

Information Needs of Cancer Patients Receiving Chemotherapy in an Ambulatory-Care Setting

Karen K. Lock and Barbara Willson

Cette recherche avait pour but d'évaluer les besoins en matière d'information des cancéreux recevant des traitements de chimiothérapie et de connaître les modes de communication qu'ils privilégient dans le contexte des soins ambulatoires. Les besoins et les préférences des patients ont été mesurés à l'aide d'un questionnaire comportant 17 éléments. L'étude, de nature descriptive, porte sur un échantillon de 101 cancéreux recevant des traitements de chimiothérapie. Les besoins les plus fréquemment exprimés en matière d'information se rapportaient aux sujets suivants : effets secondaires du traitement, information sur les médicaments et stratégies d'adaptation. Certains patients ont indiqué leur préférence pour des renseignements dans leur langue maternelle. Les résultats appuient le recours à l'apprentissage en ligne dans ce contexte. Les patients ont indiqué qu'ils préféreraient les rencontres personnalisées avec les infirmières et les médecins comme mode de transmission de l'information. Pour répondre aux besoins particuliers des cancéreux, différentes modalités éducatives devraient être offertes. Les résultats de cette étude devraient servir à orienter les programmes d'éducation au sein des soins ambulatoires en oncologie.

Mots clés : Besoins en information, cancéreux, chimiothérapie, soins ambulatoires

The purpose of this study was to assess the information needs of cancer patients receiving chemotherapy and to explore their preferred styles of receiving education in an ambulatory-care setting. Patient information needs and preferences were measured using a 17-item questionnaire. This descriptive study included a sample of 101 cancer patients undergoing outpatient chemotherapy. The most commonly expressed information needs concerned: side effects of treatment, drug information, and coping strategies. Some patients expressed a preference for information in their primary language. The results support the use of online learning in this setting. Patients identified one-on-one discussion with nurses and doctors as the preferred way to receive information. In order to meet the individual needs of cancer patients, education should be provided in a variety of learning modalities. The results of this study should help to guide patient education initiatives in oncology ambulatory care.

Keywords: Information needs, cancer patients, chemotherapy, ambulatory care

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Introduction

Advances in medical science and cancer care have led to an increased use of chemotherapy in the outpatient setting. Cancer patients receiving chemotherapy require accurate and reliable information in order to adequately perform self-care and cope with the side effects of treatment. The provision of information, a major component of patient education, is therefore an essential and crucial dimension of oncology nursing practice in ambulatory care. Oncology nurses have long recognized the need for patient education in optimizing care. Quality education informs patients and empowers them to safely and effectively manage their self-care needs at home, and thus helps to avoid chemotherapy-related complications (Dodds, 1997).

In the oncology setting, patients have high information needs with regard to their diseases, treatments, and investigative procedures (Graydon et al., 1997). Research evidence suggests that doctors and nurses are the preferred source of information on the management of chemotherapy side effects and that written material is the second most desired source (Nair, Hickok, Roscoe, & Morrow, 2000). Most cancer patients welcome written material in the form of a supplementary cancer information booklet (Iconomou, Viha, Koutras, Vagenakis, & Kalofonos, 2002). The provision of accurate and relevant information to patients can lead to such outcomes as reduced emotional distress, enhanced self-care ability, and increased participation in usual activities (Graydon et al.; Poroch, 1995). Furthermore, information about the diagnosis, prognosis, and treatment can effect such positive patient outcomes as satisfaction with communication, emotional well-being, enhanced coping, and functional adjustment (Iconomou et al.).

Purpose

The purpose of this study was to assess the specific information needs of cancer patients receiving chemotherapy and to elicit their preferred ways of receiving information in an ambulatory-care setting at a large Canadian cancer hospital. There is limited clinical research evidence on the information needs of cancer patients receiving outpatient chemotherapy. Hence, the aim of this study was to contribute to nursing knowledge and to help guide oncology patient education in ambulatory care.

Methods

This descriptive study used a questionnaire and convenience sampling to explore the information needs of cancer patients receiving chemotherapy.

Setting and Sample

Princess Margaret Hospital, a member of the University Health Network, is a large, comprehensive cancer centre located in Toronto, Ontario. Over 90 patients attend the ambulatory chemotherapy clinic daily for chemotherapy, intravenous antibiotics, hormonal injections, minor procedures, and blood transfusions. This study took place in the clinic over a 2-week period in July 2002. Cancer patients scheduled for outpatient chemotherapy were approached during their routine appointments by the first author and were invited to participate in the study. Due to the limited availability of the first author, not all patients scheduled for chemotherapy were recruited for the study. The eligibility criteria for participation were: over 18 years of age; undergoing chemotherapy, regardless of the number of treatments received prior to the study; and able to understand written and spoken English, or have someone who could interpret and assist in completing the questionnaire. The final sample consisted of 101 men and women with various types of cancer. The demographic and clinical characteristics of the sample population were collected (see Table 1 for sample characteristics). The majority of participants (49.5%) were between the ages of 50 and 69 and there was no significant difference between the numbers of men ($n = 54$) and women ($n = 47$). The most common diagnoses (gastrointestinal and breast cancers) were the same as those for the entire clinic population in the previous year (McCullagh, 2001).

Measures and Procedure

The first author approached patients in the clinic waiting area and introduced herself as a staff nurse conducting a research project. The purpose of the study, as explained to all potential participants, was to explore the information needs of patients receiving chemotherapy with the goal of improving patient education within the institution. Patients were told that participation was voluntary. They were also told that all information collected would remain confidential and anonymous, and that only group data would be disclosed in the final report. In addition, they were told that they would be free to withdraw from the study at any time and that refusal to participate would not affect the care and treatment they received in the clinic. Verbal consent was obtained prior to administration of the questionnaire and contact information of the first author was provided for future inquiries. Most patients completed the questionnaire while awaiting their treatment in the waiting area. For patients who preferred to complete the questionnaire in the privacy of their own home, a self-addressed envelope was provided for them

Variable	Number of Respondents (n)	Characteristic	Number (%)
Person who completed survey	101	Patient	93 (92.1)
		Family/friend	8 (7.9)
Age	100	< 30	5 (5.0)
		30–49	21 (20.8)
		50–69	50 (49.5)
		> 70	24 (23.8)
Gender	101	Male	54 (53.5)
		Female	47 (46.5)
Education	96	Elementary school	11 (10.9)
		High school	40 (39.6)
		College/university	29 (28.7)
		Graduate	16 (15.8)
First language	97	English	59 (58.4)
		Italian	7 (6.9)
		Chinese	6 (5.9)
		Other	25 (24.8)
Computer/ Internet access	96	Yes	60 (59.4)
		No	36 (35.6)
Diagnosis (cancer)	83	Gastrointestinal	27 (26.7)
		Malignant hematology	15 (14.9)
		Breast	13 (12.9)
		Prostate	9 (8.9)
		Lung	6 (5.9)
		Gynecological	5 (4.9)
		Genitourinary	4 (4.0)
		Other	4 (4.0)
Chemotherapy experience	96	Yes	65 (64.4)
		No	31 (30.6)

to return it at the next appointment. Of the patients who were approached, 104 consented to participate and three of those did not return their questionnaires. Of those who declined to participate during the recruitment phase, most stated that they were not interested, too ill, or unable to read English.

The questionnaire consisted of 17 items, as follows: (a) eight questions exploring background information and demographics (see Table

1 for question variables); (b) five close-ended questions measuring information needs and preferences (whether any printed or online information was received before the first treatment, types of information received prior to treatment, preferred language for receiving educational resources, types of information preferred before the first chemotherapy appointment, and interest in attending an education session); (c) two open-ended questions (suggested topics for chemotherapy education and perceived information needs of new patients); (d) one rank-ordering question to determine preferred sources of information; and (e) one open-ended question for comments. On average, the participants took approximately 10 minutes to complete the questionnaire. The questionnaire was developed in collaboration with experts in nursing research and patient education at Princess Margaret Hospital and received the approval of the institution's Chemotherapy Daycare Quality Committee. To ensure readability, it was consumer tested prior to commencement of the study. Three patients were selected from the same clinic to review the questionnaire, and revisions were made based on their feedback.

Data Analysis

The first author entered all data using Microsoft Access. A data analyst was consulted to verify the accuracy of data entries and results. The quantitative analysis of all demographics and close-ended questions was based on the percentages generated by Microsoft Excel. With respect to the qualitative data collected from the open-ended questions, content analysis was performed to determine predominant themes and categories (Burns & Grove, 2001). The first author coded all major themes and verified these with the second author. The occurrences of each theme were then compiled using Excel.

Results

Eight questions explored the information needs of cancer patients receiving chemotherapy in the ambulatory clinic. The first two concerned various information needs. Over 57% of patients had received information about chemotherapy prior to their first chemotherapy session in the clinic; more than 80% were aware of how chemotherapy would be administered, the side effects associated with chemotherapy, and ways to prevent and control adverse side effects. Only 38% of patients received information about types of resources and support services available at the hospital; 30% received information regarding transportation.

Table 2 Preferred Styles of Information Among Patients Receiving Chemotherapy

Types of Information	Variables	Number of Respondents (%)
Preferred source of information (<i>n</i> = 24) (1 = most important; 6 = least important)	1. One-on-one discussions with nurses or physicians	15 (63)
	2. Printed materials	12 (50)
	3. Audiotapes/videotapes	7 (29)
	4. Internet	9 (38)
	5. CD-ROM/computer programs	6 (25)
	6. Formal education session	11 (46)
Preferred learning modalities (<i>n</i> = 63) (participants were asked to choose as many modalities as they wished)	Printed materials on chemotherapy and side effects	53 (84)
	Orientation booklet for Chemotherapy Daycare	42 (67)
	Online patient information on hospital Web site	25 (40)
	Videotape about chemotherapy	16 (25)
	Virtual tour of the clinic on hospital Web site	16 (25)
	Guided tour of the clinic	13 (21)
	Education session	13 (21)
	CD-ROM	10 (16)
Information from other Web sites	4 (6)	

As shown in Table 1, 37.6% of patients identified English as their second language. Interestingly, in the item concerning preferred language for educational resources, 71% chose English. In one open-ended question, the patients were asked to identify specific treatment-related topics they wished to know more about. For this question the response rate was 38% and three major information categories were identified: (a) side effects, (b) drug information, and (c) coping strategies. In another open-ended question, patients who had received chemotherapy previously were asked to select the main information needs of chemotherapy-naïve patients. The response rate for this question was 47% and the three major categories were: (a) side effects of chemotherapy, (b) chemotherapy procedure and administration, and (c) coping strategies. The responses to these questions demonstrate the similarities and differences in the information needs of patients with and without previous chemotherapy experience.

The last three questions explored the patients' preferred information styles, the characteristics of which are summarized in Table 2. One question used rank ordering to identify patients' preferred sources of information. The participants were asked to rank their preferences from the lowest value (1 = most important) to the highest (6 = least important). This question had a response rate of 88%; however, only 24 participants answered the question accurately. One-on-one discussions with nurses or physicians was the highest-ranked source. The second choice was printed materials, followed by audiotapes/videotapes, Internet, CD-ROMs/computer programs, and, lastly, a formal education session. Patients were then given nine suggested learning modalities and were asked to choose as many as they wished. The modalities were: (a) printed materials on chemotherapy and the management of side effects (84%); (b) an orientation booklet with information on the department, information on hospital services, and a brief introduction to other support programs at the institution (67%); (c) online patient information on the hospital Web site (40%); (d) a videotape about chemotherapy (25%); (e) a virtual tour of the clinic on the hospital Web site (25%); (f) a guided tour of the clinic (21%); (g) an education session (21%); (h) CD-ROMs in the patient library (16%); and (i) information from other Web sites (6%).

Finally, the issue of receiving information through a formal education session was addressed. Twenty-seven percent of patients ($n = 27$) indicated that they would attend an education session. This response, together with the responses to the two previous questions, indicates only moderate support for an education session in the clinic. Content analysis of the open-ended question revealed four major reasons why

the participants did not favour such a session: (a) they had already received enough information, (b) the session was best suited to new patients, (c) language barriers, and (d) problems with transportation.

Discussion

The findings of this study suggest that the education of cancer patients receiving outpatient chemotherapy must address the side effects of treatment, drug information, and coping strategies. Patients with no previous chemotherapy experience must also be given information on treatment procedure and drug administration. These results validate the findings of a study conducted by Jazieh and Brown (1999) into the education of cancer patients with regard to treatment and treatment-related side effects. The patients in the present study had, for the most part, been informed about their chemotherapy by their medical oncologists and ambulatory-care nurses. However, they could have used more information regarding support services and transportation. The survey found that patients wished to have more information, especially through one-on-one discussions with their health-care professionals. This finding supports that of Nair et al. (2000), who found doctors and nurses to be the preferred sources of information. In order to optimize patient-care outcomes, it is important for oncology nurses to continuously reinforce appropriate educational information by engaging in one-on-one discussions with patients during routine nursing care.

The language data collected indicate that some patients prefer to receive information in their primary language, implying that oncology nurses should find ways to tailor education to the different cultural and linguistic needs of patients.

In this era of information technology, the results confirm the benefits of online learning. More than half of the participants had access to a computer and many chose the hospital patient-education Web site as the preferred means of obtaining information. Hence, hospitals should consider providing quality online information that is accessible to patients.

Jazieh and Brown (1999) suggest that patient education is enhanced if the information is provided both verbally and in written form. The participants in the present study expressed a preference for one-on-one discussions with their doctors or nurses. This finding is congruent with the results of a 1998 study with patients undergoing radiation therapy at the same hospital (B. Willson, personal communication, August 9, 2002). Thus, if patient-focused care is the priority, ways must be found

to engage oncology nurses, doctors, and other health-care professionals in one-on-one discussions with patients, and to provide patients with high-quality treatment-related literature.

Although the need for an education session was not well supported in this study, oncology nurses should, in future research, explore various strategies to enhance the delivery and quality of education sessions. As indicated by the participants, such sessions might be more suitable for patients with no previous chemotherapy experience. Since most participants expressed a preference for one-on-one discussions, the education sessions could, alternatively, be transformed into small group discussions in order for patients to receive more individualized information and attention.

Nurses should offer patients different kinds of information to facilitate learning and enhance patient education. This study has identified various learning modalities for cancer patients. Nair et al. (2000) also support the use of different learning modalities in order to offer patients different perspectives on their diseases and treatments.

Limitations

The study had a number of limitations. The environment of the clinic waiting area contributed to extraneous factors influencing the study. The high volume of patients and level of noise in the clinic could affect the cognitive process of some individuals. In addition, it is unclear whether the emotional or physical state of participants could have influenced the responses (Burns & Grove, 2001).

The questionnaire was designed using expert opinion only. It had not undergone rigorous validation processes in order to establish internal consistency and reliability. The question using the rank-ordering method in exploring patients' preferred information styles was poorly completed. It is unclear whether this was because the patients had difficulty understanding the question or because the instruction was inappropriate. Also, the response rates were low for the open-ended questions as compared to the close-ended questions. Since the questionnaire consisted of 17 items, the cognitive demand might have been overwhelming for already fatigued cancer patients.

The total number of patients approached during recruitment was not documented; thus, the response rate for the survey is unavailable. This study used a convenience sample and excluded patients who could not speak and read English without an interpreter. The various stages of cancer treatment and different diagnoses of the participants

contributed to the heterogeneity of the sample. Graydon et al. (1997) note that the information needs of patients can change over the course of treatment. Therefore, the present findings may not be representative of all groups of chemotherapy patients. Furthermore, the sample was limited to one teaching hospital; hence, the results may not be generalizable to other populations of cancer patients.

Implications for Nursing Practice and Research

This study was designed to support implementation of the *Nursing Best Practice Guideline in Client Centred Care* (Registered Nurses Association of Ontario, 2002) at the authors' institution. Encouraging patients to identify their information needs and incorporating their goals and wishes into the delivery of care is consistent with the future direction of patient education initiatives at the institution. A commitment to excellence in patient care and education entails discovering and addressing the individual needs of patients. The use of the present research findings in designing patient education will serve to enhance patient outcomes in the ambulatory oncology setting. In addition, the study was undertaken with a view to stimulating an interest in nursing research among oncology nurses in the chemotherapy clinic at the institution.

Conclusions

In spite of the limitations of this study, the results indicate that cancer patients have specific preferences with regard to cancer and treatment-related information, and favour one-on-one interactions with their health-care providers. The findings provide valuable information about online learning within the cancer population. However, this area should be the focus of future research, with the goal of developing a computer-based education program for cancer patients undergoing chemotherapy.

This study offers useful information to enhance patient care and guide future initiatives in an oncology ambulatory-care setting. In addition, the findings contribute to the areas of cancer nursing and patient education.

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