

REVIEW

A critical review of the evidence for nurses as information providers to cancer patients

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Aims. To review evidence on the role of oncology nurses in the provision of information to cancer patients and to delineate evidence-based implications for clinical practice and research.

Background. Provision of information is central for the empowerment of patients to participate in their care. There is not enough evidence regarding the nursing role in the information delivery process in cancer patients.

Design. Descriptive literature review.

Methods. From January 1990–2008, databases searched included Medline, CINAHL, PubMed, CancerLit and the Cochrane Library. Original research articles addressing the role of nurses in information delivery were included. We explored evidence on: (1) the effectiveness of nurses as information providers, (2) the way patients evaluate nurses' input to information delivery, (3) the extent to which nurses contribute to information delivery to cancer patients and (4) the types of information provided by nurses.

Results. The most important findings were: (1) nurses' role as information providers for cancer patients is prominent, especially after the initiation of treatment, (2) specialist nurses are very effective in providing information, (3) no clear evidence exists on how nurses compare with other health-care professionals as information providers and (4) some evidence exists that patients may prefer nurses as information providers at specific times in their treatment and especially in regards to symptom management.

Conclusion. Well-designed studies provide some evidence that nurses are effective as information providers to cancer patients. Specifically, oncology nurses are able to provide information of both high quality and of appropriate quantity and to assist individuals to interpret information provided by others.

Relevance to clinical practice. Oncology nurses should be specifically educated and prepared to offer explicit, practical and timely information and they should be trained in interpersonal communication skills, which will increase their ability to comprehend patient information needs.

Key words: cancer, critical review, information delivery, information provider, nurse, oncology

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Introduction

Obtaining access to high quality and reliable information regarding their treatment is a top priority for cancer patients

(Meredith *et al.* 1996, Veronesi *et al.* 1999). Information is data acquired by cancer patients in any manner (Chelf *et al.* 2001) and information delivery is a core nursing intervention (Benner 1984). To deal with cancer and its consequences,

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individuals require accurate information, relevant to their situation, which they themselves perceive as important. This type of information may enhance patients' adherence to the prescribed treatment, their sense of control over their disease (Sainio & Eriksson 2003, Skalla *et al.* 2004) and, presumably, their clinical outcomes as well (Veronesi *et al.* 1999). Provision of information is central for the empowerment of patients to participate in and to make informed decisions about their care (Hinds *et al.* 1995, Chelf *et al.* 2001, Davison *et al.* 2003). Additionally, studies by Johnson *et al.* (1997) and evidence pertinent to the self-regulation theory of coping (Lundberg & Trichorb 2001), suggest that provision of specific information may enhance patients' well-being and recovery and may decrease their stress (Bilodeau & Degner 1996, Luker *et al.* 1996, Harrison *et al.* 1999, Leydon *et al.* 2000). This may be especially important for cancer patients since stress has been identified as a significant factor in patients' outcomes (Johnson *et al.* 1997).

The provision of information to cancer patients constitutes a distinct field of important nursing interventions. Nurses who work in oncology settings may function in several roles, providing expert clinical, educational, emotional and supportive care to cancer patients. However, to enhance this significant aspect of their practice, so as to confidently target desired patient outcomes, nurses need to develop a clear and meaningful definition of their role in information delivery and, subsequently, in patient education and counselling.

However, there is not enough evidence regarding the nursing role in the information delivery process in specific populations of patients, including cancer patients. According to an overview of 176 articles on cancer-related education (Chelf *et al.* 2001), although physicians were the preferred source of information for patients with cancer, nurses were identified as 'extremely helpful' resources. Patients preferred to obtain information through discussion, which means that interpersonal information providers are especially valuable during the cancer trajectory. Similarly, six other review studies present findings which establish that the role of health care professionals (HCPs) as information providers is a measure of the quality of healthcare services (Mills & Sullivan 1999, Flanagan & Holmes 2000, Rees & Bath 2000, Echlin & Rees 2002, Semple & MCGowan 2002, Davies & Higginson 2003), whereas, Rutten *et al.* (2005) found that during post-treatment, physicians, nurses and other HCPs become equally important as sources of information.

Aims of the review

The aim of this literature review is to summarise evidence from qualitative and quantitative research on the provision of

information as a nursing intervention implemented for cancer patients. Specifically, we explored evidence on: (1) the extent to which nurses contribute to the information delivery to cancer patients, (2) the effectiveness of nurses as information providers, (3) the way patients evaluate nurses' input to the information delivery and (4) the types of information provided by nurses. This is the first review which focuses exclusively on nurses' role as information providers, placing a special focus on information provided exclusively to cancer patients. Although the nurse also has an important role in the provision of information and support to these patients' families and significant others, this review focuses only on nurse-patient interactions, since these bear the potential to directly enhance patient outcomes and reduce stress responses.

Methods

Design

A descriptive critical review methodology was employed. The study was based on published research from January 1990–2008.

Search methods

Articles were selected and reviewed based on the following review questions:

- What is the role of nurses in the provision of information to cancer patients?
- Is there evidence on the effectiveness of oncology nurses as information providers and how do they compare to other HCPs?
- How do cancer patients appraise nurses as information providers?
- What kinds of information do patients require and/or obtain from oncology nurses?

Databases searched included Medline, CINAHL, PubMed, CancerLit and the Cochrane Library. Studies were retrieved by using the following key words in a variety of combinations: 'information provider', 'information delivery', 'information source', 'oncology nurse', 'oncology' and 'cancer'. References of identified studies were also checked for relevancy to the aims of the study.

Search outcome

Studies were classified as randomised clinical trials, prospective studies, retrospective studies, cross-sectional studies, surveys and qualitative studies. The selection criteria for articles were as follows:

- Articles published since 1990, as evidence on the role of nurses as information providers was very scarce before this date.
- Studies with an oncology focus.
- Studies investigating the nursing role in the information giving process.

The exclusion criteria were:

- Articles addressing types of information sources other than nurses.
- Articles addressing provision of information to family members.

Articles were assessed and analysed using a two-phase process (Fig. 1). During the first phase, 185 abstracts were examined, focusing on the questions mentioned above. In the second phase, approximately 65 studies were critiqued and graded for quality. Nineteen articles were excluded. The specific exclusion criteria employed at the second phase of selection were:

- Studies expressing opinions on nurses' input rather than research based data.
- Expert's views.
- Clinical audit results.
- Clinical trials of nursing interventions that do not provide results for information delivery, specifically.

The final literature review examined 46 articles: 17 qualitative studies and 28 studies with a quantitative design

and 1 study with mixed qualitative and quantitative methodology.

Data extraction and synthesis

The articles were read and were categorised according to their specific focus (e.g. general nurses' role, specialist nurses' role etc.). Next they were assessed for methodological quality and their attributes were entered into a table that included a crude rating of their methodological quality along with a brief description of potential limitations, the specific population, the research design and the main results. The table was used as a guide for data extraction and synthesis, which was undertaken by the first author and confirmed by the rest of authors. Data were synthesised descriptively, taking into account the specific merits and limitations of each study.

Quality appraisal

The quality of the studies reviewed was diverse. Investigators have employed various methodologies and in their majority results are based on convenience or purposeful samples, which may have limited the external validity of the studies. All studies retrieved were either quantitative descriptive or qualitative (Tables 1 and 2), therefore, rating of evidence levels could not be performed. Moreover, study-specific

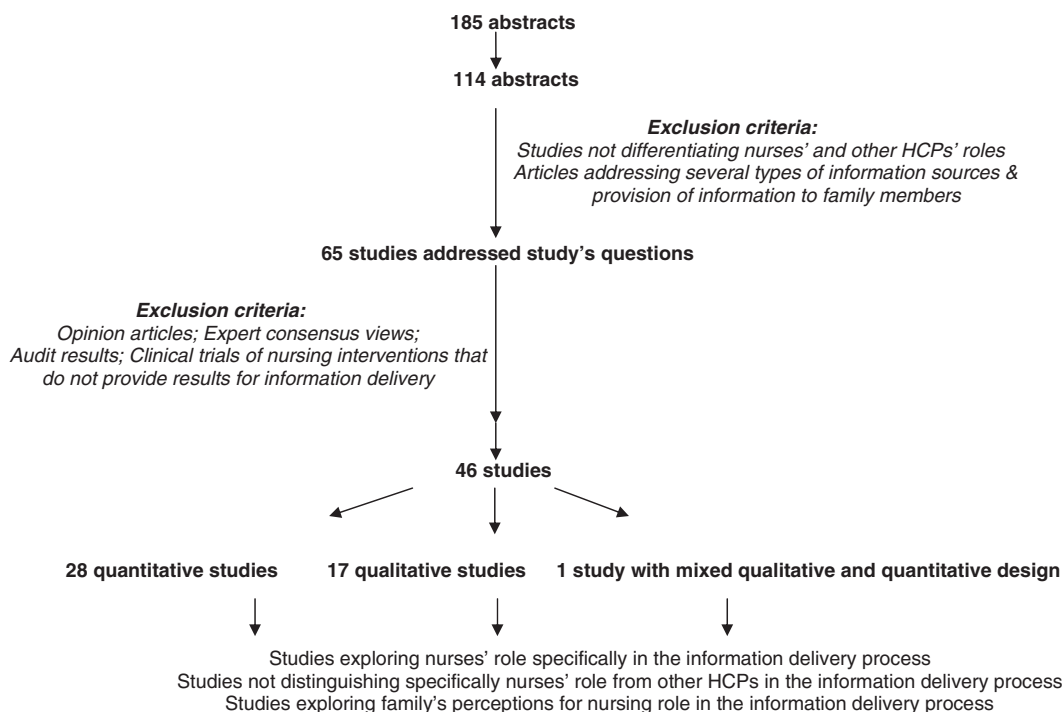


Figure 1 Retrieval and selection process of studies.

survey-type questionnaires were most commonly used which may have limited the validity of inferences. Nonetheless, since the aim of the review was to critically appraise nurses' input to the information delivery from the patients' perspective and since stringent quality criteria would exclude many studies, all studies which addressed the research questions and complied with the inclusion/exclusion criteria were included. Potential methodological limitations are noted, alongside with the presentation of the results.

Data synthesis

Results were categorised as those (1) addressing nurses' role specifically, (2) exploring specialist nurses' roles and (3) not distinguishing nurses' role from that of other HCPs. Throughout data synthesis, the nationality of patients was taken into consideration due to potential differences in nurses' roles in different countries.

Results

Studies exploring nurses' role specifically

Results referring to nurses in general

Hinds *et al.* (1995) interviewed a convenience sample of 83 American patients before and after a full course of radiotherapy. The most often mentioned method of information delivery, either at pre-treatment or at post-treatment, was verbal communication, especially with the physician. However, nurses were perceived as an information source more often at post-treatment. One explanation involved the treatment procedure, since all radiotherapy patients had weekly appointments with a department nurse that allowed them to ask questions. The authors presumed that nurses were in a position to provide patients with timely information, at an individual level. The other explanation was based on the particular content of information that patients needed as treatment progressed, which was increasingly related to the side effects and to family concerns. However, the above are presumptuous.

The results of an ethnographic study, carried out in Denmark, appeared to corroborate the assumption that nurses are seen as sources of information which differs from that delivered by physicians. Specifically, patients with acute myeloid leukaemia sought information primarily by asking nurses and fellow patients (Friis *et al.* 2003), whereas, they avoided to receive further medical details about their disease and prognosis as a strategy to maintain hope. Rather, they focused on information related to problems affecting everyday life. Moreover, in a qualitative content-analysis study

from China (Liu *et al.* 2006), nurses were seen as the main source of informational support and met patients' needs for knowledge.

Similarly, in a descriptive quantitative study of Thai Buddhist patients undergoing radiation therapy, high levels of satisfaction with nurse-provided information delivery were reported. The results indicated that patients wished oncology nurses to educate them before commencement of therapy, since such information assisted them to prepare mentally, to reduce their anxiety and to understand what to expect (Lundberg & Trichorb 2001). Most participants believed that nurses were good in providing explanations and that they used simple language. In line with the above, in Canada, Deane and Degner (1998) noted that women who had undergone breast biopsy wanted nurses to provide them with information mainly about the diagnosis of the breast biopsy, because they were too anxious to remember all the information they had received by their physician. These results are consistent with the findings from a Canadian qualitative (Gray *et al.* 1998) and a French study (Negrier *et al.* 2007). Sainio and Eriksson (2003), in a study involving 273 Finnish cancer patients, reported that nurses compared to physicians had provided more information to patients, using a variety of methods of oral or written information. Patients felt that nurses provided information understandably, truthfully, willingly and at a suitable amount of time.

The findings of the aforementioned studies suggest that the role of nurses in information delivery is central and that they may provide different types of information and in a different manner compared to physicians. Overall, the studies reviewed above suggest that the majority of cancer patients were able to orientate to the new situation through the information provided by nurses. In general, through specific informational support, patients adapted better to their disease and developed a stronger faith in the future (Lauri & Sainio 1998). Nonetheless, two phenomenological studies reported that the participants experienced nurses as unavailable or uninvolved in their decision-making (Lacey 2002) and that the role of nurses in providing information was not clearly discernible (Brown *et al.* 2000). The reason for this discrepancy is unclear; presumably, in-depth interviews may reveal concealed meanings, that is, not only whether information was provided or not, but also patients' perceptions of the willingness and quality of nurses' engagement in the process.

In summary, these results appear to suggest that nurses are perceived as effective and important information providers by cancer patients, especially in relation to the provision of explanations and clarifications on information previously provided by physicians. However, the lack of clarity

Table 1 Selected studies on the role of nurses in the process of information delivery to oncology patients

Authors (year)	Study design	Sample size – participants (nationality) – cancer diagnosis	Instruments used	Main findings	Content of information provided
<i>Results referring to nurses in general</i>					
Hinds <i>et al.</i> (1995)	Descriptive study as part of a large randomised clinical trial (RCT). Pre-treatment, post-treatment, pre- and post-treatment samples	83 American patients (convenience sample) – diverse cancer diagnoses	Questionnaire	Nurses were mentioned as an information source more frequently at post-treatment	Treatment issues, side-effects, discussion of family concerns
Friis <i>et al.</i> (2003)	Qualitative, ethnographic study	21 Danish patients with acute myeloid leukaemia	Semi-structured interviews	Patients sought information primarily by asking nurses and fellow patients. Information was related to problems affecting everyday life, such as supportive care, nutrition and complementary medicine	Supportive care, nutrition, complementary medicine
Liu <i>et al.</i> (2006)	Qualitative study – content analysis	20 Chinese cancer patients – diverse cancer diagnoses	Semi-structured interviews	Nurses were the main source of information support	No specific type of information mentioned
Gray <i>et al.</i> (1998)	Qualitative study – focus group methodology	Nine focus groups – 70 Canadian breast cancer patients	Semi-structured interviews	Cancer nurses were regarded to play a key role in the information delivery	Follow-up protocols, tamoxifen treatment issues, chances of recurrence, prevention strategies for daughters, treatment side-effects, health-insurance issues, lifestyle changes, unconventional therapies
Négrier <i>et al.</i> (2007)	Descriptive quantitative study	140 French patients with advanced cancer	Questionnaire on emotional satisfaction with information delivery	A second interview with the nurse increased patient satisfaction with the information from 63–95%	No specific type of information mentioned
Lundberg and Trichorb (2001)	Descriptive quantitative study	179 Thai Buddhist patients – diverse cancer diagnoses	Questionnaire on patient experiences	High level of satisfaction with nurse-provided education, including information before commencement of treatment	Treatment issues

Table 1 (Continued)

Authors (year)	Study design	Sample size – participants (nationality) – cancer diagnosis	Instruments used	Main findings	Content of information provided
Deane and Degner (1998)	Retrospective, descriptive study	70 Canadian women with possible breast cancer (quota sampling)	Interviews – questionnaire on information needs	Women who had undergone breast biopsy wanted nurses to provide them with information because they had been too anxious to remember all of what their doctor had told them	Diagnosis issues
Sainio and Eriksson (2003)	Retrospective, descriptive study	273 Finnish patients – diverse cancer diagnoses	Questionnaire	Nurses had given more information to their patients than physicians using several methods	Information on disease, treatment, side-effects of cancer or treatment, patient participation in care
Lauri and Sainio (1998)	Action research	96 Finnish breast cancer patients	Questionnaires	The majority of oncology patients had been able to orientate to the new situation, they adapted better to their disease and they showed a stronger faith in the future owing to the information provided by nursing staff	Information on disease, treatment issues, coping strategies, self-care issues
Lacey (2002)	Descriptive, phenomenologic study	12 American breast cancer patients	Audiotaped interviews (Colaizzi's method)	Nurses were unavailable or uninvolved in patients' decision-making (no informal support prior to diagnosis)	Decisional support throughout the treatment process
Brown <i>et al.</i> (2000)	Qualitative – phenomenologic study – constructive paradigm	Six Australian breast cancer patients	In-depth interviews	The role of nurses in providing information was not clearly discernible	No specific type of information mentioned
<i>Results referring to APNs/nurse specialists</i> Booth <i>et al.</i> (2005)	Survey (prospective)	70 British patients with gynaecological cancer	Semi-structured interviews – Hospital Anxiety and Depression Scale (HADS)	Clinical nurse specialists were well used as information and support sources. Patients supported and informed by a nurse specialist, experienced less psychological distress six months after the diagnosis	Current illness issues, future and treatment issues, physical symptoms, coping with daily activities

Table 1 (Continued)

Authors (year)	Study design	Sample size – participants (nationality) – cancer diagnosis	Instruments used	Main findings	Content of information provided
Mills and Davidson (2002)	Part of a wide-range attitudinal survey	341 Irish patients – diverse cancer diagnoses	Likert scale questionnaire on information sources	The source which scored the highest in terms of quality of information was the specialist/Macmillan nurses who were the preferred source of information for the majority of cancer patients	No specific type of information mentioned
Luker <i>et al.</i> (2000)	Triangulated qualitative and quantitative study	76 British breast cancer patients	Telephone interviews- Informal content analysis	Breast care cancer nurses were perceived more knowledgeable than the primary health care team	No specific type of information mentioned
Hallowell (2000)	Retrospective qualitative study	23 British women undergoing prophylactic oophorectomy	In-depth interviews	There was a need for gynaecology nurse specialist before and after surgery	Treatment issues, treatment after-effects
Raupach and Hiller (2002)	Cross-sectional survey	A cohort of 266 Australian breast cancer patients	Interviews	More extensive use of the breast care nurse during follow-up visits to specialist clinics, as this could reduce the level of unmet informational needs	Treatment issues, information on potential recurrence, risk to family members
Mills and Sullivan (2000)	Retrospective, descriptive qualitative study	10 British patients with esophageal cancer	Semi-structured interviews	Need for a nurse specialist in thoracic surgery	Treatment issues, side-effects, extent of disease, chances of cure, prognosis, return to normality
Viklund <i>et al.</i> (2006)	Retrospective, descriptive study	73 Swedish patients with upper gastrointestinal cancer	Questionnaire on satisfaction with supportive care	Non-significant trend to appraise nurse specialist provided information higher compared to physician-provided information	Decision and treatment issues
Luker <i>et al.</i> (1996)	Descriptive, quantitative study	105 British breast cancer patients	Structured interviews	Breast care nurse specialists were considered as very useful sources of information by 80% of participants	Treatment issues, side-effects, survival issues, risk to family members
Stacey <i>et al.</i> (2002)	Descriptive, quantitative study	97 Canadian patients with possible breast cancer	Self-assessment questionnaire (pre-visit) satisfaction survey (post-visit)	The informational needs were met with a high level of satisfaction (90%) by APNs	Personal risk factors, breast cancer screening, lifestyle options

Table 1 (Continued)

Authors (year)	Study design	Sample size – participants (nationality) – cancer diagnosis	Instruments used	Main findings	Content of information provided
Chapple <i>et al.</i> (2006)	Qualitative study – thematic analysis	41 British patients with terminal illness	Semi-structured interviews	Patients valued informational support delivered by nurses	No specific type of information mentioned
Halkett <i>et al.</i> (2006)	Qualitative study – thematic analysis	18 Australian women with early breast cancer	In-depth interviews	Patients valued practical information delivered by nurses	No specific type of information mentioned
Raja Gopal <i>et al.</i> (2005)	Survey	100 Malaysian women – 150 British women with breast cancer	Structured interviews – questionnaire on information needs	Although breast care nurses are not a feature of the Malaysian healthcare system, they have a vital role to play in meeting the informational and psychosocial needs of women with breast cancer in non-Western societies	Information on disease, chances of cure, self-care issues, treatment options and side-effects, risk to family members, sexual issues, impact of treatment on social activities
Wolf (2004a)	Qualitative study – Framework Analysis	8 British women who had undergone breast reconstruction	Focus group interviews	Breast care nurses played a key role in facilitating the information process	Issues pertinent to decision-making about mastectomy and reconstructive surgery
Wolf (2004b)	Qualitative study – Framework Analysis	8 British women who had undergone breast reconstruction	Focus group interviews	In addition to other types of information, breast care nurses explored patient-centred concerns, whereas surgeons offered only factual details about surgery	Breast reconstruction issues
Koinberg <i>et al.</i> (2002)	Qualitative descriptive study (phenomenography)	19 Swedish breast cancer patients	Interviews	Patients were highly satisfied with the knowledgeable and professional skills of specialist nurses	Self-care issues, patient education, breast self-examination

Table 2 Selected studies in which nurses' input to the information delivery process is not distinguished from that of other health care professionals (HCPs)

Authors (year)	Study design	Sample size – participants (nationality) – cancer diagnosis	Instruments used	Main findings	Content of information provided
Neill <i>et al.</i> (1998)	Exploratory descriptive, qualitative study	11 American breast cancer patients	Semi-structured, face-to-face interviews	Several important sources of information were mentioned, including HCPs (with the plastic surgeon and other physicians being the most important)	Treatment options, issues pertinent to the decision-making process
Meredith <i>et al.</i> (1996)	Cross-sectional survey	250 Scottish patients – diverse cancer diagnoses	Semi-structured interviews based on questionnaires	Hospital doctors were identified as the most important sources of information regarding diagnosis	Diagnosis, chances of cure, treatment options and side-effects
Silliman <i>et al.</i> (1998)	Descriptive quantitative study	302 American breast cancer patients	Review of surgical records and computer-assisted telephone interviews	Breast cancer physicians or staff were identified as the most important sources of information	No specific type of information mentioned
Chelf <i>et al.</i> (2002)	Exploratory descriptive survey	62.5 American patients – diverse cancer diagnoses	Structured interviews	Patients preferred to engage in interactive, interpersonal communication with physicians or nurses	Treatment and diagnosis issues, management of side-effects, coping strategies, nutrition
Veronesi <i>et al.</i> (1999)	Descriptive survey	13-136 European women with diverse cancer diagnoses	Focus groups interviews – questionnaire	HCPs were identified as the most important sources of information (the most important for the diagnosis was their hospital doctor)	Issues related to diagnostic tests, diagnosis, treatment, emotional and practical support, relationships and lifestyle
Kyngäs <i>et al.</i> (2001)	Qualitative content analysis	14 young Finnish patients with diverse cancer diagnoses	Interviews	Most of the subjects got enough information from the physician and nurses	Disease and treatment issues, coping strategies
Stewart <i>et al.</i> (2000)	Descriptive quantitative study	105 Canadian women with ovarian cancer	Questionnaire	Most women preferred to receive information from their physician or other HCPs	Disease, treatment and self-care issues
Hope <i>et al.</i> (2000)	Survey	282 British patients with diverse cancer diagnoses	Questionnaire	Most patients preferred to receive information from their physician or other HCPs	Disease and care issues, treatment options and side-effects, contact names and numbers of HCPs
Montrazeri <i>et al.</i> (2002)	Descriptive quantitative study	310 Iranian patients – diverse cancer diagnoses	Questionnaire	Most patients preferred to receive information from HCPs	Disease issues, treatment options and side-effects
Fridfinnsdóttir (1997)	Exploratory descriptive, qualitative study	12 Icelandic breast cancer patients	Semi-structured interviews	Participants sought detailed and honest informational support first from HCPs and they were satisfied with it	No specific type of information mentioned

Table 2 (Continued)

Authors (year)	Study design	Sample size – participants (nationality) – cancer diagnosis	Instruments used	Main findings	Content of information provided
Carlsson (2000)	Survey	142 Swedish patients – diverse cancer diagnoses	Questionnaire including 11 close-ended questions and 3 open-ended questions (analysed by content analysis)	Most patients reported that they were quite satisfied with the information provided by HCPs	No specific type of information mentioned
Leydon <i>et al.</i> (2000)	Qualitative study	17 British patients – diverse cancer diagnoses	In-depth interviews	Patients preferred to receive information which was delivered verbally by hospital staff rather than to ask for additional information themselves	Diagnosis and treatment issues
Kerr <i>et al.</i> (2003)	Prospective, observational, quantitative study	990 German breast cancer patients	Questionnaire delivered by mail	44.7% of the participants reported that they received unclear information and 38.6% wished they had more time to speak with medical staff	No specific type of information mentioned
Davison <i>et al.</i> (2004)	Survey	200 North American men with prostate cancer	Two-part survey, questionnaire	Urologists were the main source of sexual information (59%), but 3/4 of participants would like to discuss sexual concerns with other HCP either before or after treatment	Sexual issues
Skalla <i>et al.</i> (2004)	Qualitative study	65 Americans – diverse cancer diagnoses	Focus groups	Several sources of information were identified including physicians, APNs, infusion room nurses, with the most helpful source being other patients	Treatment side-effects, impact of treatment on daily living
Cox <i>et al.</i> (2006)	Descriptive quantitative study	394 British – diverse cancer diagnoses	Audit questionnaire	Patients reported receiving insufficient information by HCPs	Information on every aspect of diagnosis and treatment
Edgar <i>et al.</i> (2000)	Descriptive study as part of a large randomised clinical trial (RCT)	156 Canadian breast cancer patients	Resource use questionnaire	Nurses were the most frequently identified source of information after oncologists and more than family doctors	No specific type of information mentioned

Table 2 (Continued)

Authors (year)	Study design	Sample size – participants (nationality) – cancer diagnosis	Instruments used	Main findings	Content of information provided
Rehnberg <i>et al.</i> (2001)	Descriptive quantitative study	45 Finnish women referred for surgical biopsy in mammography screening (23 with benign and 22 with malignant lesions)	Questionnaire delivered by mail	HCPs, including doctors, nurses, social workers, peer counsellors and rehabilitation counsellors were the primary information sources, but several shortcomings were revealed in the information delivery process	No specific type of information mentioned
Gray <i>et al.</i> (2002)	Survey	731 Canadian breast cancer patients	Survey questionnaire delivered by mail	Physicians and nurses provided important supportive care to most women with breast cancer, including the provision of information	No specific type of information mentioned
Bilodeau and Degner (1996)	Cross-sectional survey	74 Canadian breast cancer patients	Questionnaire with ranking of informational resources	Nurses were the third most frequently used information source, but the second most preferred one	Stage of disease, likelihood of cure, treatment options, self-care issues, sexuality issues

regarding the types of information provided precludes more specific conclusions (Table 1).

Results referring to Advanced Nurse Practitioners (APNs)/ Specialist Nurses

The observations reported by Booth *et al.* (2005) who conducted a prospective survey of 70 British patients with gynaecological cancer are worth noticing. Those participants, who were supported and informed by a nurse specialist, reported fewer worries six months from diagnosis. Most of the participants in the study preferred clinical nurse specialists as information and support sources. The most important patients' concerns involved questions regarding the current illness, the future, treatment issues, the physical symptoms and 'being able to do things'. In a study undertaken in Ireland by Mills and Davidson (2002), with 430 cancer patients who were asked to rate 19 commonly available sources of information, Specialist/Macmillan nurses were the preferred source of information for the majority patients and they were rated the highest in terms of quality of information. However, the most frequently cited source of information was the hospital consultant, with nurses being at the fourth position as ward staff. These results are in accordance with those by Luker *et al.* (2000) who conducted a mixed methods qualitative and quantitative study. More specifically, breast care cancer nurses were perceived more knowledgeable and qualified to provide information than the primary health care team. The types of information required were not mentioned specifically.

The findings summarised below involve either clinical nurse specialists or nurse practitioners. Hallowell (2000), in a qualitative study involving 23 British women undergoing prophylactic oophorectomy, concluded that patients should have access to gynaecology nurse specialists both before and after surgery to receive information related to oophorectomy and associated after-effects. Similarly, in an Australian study, Raupach and Hiller (2002) reported that women undergoing primary treatment for breast cancer received decreasing amounts of information about treatment, recurrence and risk to family members further on from the time of diagnosis. In a UK study of 105 breast cancer patients (Luker *et al.* 1996), the breast care nurse specialist was considered as a very useful source of information by 80% of participants, being preceded only by the hospital consultant (95%). Ward and clinic nurses were identified as sources of information by 37% of participants compared to those who received information by general practitioners (25%). Further, in a British qualitative study on the experiences of patients with operable esophageal cancer, although the surgeon and other patients were identified as key sources

of information, the need for nurses specialised in thoracic surgery was emphasised (Mills & Sullivan 2000). In a retrospective descriptive study of satisfaction with supportive care in Swedish patients with upper gastrointestinal cancers, patients reported that the information given by the specialist nurse was easier to understand and that they found it easier to put questions to nurses than to physicians. Nonetheless, these differences were not statistically significant (Viklund *et al.* 2006). Likewise, in a qualitative British study (Chapple *et al.* 2006), palliative care patients valued information on practical matters provided by specialist nurses, which is in agreement with results in Australian breast cancer patients (Halkett *et al.* 2006).

Several studies emphasise the advanced knowledge and the specialised competencies of APNs in assessing and responding to the informational needs of individuals with cancer (Wolf 2004a, Raja Gopal *et al.* 2005). In a qualitative UK study, it was found that breast care nurses assessed patient-centred concerns in addition to the provision of standard information, whereas surgeons offered only factual details about surgery (Wolf 2004b). Accordingly, in a Canadian study, the informational needs of 97 women at high-risk for breast cancer were met by nurse specialists with a high level of satisfaction (Stacey *et al.* 2002). The most important information needs identified were personal risk factors, breast cancer screening and lifestyle options. Koinberg *et al.* (2002), in a phenomenographic study in Sweden, reported that breast cancer patients' satisfaction with check-up visits to a specialist nurse was high. They were very satisfied with the knowledge and skills of the specialist nurses who provided them with the suitable amount of information including self-care education and breast self-examination.

The above studies suggest that APN/specialist nurses are vital in providing information to cancer patients. They are commonly identified as primary sources of information, however, not as frequently as physicians. Based on the studies reviewed, it could be inferred that nurses may provide information of different type and content and, presumably, in a different manner than physicians and other HCPs. The specific content, quality and means of information delivery by specialist nurses were not always made explicit.

Studies not distinguishing specifically nurses' role from that of other HCPs

Based on such studies one can only infer the role of nurses since they refer to nurses in general and only in one, APNs are specifically mentioned. Some investigators referred to an 'assisting' nursing role in information delivery, usually complementary to the medical role. Others referred to the

informational role of the therapeutic team, through inclusive terms such as 'HCPs', 'hospital staff', or 'medical staff' and they did not differentiate nurses' input from that of others HCPs.

The results of an exploratory qualitative study with breast cancer reconstruction patients conducted in the USA, supported that information was sought from several sources, however, the most important sources of information were the plastic surgeon and other physicians (Neill *et al.* 1998). The type of information provided included treatment options and the decision-making process. These results were consistent with those of several recent studies, which explored information needs and information giving (Meredith *et al.* 1996, Silliman *et al.* 1998).

Chelf *et al.* (2002) studied 625 adult cancer patients in the USA and reported that patients preferred interactive, interpersonal communication with physicians or nurses. Patients desired accurate information about issues including treatment, diagnosis, side-effects management, coping strategies and nutrition. In support of these results, several studies concluded that individuals with cancer prefer mostly HCPs as information providers (Veronesi *et al.* 1999, Hope *et al.* 2000, Kyngäs *et al.* 2001, Stewart *et al.* 2000, Rehnberg *et al.* 2001, Montazeri *et al.* 2002).

Similarly, in a qualitative study exploring the nature of stressors in 12 Icelandic women during the diagnostic phase of breast cancer, participants related that they sought detailed and honest informational support first and foremost from HCPs and that they were satisfied with the information received from them (Fridfinnsdottir 1997). This finding is consistent with the results of others who reported that most of the patients are satisfied with the information provided by HCPs (Carlsson 2000, Kyngäs *et al.* 2001, Leydon *et al.* 2000, Gray *et al.* 2002). However, Kerr *et al.* (2003), in a prospective observational study with breast cancer patients in Germany, reported that the information received from physicians was perceived as unclear, incomprehensible and incomplete by patients, who wished to have more time to speak with medical staff. In line with these, in a British study, cancer patients reported that they often received insufficient information (Cox *et al.* 2006).

In a Canadian study with women completing treatment for breast cancer, nurses were pointed out as the most important information source after the oncologist and more frequently than the family doctor (Edgar *et al.* 2000). In another Canadian study (Bilodeau & Degner 1996), 74 women ranked nurses as being their third most frequent source of information, after physicians and family or friends and the most preferred information source after physicians. The investigators concluded that patient's informational needs were unmet by nurses.

Nonetheless, HCPs are not always the preferred information providers and other kinds of information resources have been reported. Several investigators reported that individuals with cancer may prefer informal sources of information such as other patients, media, friends and relatives (Griffiths & Leek 1995, Luker *et al.* 1996, Shingler *et al.* 1997, Davison *et al.* 2003). Similarly, in the USA, a qualitative study highlighted that although patients sought information from a variety of sources, one of the most common and helpful sources of information was other patients who had had similar experiences (Skalla *et al.* 2004). Such observations may raise concerns about the quality, efficacy and appropriateness of the information delivery by HCPs.

Discussion

This review attempted to delineate the degree and effectiveness of nurses' input into the provision of treatment- and disease-specific information to individuals with cancer. The most important findings were: (1) nurses' role as information providers for cancer patients is prominent, especially after the initiation of treatment, (2) specialist nurses are very effective in providing information, (3) no clear evidence exists on how nurses compare to other physicians and social workers as information providers and (4) some evidence exists that patients may prefer nurses as information providers at specific times in their treatment and especially in regards with symptom management.

The limitations of this review stem mainly from the diversity of studies synthesised regarding:

- the diversity in the categories of oncology nurses (i.e. APNs, staff nurses, specialist nurses),
- the different countries of origin, since discrepant delineations of nurses' roles may exist and
- the different settings. Studies carried out in oncology vs. general hospitals may yield discrepant results due to differences in the background, education and roles of nurses.

Additionally, studies lacked a common definition of information delivery and the specific types of information delivered and/or requested were not always clarified.

Provision of information is regarded as an essential part of patient education, which may also have an impact on patient outcomes (Veronesi *et al.* 1999) and satisfaction with care (Koinberg *et al.* 2002, Stacey *et al.* 2002). Although the information delivery by nurses has been explored in several studies, the lack of a universal definition and the vagueness regarding the specific contents and means of information delivery renders the extraction of definite conclusions difficult. Moreover, given the methodology of the studies reviewed, the effectiveness and quality of nurses' input can

only be inferred based on patients' reports. It would be desirable to be able to discern any potential effects of nurses' information delivery on the clinical outcomes and satisfaction of individual patients. Nurses provide information as part of a therapeutic plan, based on the assumption that they may enhance individuals' potential for recovery and well-being. However, this hypothesis, although highly relevant to the premises of 'therapeutic nursing' and of evidence-based practice, has not been addressed in the studies reviewed.

Most of the existing literature and almost all of the studies reported in this review originated from North American, Australian, Canadian or UK health care systems. There is limited research evidence relating to the provision of information for individuals with cancer in other countries. A possible reason is that information delivery is directly involved with truth-telling practices. Significant cultural influences on the attitudes of nurses caring for cancer patients may shape their professional values and communication/information delivery practices. For example, in Hellas and in other Mediterranean or Eastern countries, HCPs face several difficulties in their day-to-day communication with cancer patients (Vinton 2001, Mystakidou *et al.* 2004). As a consequence of cultural and role barriers, there is a lack of evidence regarding nurses' role in the information providing process. Moreover, in countries where nurses experience low professional autonomy, such as in Hellas, provision of information may not be regarded as a nursing role (Papathanassoglou *et al.* 2005). Given the medical-dominance in health-care in some countries, involvement of nurses with the information delivery process may be regarded as threatening to the power-balance of the health-care system (Patiraki 2003). Another possible explanation for the paucity of studies in countries with cultures other than the Anglo-Saxonic may be that advanced nursing roles are not fully developed in most European and Eastern countries (Kearney 2000). In Europe, educational criteria for advanced practice have not been defined. Consequently, the educational preparation of nurses working in advanced practice roles is variable, sporadic, limited and even non-existent (Richardson *et al.* 2000). For example, in Hellas it was just in 2003 that a two-year programme for a master's degree in oncology nursing and palliative care was developed by the School of Nursing of the University of Athens, whereas in the USA and throughout the UK the number of APNs providing cancer care nursing has increased progressively over the last years (Hill 2000, Murphy-Ende 2002). Moreover, language remains a major barrier for implementing research findings and for publishing nursing research conducted in non-English speaking countries (Patiraki *et al.* 2004).

However, several conclusions can be drawn from these studies. First, information was portrayed as a very

individualised part of care and, at the same time, nurses appeared to be regarded by patients as having both the opportunity and the competence to provide appropriate and individualised information. Individuals can cope better with their health problems when they are provided with information that is accurate, relevant to their situation and considered important by themselves (Harrison *et al.* 1999). Although nurses may be assumed to possess some essential skills for effective communication and successful provision of information, the particular skills involved, along with the means to teach and to develop them remain to be corroborated by specific research evidence.

As reviewed earlier, patients with cancer frequently rely on their physicians to inform them about their medical care. On the other hand, nurses are seen as a key source of information, especially by the end of treatment, presumably due to the increased contact with cancer patients and the shift of the information needs of patients towards self-care and issues of daily activities. Clearly, nurses who have the longest exposure to individuals with cancer are an obvious and easily accessible source of information. Nonetheless, there is no evidence regarding either the amount of time that nurses may spent on information-giving, or the type of patients' concerns and queries that may be addressed to nurses more frequently than to doctors. Although not concretely supported by evidence, it is presumable that, without the nursing participation, many patients would not correctly comprehend the information provided by their physicians, regarding their diagnosis, prognosis and treatment options and that this could affect their decision-making process negatively. Repetition of explicit information, given in everyday language was found essential in helping cancer patients to cope with illness and its uncertainty (Van Der Molen 1999). However, although we are inclined to presume that oncology nurses can enhance patient knowledge by translating information about the illness and its outcomes, their methods of patient assessment and the means and strategy of information giving are unclear. Based on the lack of pertinent evidence, one may conclude that probably, with the exception of specialists, the majority of nurses employ an intuitive rather than a systematic approach for the delivery of information, the content of which varies according to the specific patient needs and queries. Another important finding was that, overall, specialist nurses are perceived as being very skillful and effective in the provision of information. This is corroborated by international findings that the role of specialist breast care nurses is perceived as very important by patients throughout the trajectory of their care (Halkett *et al.* 2006). Based on such evidence, it is reasonable to promote the development of diverse specialist

cancer care nursing roles, both in Anglo-Saxon countries that may have already embraced specialist nursing roles, as well as in the rest of the world.

Relevance to clinical practice

The results of this review indicated that cancer patients have strong preferences for interpersonal sources of information, such as nurses. Therefore, nurses should be specifically educated and prepared to offer explicit, practical and timely information. Moreover, it appears important that nurses are trained in interpersonal communication skills, which will increase their ability to comprehend patient information needs, to perceive the barriers of communication and to intervene appropriately. Oncology nurses should be accessible to provide individualised information of desirable amount during their daily clinical practice to cancer patients. Additionally, nurses can assist individuals to access information using methods they feel comfortable with, such as Internet sources, books and periodicals, as they have the knowledge and skills to assess the appropriateness of such educational materials and to offer guidance. However, for nurses to realise their important educational role, nursing management support is required. In many countries, nurses may need to be empowered to extend their practice and to claim and develop patient education practices. Since provision of information to individuals with cancer is intertwined with truth-telling practices, clinicians may need to reflect on interrelated issues such as cultural directives, attitudes and patients' rights to develop appropriate and effective plans for the delivery of information.

Conclusion

Nurses are seen as a key source of information during and by the end of treatment. More research is needed to elucidate the specific contents of information delivered by nurses and the communication means and skills employed.

Implications for research

The effectiveness of oncology nurses as information providers to patients with cancer still requires study. The major and crucial role of nurses as information providers seems under-represented in the nursing literature. It could be argued that the above findings are neither representative of, nor transferable to different cultures and countries. Thus, more nursing research is needed to explore the information provision process in countries and cultures of non Anglo-Saxon origin. Future research needs to address the type of patient queries that are

addressed to nursing, the content of the information provided and the practical means and interpersonal skills employed.

It is important to address any potential effects of nurses' provision of information on cancer patients' psychological and physiological outcomes, as well as on patients' satisfaction with care and quality of life. These may be explored through either standard experimental designs or through interpretive modes of investigation.

Contributions

Study design: EIP, SK, EP; data collection and analysis: EP, SK, MK and manuscript preparation: EP, SK, EIP.

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