCNS) by Bonevski et al. (12%) (15) (see Table 2). There was great variation in focus and number of items across instruments.

Older patients' needs for information and support

Of the studies that were included, 15 mentioned a relation between treatment related needs and age (7;16-29), and two mentioned the absence of an age effect (30;31).

Amount of information

Five studies specifically addressed age differences in relation to the amount of information about treatment that patients prefer to receive and reported mixed findings (see Table 2). Jenkins et al. (21) found in a heterogeneous sample of 2331 cancer patients that, compared to younger patients, relatively more older patients (>70) preferred to leave disclosure of details up to the doctor. They note, however, that a large proportion of patients over 70 years of age did want as much information as possible (81%). Similarly, Galloway et al. (7) and Graydon et al. (19) reported that younger women with breast cancer demonstrated greater need for information than older women. In the one qualitative study that mentioned age differences related to preferred amount of information, 21 acute myeloid leukemia (AML) patients were interviewed. The results showed that older patients especially, age not specified, were rarely interested in further medical information on their disease apart from basic information such as the duration of the treatment (18). A study by Muthu et al. (25) showed that cultural background may play a role. They explored the patients' needs during a course of radiotherapy or chemotherapy and found that 65.5% of Asian patients older than 60 years wanted as much information as possible, compared to 91.3% of white British patients of the same age.

Two studies failed to show a relation between amount of information and age (30;31). Knowles et al. (31) examined the information needs of patients throughout their chemotherapy treatment period and found no significant relations between information needs either pre-, during and post treatment and age. The majority of patients reported that they would want information, irrespective of age. Similar result are reported by Iconomou et al. (30), who assessed the overall and specific needs of patients during chemotherapy treatment.

To sum up, the majority of these studies show that most older patients prefer to receive less information about treatment than younger patients (7;18;19;21). However, in two studies no relation between needs and age was found (25;30;31). Furthermore, the needs of older patients may vary according to their cultural background (25).

Type of information

Treatment-specific information

Six studies showed that older and younger patients may need different types of information when discussing their treatment for cancer (20;21;24;26;28;29). Wong et al. (29) examined the information needs of men with prostate cancer during treatment or at follow-up and found that patients wanting information on treatment-related issues were younger than 70 (and generally more optimistic). Stewart et al. (28) explored the information needs of women with ovarian cancer in different stages of their disease and found that women aged 60 or over (who reported to be more in control) were more likely to need information only about the physical aspects of their health. In addition, the older women that were less depressed preferred to be told "the best possible outcome of the disease". A couple of studies also reported more specific age related differences in the type of information patients want about treatment. For example, Jenkins et al. (21) found that, compared to older patients, significantly more patients younger than 70 absolutely needed or would have liked information about: 1) the week by week progress, 2) all possible treatments, 3) all possible side effects of treatment, 4) how the treatment works. Similarly, Jahrhaus et al (20) reported that, compared with subjects aged 20-45 and aged 46-55, proportionally more so-called older patients (aged 56 and older) with primary breast cancer undergoing radiation therapy responded that they would "like to have" rather than "absolutely needed" information about: 1) all possible side-effects, 2) what the treatment would accomplish, 3) exactly what treatment would do, what the week-to-week progress is, 4) examples of cases in which treatment was effective and not effective. In addition to the previous results, a study on the information needs of recently diagnosed cancer patients showed that younger patients (aged <65) were more likely to want information about all possible treatments than older patients (aged 65-74) (24). Sanson-Fisher et al. (26) showed that younger cancer patients (aged 31-60) consistently displayed higher levels of need to be informed about "the things you can do to help yourself get well" than older patients (aged 71-90).

[TABLE 2]

To summarize, compared to younger patients older patients reported less often that they needed information about treatment (26;29) and they more likely wanted to be told "the best outcome of the disease" and receive information on the physical effects of the disease only (28). More specifically, information about: the week by week progress (20;21), all possible treatments (21;24), all possible side effects of treatment (20), what the treatment would exactly do and accomplish (20;21) and things you can do to help yourself get well (26) seem to be relatively less important for older patients.

Sexuality and body image

Three studies reporting age differences in needs related to treatment effects on sexuality and body image (16;17;23) were included in the review. Bourgeois-Law et al. (16) investigated the information needs of patients with gynecological cancer. They found that 50% of the women over 50 would have liked more information on sexuality and cancer compared to 67.6% of those under 50. Older women were also less likely to prefer a pamphlet as a format for receiving information about sexuality and cancer(treatment). Corney et al. (17) found that younger women who had undergone major gynecological surgery for cancer would have liked information on the effects of the operation on sexual function. They particularly would have liked their spouse to have received more information on sexuality (30% of the women in their 40s vs 8% of the women aged over 50). Similarly, the younger breast cancer patients (<40 years and 40-60) in the study by Luker et al. (23) rated information pertaining to sexual attractiveness as more important than did women in the 60+ age group. However, in this study the need for information about sexuality of the women was low, regardless of age. Apparently, older patients with gynecological cancer

have less prominent needs for information about cancer treatment and sexuality than younger patients.

Three studies reported age differences related to needs for support in dealing with treatment effects on sexuality (22;26;27). In the study by Sanson-Fisher et al. (26) cancer patients aged 31-60 years displayed higher need for help in the sexuality domain than those aged 70 years or older. Steginga et al. (27) measured the supportive care needs of men with prostate cancer between 1 month and 5 years after diagnosis, during treatment or after treatment. In their study, younger men reported greater need in the sexuality domain. The mean age of patients in this sample was 68 (range 48-85). Lindop et al (22) identified support needs of women with breast cancer at various points of the illness. The younger age groups in their study (20-45 and especially the 46-53 group) expressed significantly higher needs than the 54+ group. Of particular importance to the middle-aged group was the concept of body image and femininity, these women in this age group expressed a stronger need to adjust to their changed appearance and to have this accepted by their husband/partner.

To summarize, older patients report less need for information about the effects of treatment and cancer on sexuality and body image either for themselves (16;17;23) or for their partners (17) than younger patients do. In addition, younger patients seem to need more help in dealing with the effects of the disease and treatment on sexuality (22;26;27).

Psychosocial issues

Three studies reported that older and younger patients have different needs for information about psychosocial issues (23;28;29). Stewart et al. (28) found that women with ovarian cancer under 60 years (who were more depressed) were more likely to report a need for information about coping techniques than other patients. Older women who felt in control were more likely to need information about the physical aspects of their health only and not about the psychological aspects. On the contrary, Wong et al. (29) found that prostate cancer patients aged 70 or over (who were less depressed) wanted more psychological information, whereas, in general, men whose moods were less positive wanted more psychological information. In a study with newly diagnosed breast cancer patients, Luker et al. found that older women (60+) rated information pertaining to their social life as more important than did younger women (23).

Age differences in relation to the need for psychological support were reported in two studies (26;29). Wong et al. (29) showed that younger men with mental health issues needed more support and help with coping than older patients, as correlations between mental health indices (such as anxiety, depression and optimism) and coping and support needs were the strongest for patients under 70. Similarly, Sanson-Fisher et al. (26) found that age was negatively associated with higher levels of need for help, for example in dealing with fears of the cancer spreading and concerns about the worries of those close to them. Cancer patients aged 31-60 years consistently displayed higher levels of unmet psychosocial needs than patients aged 70 or over.

To sum up, the results on age differences and information needs pertaining to psychosocial issues are mixed. Compared to their younger counterparts, older men (who were less depressed) reported higher needs for psychosocial information (29), in addition older women expressed a higher need for information about their social life (23). One study showed that younger women (who were more depressed) reported higher needs for information about coping with psychosocial issues than older women (28). The relations between age and need for psychosocial support were more uniform. Younger patients displayed greater need for support and help in dealing with the disease than older patients (26;29). The question remains which role general mental health plays.

DISCUSSION

The results from the studies that were included in this review suggest a small but marked difference between the amount and type of information older and younger patients want

concerning treatment for cancer. In general, a large percentage of both older and younger patients want as much information as possible, but some studies showed that younger patients have a higher need for information than older patients. In addition, results seem to indicate that older patients prefer to receive information about the most important aspects of the disease and treatment but are relatively less interested in more detailed information. Compared to younger patients, older patients reported less often that they needed information about treatment and they were more likely to want to be told "the best outcome of the disease". Older patients were also less likely than younger patients to report a need for information about: how the treatment works and what it accomplishes, what the week by week progress is, what all the possible treatments are, what all the possible side effects of the treatment are and things you can do to help yourself get well. The slightly higher information needs in younger people may be a reflection of a generational effect whereby younger people expect to be better informed and to be active participants in making decisions about their health care than people who are older (7). Jenkins et al. (21) suggested that negative stereotypes of the elderly are common among health care professionals. If clinicians assume that there is an increase in passivity and helplessness in the elderly patient, then it is more likely that these negative aspects will prevail in the consultation. This leads to a doctor-centered rather than a patient-centered interaction, with the doctor in control of information giving. Although some older people may want the doctor to make decisions about management, they still require information about the reasons for decisions affecting their care (21). Alternatively, the personal and social responsibilities of younger people might increase their need for information (7).

In the literature reviewed, the need for information about the effects of treatment and cancer on sexuality and body image and the need for help and support with these effects of treatment seems to be higher in younger compared to older patients, irrespective of sex. This does not necessarily mean that treatment does not have an effect on older patients. In a study assessing the information needs of patients with gynecological cancer, Bourgeois-Law et al. (16) found that older women were as likely as younger women to say that cancer and treatments had affected their sexuality. It must, however, be noted that the relative need for sexuality topics was low in general, regardless of age (23). Older patients may have already adapted to age-related changes in sexual function, hence the reduced need for information and support on this topic (32). In addition, widowhood is more likely to figure in the lives of older people, which may help to explain why being informed about sexuality issues was shown to be less important to older patients (22).

This review shows that younger patients appear to need more support in coping with the disease and treatment than older patients do. These results support previous findings that indicate that older patients succeed better at coping with their disease compared to their younger counterparts (3;11) and are less insecure about for example their prognosis and treatment (12). Nevertheless, in two studies, older patients reported higher needs for psychosocial information. These results seem to be influenced by patients' gender and general mental health and clearly more research is needed to gain knowledge about older patients' emotional and psychological needs.

There are several methodological issues that preclude drawing any strong conclusions. Since no specific articles on older patients' needs were discovered, the current review included studies in which the relation between age and needs in cancer treatment was investigated, although they were not necessarily a primary focus of the research. Consequently, most of the studies did not control for age-related variables that are expected to influence the needs of older patients, such as level of education and cognitive function. In addition, a limitation of many of the studies was that they predominantly used cross-sectional and retrospective designs. As needs of cancer patients changes during the different stages of the disease (6) looking back at a previous treatment stage may elicit a colored viewpoint. Furthermore, the instruments used are all developed from a different perspective

and often contain items and domains with similar names that are conceptually and operationally quite different. As a consequence, there is great variation in domains and number of items across instruments in the articles under review. Also, the type and amount of information and support patients need depends on the type of cancer, the extent of disease progression and the type of treatment they receive (6). Since we included only a few studies, all with patients with different diagnoses and treatments, it is difficult to look at the effects of the abovementioned factors. Additionally, the age categories in the different studies were far from uniform. In some studies patients were considered “old” when they were older than 50, whereas in other studies “older” patients were aged 70 or over. It is obvious that these differences may have influenced the results.

Effective patient education is known to be the key to outcomes in terms of more patient satisfaction, recall and understanding of information, less anxiety and mood disturbances and, ultimately, improved patient health status (33;34). Good communication with older patients requires knowledge of older peoples' experiences with cancer and their needs. Nurses should stimulate patients, especially older ones, and give them the opportunity to ask questions. They should also be attentive to the individualistic nature of each older patient's unique needs. An important first step may be to ask patients themselves what they need.

To conclude, this review has shown that even though age is taken in account in some studies, few studies have focused particularly on the needs of older patients concerning cancer treatment. In view of the rapid growing elderly population this is a rather surprising but not uncommon phenomenon. Older patients are underrepresented in cancer clinical trials (35). Similarly, behavioral research has focused largely on younger adults whilst excluding older patients. Research is needed that explicitly investigates the needs of older cancer patients and the influence of age-related changes in cognitive, physical and psychosocial functioning on these needs. These age-related changes show differences within the elderly population between the young-old (65-75 yrs) and the old-old (>75 yrs) (32) and should be taken into account in further studies. Both qualitative and quantitative research should be carried out in order to explore more fully the needs of older cancer patients through the cancer journey.

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[TABLES EN FIGURES]

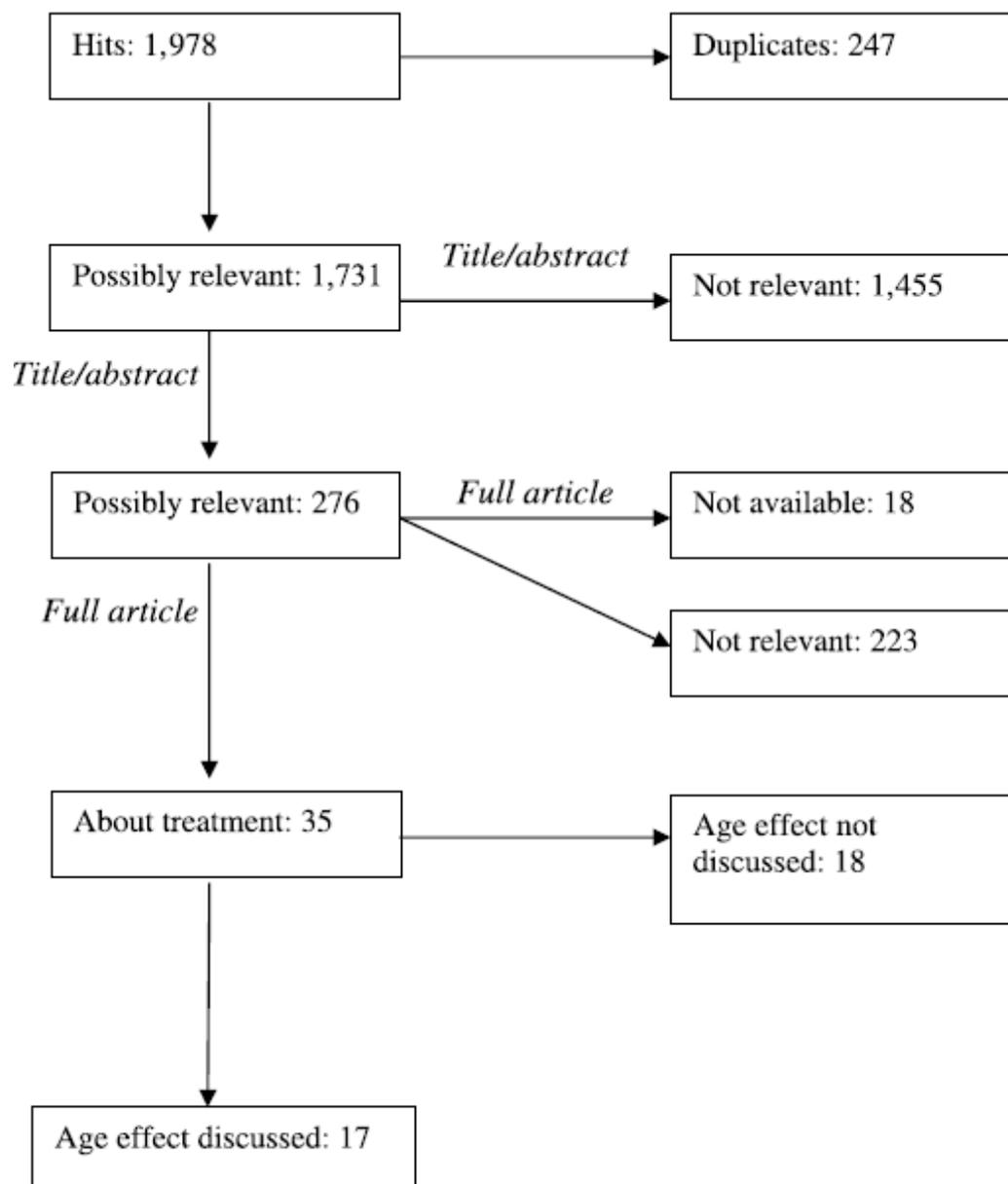


Figure 1 ■ Results of data extraction.

 **Table 1 • Characteristics of Studies Included in the Review (n = 17 articles)**

	N	%	References
Cancer phase			
During treatment	1	5.9	25
After treatment	5	29.4	16,17,26,27,30
Multiple stages	3	17.6	18,20,31
Various stages	8	47.0	7,19,21–24,28,29
Cancer site			
Breast	5	29.4	7,19,20,22,23
Gynecologic	3	17.6	16,17,28
Colorectal	1	5.9	31
Acute myeloid leukemia	1	5.9	18
Prostate	2	11.8	27,29
Multiple sites	5	29.4	21,24–26,30
Treatment			
Surgery	1	5.9	17
Chemotherapy	3	17.6	18,30,31
Mixed treatments	8	47.0	7,19,20,22,25–28
Not specified	5	29.4	16,21,23,24,29
Treatment intent			
Adjuvant	1	5.9	31
Mixed (palliative and curative)	7	41.2	21,24,25,27–30
Not specified	9	52.9	7,16–20,22,23,26
Stage of disease/prognosis			
Mixed stages	10	58.8	7,16,17,19,21–25,30
Not specified	7	41.2	18,20,26–29,31

Table 2 • Aims and Results of Studies Included in the Review (n = 17 articles)

Reference	N	Age of Sample	Design and Method	Aim Study	Age Difference	Amount of Information	Type of Information
Bourgeois-Law and Lotocki ¹⁶ (Canada)	73	Range: 25–82 <50 (50.7%) >50 (49.3%)	Design: retrospective Method: newly developed questionnaire (quantitative)	Determine what information patients had received regarding the effects of cancer and its treatment on sexuality, what information they would have liked, and when and in what format they would have preferred to receive it	Yes	—	Older patients: < need for information on sexuality
Corney et al ¹⁷ (UK)	105	Not given	Design: retrospective Method: semistructured interviews (qualitative)	Investigate the psychosocial adjustment of women after major gynecologic surgery for cancer	Yes	—	Older patients: < need for information on sexuality
Friis et al ¹⁸ (Denmark)	21	<50 (n = 9) 50–70 (n = 6) >70 (n = 6)	Design: cross-sectional Method: semi structured interviews (qualitative)	Describe the information needs from the patient's perspective and their information seeking behavior	Yes	Older patients: < need for information	—
Galloway et al, 1997 ⁷ (Canada)	114	Average: 53.9 Range: 21–91	Design: cross-sectional Method: Toronto Informational Needs Questionnaire-Breast Cancer (TINQ-BC ⁷) (quantitative)	Develop a questionnaire designed to identify the information that women with a recent diagnosis of breast cancer need to deal with their illness	Yes	Older patients: < need for information	—
Graydon et al ¹⁹ (Canada)	70	Average: 49.7 Range: 21–91	Design: cross-sectional Method: TINQ-BC ⁷ (quantitative)	Assess the information needs of women with breast cancer being treated by surgery, chemotherapy, or radiation therapy	Yes	Older patients: < need for information	—
Iconomou et al ³⁰ (Greece)	100	Average: 59.7 Range: 20–80	Design: retrospective Method: newly developed questionnaire (quantitative)	Assess the overall preference for information and to identify specific information needs of Greek patients with cancer receiving chemotherapy and to delineate the profile of patients who knew the true diagnosis and to examine whether awareness had any effects on levels of satisfaction, emotional distress and global quality of life	No	No significant effects of age were found.	No significant effects of age were found.
Jahraus et al ²⁰ (Canada)	79	20–45 (n = 23) 46–55 (n = 28) ≥56 (n = 28)	Design: retrospective Method: questionnaire based on Cassileth et al ¹² (quantitative)	Evaluate the impact of an education program on the perceived adequacy of knowledge of patients with breast cancer receiving radiation therapy.	Yes	—	Older patients: < need for information on: – all possible adverse effects – effect treatment

Table 2 • continued

Reference	N	Age of Sample	Design and Method	Aim Study	Age Difference	Amount of Information	Type of Information
Jenkins et al ²¹ (UK)	2,331	≤30 (4.8%) 31-50 (24.9%) 51-70 (46.4%) >70 (18.9%) Unknown (5%)	Design: retrospective Method: questionnaire based on Cassileth et al ¹² (quantitative)	Second, investigate patients' preferences regarding involvement in decision making, amount and type of information wanted, and preferred information-seeking activities Collect patients' information preferences using an adaptation of Cassileth's Information Needs Questionnaire	Yes	Older patients: < details	Older patients: < need for information about: - week-by-week progress - all possible treatments - how treatment works No significant effects of age were found.
Knowles et al ³¹ (UK)	80	Main sample: Average: 62 Range: 40-83 Subsample: Average: 59 Range: 40-72	Design: prospective/longitudinal Method: newly developed questionnaire, partially based on Cassileth et al ¹² and semistructured interviews (quantitative and qualitative)	Examine the existing knowledge and information needs of patients newly referred to an oncology clinic for consideration of adjuvant chemotherapy after surgical resection for colorectal cancer. Forty of these patients went on to receive treatment and were assessed at 4 time points throughout their 6 months of chemotherapy.	No	No significant effects of age were found.	
Lindop and Cannon ²² (UK)	12 + 489	20-45 (n = 57) 46-53 (n = 112) 54+ (n = 318)	Design: retrospective Method: newly developed questionnaire based on semistructured interviews (quantitative and qualitative)	Identify the self-assessed support needs of women with breast cancer at various points of illness and establish if these needs formed clusters that could provide the basis for developing a standardized scale of needs for use by breast care teams in the evaluation of care	Yes	—	Older patients: < need for support with issues related to body image and femininity
Luker et al ²³ (UK)	150	<40 (n = 11) 40-60 (n = 88) >60 (n = 51)	Design: retrospective Method: Card Sorting Technique ²³ (quantitative)	Establish the priority information needs of a sample of women newly diagnosed with breast cancer and assess if information need was influenced by variables such as age, level of education, and social class	Yes	—	Older patients: < need for information on sexual attractiveness > need for information on issues related to their social life

Meredith et al ²⁴ (UK)	250	15-64 (56%) 65-74 (44%)	Design: concurrent Method: questionnaire based on Cassileth et al ¹² (quantitative)	Assess the needs of patients for information on their condition	Yes	—	Older patients: < need for information on all possible treatments
Muthu et al ²⁵ (UK)	82 Asian, 220 White	Median: 20 Range: 18-77	Design: concurrent Method: questionnaire based on Cassileth et al ¹² (quantitative)	Find the information needs of British Asian patients with cancer and the extent of family involvement when the patient was given the cancer diagnosis and the patient's views about information disclosure	Yes	A small minority wanted very little information, particularly patients older than 60 years and non-English speaking.	Older patients: < need for support with: - the health system - information - sexuality - psychosocial issues
Sanson-Fisher et al ²⁶ (Australia)	888	18-30 (2%) 31-40 (6%) 41-50 (16%) 51-60 (21%) 61-70 (27%) 71-85 (29%)	Design: cross-sectional Method: The Supportive Care Needs Survey (SCNS) ¹⁵ (quantitative)	(1) Measure the prevalence of unmet needs among people receiving surgery, chemotherapy, or radiation therapy for cancer (2) Examine the patients sociodemographic, disease, and treatment variables predictive of the prevalence of different types of needs	Yes	—	Older patients: < need for support and information on sexuality Older patients: < need for information: - coping - other than about physical aspects of health Preference to be told the "best possible outcome"
Steginga et al ²⁷ (Australia)	206	Average: 68 Range: 48-85	Design: retrospective Method: SCNS, ¹⁵ adaptation (quantitative)	Assess the supportive care needs of men with prostate cancer who are members of prostate cancer self-help groups	Yes	—	Older patients: < need for support and information on sexuality Older patients: < need for information: - coping - other than about physical aspects of health Preference to be told the "best possible outcome"
Stewart et al ²⁸ (Canada)	105	Average: 55.8 Range 21-87	Design: retrospective Method: newly developed questionnaire (quantitative)	Assess the information preferences of women with ovarian cancer; their preferred role in decision making; and the influence of sociodemographic, disease, related and psychological factors	Yes	—	Older patients: > need for information on: - treatment - psychosocial issues < need for support with coping
Wong et al ²⁹ (Canada)	101	Average: 70 <70 (n = 39) ≥70 (n = 62)	Design: cross-sectional Method: newly developed questionnaire (quantitative)	Determine the influence of psychological factors on how much and what type of information patients want and how much they want to participate in decision making with regard to their disease	Yes	—	Older patients: > need for information on: - treatment - psychosocial issues < need for support with coping

REFERENCES

- (1) Yancik R, Ries LA. Cancer in older persons: an international issue in an aging world. *Semin Oncol.* 2004; 31(2):128-136.
- (2) Balducci L. New paradigms for treating elderly patients with cancer: the comprehensive geriatric assessment and guidelines for supportive care. *J Support Oncol.* 2003; 1(4 Suppl 2):30-37.
- (3) Greene MG, Adelman RD. Physician-older patient communication about cancer. *Patient Educ Couns.* 2003; 50(1):55-60.
- (4) Molassiotis A. Challenges and opportunities when using oral chemotherapy in the home setting: the example of capecitabine (Xeloda(R)). *Eur J Oncol Nurs.* 2004; 8(Supplement 1):S1-S3.
- (5) Young AM, Kerr DJ. Home delivery: chemotherapy and pizza? *Br Med J.* 2001; 322(7290):809-810.
- (6) Hack TF, Degner LF, Parker PA. The communication goals and needs of cancer patients: a review. *Psychooncology.* 2005; 14(10):831-845.
- (7) Galloway SC, Graydon JE. Uncertainty, symptom distress, and information needs after surgery for cancer of the colon. *Cancer Nurs.* 1996; 19(2):112-117.
- (8) Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL et al. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Soc Sci Med.* 2005; 61(7):1516-1528.
- (9) Petty RE, Wegener DT, Fabrigar LR. Attitudes and attitude change. *Annu Rev Psychol.* 1997; 48:609-647.
- (10) Fitch MI, Gray RE, Franssen E. Perspectives on living with ovarian cancer: older women's views. *Oncol Nurs Forum.* 2001; 28(9):1433-1442.
- (11) Chouliara Z, Kearney N, Stott D, Molassiotis A, Miller M. Perceptions of older people with cancer of information, decision making and treatment: a systematic review of selected literature. *Ann Oncol.* 2004; 15(11):1596-1602.
- (12) Cassileth BR, Zupkis RV, Sutton-Smith K, March V. Information and participation preferences among cancer patients. *Ann Intern Med.* 1980; 92(6):832-836.
- (13) Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Educ Couns.* 2005; 57(3):250-261.
- (14) Tishelman C. Who cares? Patients' descriptions of age-related aspects of cancer and care in Stockholm. *Cancer Nurs.* 1993; 16(4):270-282.
- (15) Bonevski B, Sanson-Fisher R, Girgis A, Burton L, Cook P, Boyes A. Evaluation of an instrument to assess the needs of patients with cancer. *Supportive Care Review Group. Cancer.* 2000; 88(1):217-225.
- (16) Bourgeois LG, Lotocki R. Sexuality and gynecological cancer: a needs assessment. *Can J Hum Sex.* 1999; 8(4):231-240.
- (17) Corney R, Everett H, Howells A, Crowther M. The care of patients undergoing surgery for gynaecological cancer: the need for information, emotional support and counselling. *J Adv Nurs.* 1992; 17(6):667-671.
- (18) 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 behaviour. *Support Care Cancer.* 2003; 11(3):162-170.
- (19) 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(1):59-64.
- (20) Jahraus D, Sokolosky S, Thurston N, Guo D. Evaluation of an education program for patients with breast cancer receiving radiation therapy. *Cancer Nurs.* 2002; 25(4):266-275.
- (21) 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(1):48-51.
- (22) Lindop E, Cannon S. Evaluating the self-assessed support needs of women with breast cancer. *J Adv Nurs.* 2001; 34(6):760-771.
- (23) 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(1):134-141.

- (24) 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. *Br Med J*. 1996; 313(7059):724-726.
- (25) Muthu KD, Symonds RP, Sundar S, Ibrahim K, Savelyich BS, Miller E. Information needs of Asian and White British cancer patients and their families in Leicestershire: a cross-sectional survey. *Br J Cancer*. 2004; 90(8):1474-1478.
- (26) 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(1):226-237.
- (27) Steginga SK, Occhipinti S, Dunn J, Gardiner RA, Heathcote P, Yaxley J. The supportive care needs of men with prostate cancer (2000). *Psychooncology*. 2001; 10(1):66-75.
- (28) Stewart DE, Wong F, Cheung AM, Dancey J, Meana M, Cameron JI et al. Information needs and decisional preferences among women with ovarian cancer. *Gynecol Oncol*. 2000; 77(3):357-361.
- (29) Wong F, Stewart DE, Dancey 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(1):13-19.
- (30) 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. *Palliat Med*. 2002; 16(4):315-321.
- (31) 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(4):208-222.
- (32) Harden J, Schafenacker A, Northouse L, Mood D, Smith D, Pienta K et al. Couples' experiences with prostate cancer: focus group research. *Oncol Nurs Forum*. 2002; 29(4):701-709.
- (33) Ong LML, Haes JCJMd, Hoos AM, Lammes FB. Doctor-patient communication: a review of the literature. *Soc Sci Med*. 1995; 40, no.7:903-918.
- (34) Stewart MA. Effective physician-patient communication and health outcomes: a review. *Can Med Assoc J*. 1995; 152(9):1423-1433.
- (35) Lewis JH, Kilgore ML, Goldman DP, Trimble EL, Kaplan R, Montello MJ et al. Participation of patients 65 years of age or older in cancer clinical trials. *J Clin Oncol*. 2003; 21(7):1383-1389.