

Educational Strategies for Informative and Supportive Patient Education for Oncology Patients and Their Families: a Literature Review

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Introduction

The need for patient education for oncology patients and their families is becoming prominent as health care shifts from the focus of cure to the focus of quality of life. Successful patient education for oncology patients and their families leads to enhanced patient participation in health care decision making, improved commitment to treatment, increased patient satisfaction, increased ability to cope with illness, improved quality of life in patients and their families, and decreased anxiety(Fernsler & Cannon, 1991; Fukui, 2002; Mills & Sullivan, 1998; Shuster, Steeves, Onega & Richardson, 1996).

In order for learners' understanding to occur in patient education, the education must be compatible with the learner's educational preferences(Grahn, 1996). Patients and their family caregivers will generally want to learn in accordance with their own learning styles, methods and resources. As individuals have their own preferred learning styles, such as

visual, aural or physical (Phillips, 1999), careful consideration should be given to preferred learning methods and informational resources(eg. direction from nurse, written handout). In particular, given that an information-giving process is one of the key elements of patient education(van den Borne, 1998), an in-depth review of informational preferences of patients and their families appears to be necessary as well. Meanwhile, interests or preferences are by their nature highly individual and widely diverse. Such differing informational preferences among individuals may result from a number of factors. There have been many studies that have explored factors influencing informational preferences. Understanding those influential factors may assist health educators in designing effective educational strategies tailored to individual patients. Furthermore, given that there is a "teachable moment" when an individual is ready, willing, and able to assimilate information provided(Katz, 1997; Knowles, 1980), careful attention should be

Key words : Educational needs assessment, Information need, Patient preference, Oncology patient

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paid to the assessment of individuals' readiness to learn.

This study reviews studies that explore information needs, including informational preferences, factors influencing informational preferences, and individuals' readiness to learn, in the context of oncology care including hematological malignancy care. The purpose of the study is to provide a foundation for educational strategies consistent with oncology and hematocology patients and their families. This review includes 2 Korean studies and 20 foreign studies located through a search of computerized databases, such as Medline, Pub-Med, and KoreaMed, from 1990 to 2002 (Table 1). Searching terms include information, information need, informational preferences, learning need, cancer patient, and oncology patient.

Informational Preferences of Patients and Their Families

As stated previously, individual patients and their family members prefer a number of learning styles or methods, such as verbal, written, or audiovisual techniques, to receive information about the illness and its treatment (Phillips, 1999). Studies that have examined patients' and their families' preferred methods to receive information, though some studies appear problematic in sampling subjects, provide a wide range of choices of educational strategies for an effective educational program. For example, Hinds, Streater, & Mood(1995) interviewed 83 patients with cancer to identify their preferred methods to receive information about radiotherapy. Most patients reported two or three approaches as their preferred methods. The most frequently mentioned method was verbal communication with physicians, followed by written communication and audiovisual techniques. Least frequently

mentioned methods were verbal communication with nurses, with radiotherapy technicians and with other patients. However, considering that the participants in this study were sampled from those who had refused to participate in another large randomized clinical trial, they might have had some passive or negative attitudes to clinical trials or their treatments, which may have influenced the results of this study. A similar study was carried out by Chelf et al.(2002) who examined the learning preferences of patients with cancer. This study had a relatively large sample size(n=625). However, there appears to be sampling bias, since more than half of the patients were over sixty years of age, and the participants were recruited from a specific cancer centre. A variety of learning methods preferred by patients were also found in this study. The most preferred method for learning was personal communication with physicians(66%), followed by discussion with nurses(34%), written materials provided by physicians and nurses(33%). Other preferred methods were self-selecting written materials(20%), talking with other patients with cancer(14%), classes or support groups(6%), written materials from library(9%), and web-based learning(7%).

Cancer patients' overwhelming preferences for verbal communication, especially with healthcare professionals, are confirmed by other studies(Biley, Robbe, & Laugharne, 2000; Nair, Hickok, Roscoe, & Morrow, 2000). Nair et al.(2000) examined 112 patients with cancer in America to identify the sources of information the patients had used frequently to obtain knowledge about the side effects of chemotherapy. The majority of patients reported that they had used more than one method to seek information. Most patients(> 90%) had accessed their doctors and nurses to learn about chemotherapy induced side effects.

〈Table 1〉 Studies exploring information needs

Author(s) (year)	sample and setting	research design
Hileman et al. (1992)	492 home caregivers of patients with cancer	Longitudinal Descriptive correlational study
Hinds et al. (1995)	83 patients with cancer before or after radiotherapy	Descriptive study
Luker et al. (1996)	105 women with breast cancer at the time of diagnosis and a mena of 21months from diagnosis	Longitudinal Descriptive correlational study
Meredith et al. (1996)	250 cancer patients hospitalised in a regional cancer centre and two university hospitals in west Scotland	Cross-sectional Descriptive correlational study
Stetz et al. (1996)	19 adult family caregivers of patients after BMT in marrow transplant units	Descriptive Cross-sectional qualitative design
Galloway et al. (1997)	114 women with a recent diagnosis of breast cancer in the first treatment phase of chemotherapy, radiation therapy or surgery	Descriptive correlational study
Choi (1999)	90 patients who were admitted to undergo BMT at three university hospitals in Korea	Cross-sectional Descriptive correlational study
Mills and Sullivan (1999)	The literature from MEDLINE and CINAHL regarding information-giving for patients newly diagnosed with cancer from 1990 to 1998	Literature review
Mossman et al. (1999)	Data from a hotline service in Cancer BACUP, a national cancer information service in the U.K. (during April 1997 to March 1998)	Retrospective descriptive study
Tarzian et al. (1999)	20 patients after autologous BMT	Phenomenologic study
Biley et al. (2000)	160 patients with cancer from a cancer hospital in the U.K	Descriptive study
Hughes et al. (2000)	148 patient notes of elderly post surgical patients with cancer, including prostate, breast, gastrointestinal, lung, or head and neck cancer, during 4 weeks of home care	Retrospective descriptive Content analysis study
Leydon et al. (2000)	17 patients with cancer diagnosed within previous 6months	Descriptive Cross-sectional qualitative design
McCaughan & Thompson (2000)	40 patients undergoing chemotherapy at a day-case unit	Cross-sectional descriptive study
Nair et al. (2000)	112 patients with cancer in America	Descriptive study
van der Molen, B. (2000)	6 adults with cancer after primary treatment for breast cancer, a brain tumour, prostate cancer, colon cancer or bladder cancer	Descriptive Cross-sectional qualitative design
Wilkes et al. (2000)	19 family members of oncology patients in palliative care	Descriptive Cross-sectional qualitative design
Chelf et al. (2001)	176 articles related to cancer patient education	Literature review
Leadbeater (2001)	10 patients with cancer at the time of diagnosis	Descriptive Cross-sectional qualitative design
Chelf et al. (2002)	625 adult outpatients with cancer in a national cancer center	Descriptive survey research
Fukui (2002)	66 family caregivers of newly diagnosed patients with cancer in two general hospitals in Japan	Cross-sectional Descriptive correlational study
Kim & Hur (2002)	73 cancer patients in Korea, who were hospitalised in general hospitals or who visited outpatient clinics	Cross-sectional Descriptive correlational study

Over half of the patients also obtained information from verbal communication with their friends and relatives. Another similar study by Biley et al.(2000) examined 160 patients with cancer from a cancer hospital in the U.K. Almost half of the patients reported that their commonest method to receive information was word of mouth(42%), followed by leaflets(34%), television(34%), newspapers (29%), magazines(24%), and books(21%). Although the patients expressed a strong preference for verbal communication to receive information, they did not clarify exact sources of verbal information.

One qualitative study that looked into the informational preferences of family members of oncology patients was found(Wilkes, White & O'Riordan, 2000). Wilkes et al.(2000) examined the support needs of family members of oncology patients in palliative care, using audio-taped interviews. Nineteen family members from 17 families in rural areas in Australia were sampled. The interviews with those family members revealed that they had used a variety of methods to obtain information. Sources of information the family members cited included their general practitioner(GP), palliative care nurses, written materials, other health professionals such as social workers or pharmacists, and the Internet. Among those informational sources, although GPs were the most preferred source of information, palliative care nurses were perceived as the primary informational source available at any time. In this study, nurses were considered as an informational source used as frequently as doctors. However, given that the subjects were sampled in rural areas, the availability of GPs or nurses in the rural areas may have influenced the result of this study.

In addition to information from communication with healthcare professionals, patients often prefer information from other patients who have had similar experiences of illness or treatment. In-depth interviews with 20 patients with hematological malignancies who underwent autologous Bone Marrow Transplantation(BMT) in America revealed that they were not only informed but also reassured by talking with the survivors of autologous BMT(Tarzian, Iwata & Cohen, 1999). The patients reported that they felt hopeful and less fearful when they were talking with autologous BMT survivors. A similar pattern has also been found among the family caregivers of BMT patients. Stetz, McDonald & Compton(1996) found that family caregivers of BMT patients in America highly valued additional information from support groups and communication with someone who had previously been through the experience. Likewise, in a U.K. study by McCaughan and Thompson(2000), patients receiving chemotherapy for cancer sought additional information from other patients with cancer. Although the majority of the patients(92.5%) had been informed by their doctors, over half of the patients(57.5%) sought additional information, predominantly from other patients with cancer.

However, it appears that gaining information from other patients with similar experiences of illness is not always a preferable method to receive information. Smeardon(2001), evaluated a psychoeducational group program for patients with breast cancer in the U.K., and argued that without considerable efforts of group facilitators, patients participating in a group education could be distressed by the presence of other patients with unresponsive or incurable disease. Furthermore, it appears that unless information other patients or families have is positive, patients and their families

are unlikely to seek information from those patients or families. From interviews with ten newly diagnosed patients with cancer in the U.K., Leadbeater(2001) found that although all patients wanted to give a positive perspective of their treatment to other patients, nine patients did not want to attend a self-help group for obtaining information. According to Tarzian et al.(1999), patients seem to want information from other patients due in part to a need for emotional support as well as a need for information. Therefore, it should be noted that information from other patients, particularly patients with life-threatening illness, could distress other vulnerable patients and their families.

Among patients' and their families' preferred informational sources, although only a small number of patients and their families have endorsed the Internet as their preferred informational source(Biley et al., 2000; Chelf et al., 2002; McCaughan & Thompson, 2000; Mossman, Boudioni & Slevin, 1999), there appears to be a potential for growth in utilizing this medium. It is interesting to note that in spite of abundant available information in the Internet, web-based learning has been found to be a less favoured method of gaining information than from conventional sources. Some of the possible reasons for this may be due to a learning style inconsistent with independent visual learning or due to limited access to computers or the Internet. For example, a recent U.K. study that examined cancer patients' informational preferences revealed that of the 160 participants in the study, only 32% of them had access to a computer and 14% had access to the Internet (Biley et al., 2000). However, another finding of the study indicated that limited access to a computer or the Internet alone did not cause patients' low preferences for web-based

learning. One interpretation of these data is that since the majority of the participants (88%) were over 40 years of age, despite having access to a computer and the Internet, they may still be unfamiliar with using computers and the Internet as informational sources or learning tools. Nevertheless, Chelf et al.(2001), who reviewed 176 articles related to cancer patient education, found evidence of the positive outcomes of computer-assisted learning for patients, such as increased knowledge, and improved physical outcomes and self-management of illness. Computer-assisted learning or the Internet as an informational source is a potentially valuable source of information, which may grow in importance with developing rates of computer accessibility and skills among patients.

In summary, patients and their families use a variety of methods to seek information, such as verbal communication with healthcare professionals or other patients, written materials, audiovisual techniques, and web-based learning. Among those methods, one-on-one personal communication with healthcare professionals is the most preferred way to access information. In particular, discussion with physicians is considered as the primary source of information, whereas communication with nurses and written materials are also perceived as helpful additional informational resources. Considering the evidence in the literature review, that patients' and their families' most preferred way to receive information is verbal communication with physicians, staff training such as in-service training programs to teach healthcare professionals, including physicians, communication skills must be taken into consideration. Furthermore, through talking with other patients who have been through similar illness experiences, patients and their

families often get emotional as well as informational support. This finding implies the need for healthcare professionals' careful attention on those patients' and families' emotional state when they gain information from other patients with similar illness experiences.

Factors Influencing Informational Needs and Preferences

A review of the literature indicates that informational needs and preferences of patients and their families vary considerably according

to a number of factors. Through a comprehensive literature review, Mills and Sullivan(1999) examined possible factors influencing informational needs of cancer patients, and found that there remained some disagreement among study findings. The current literature review found similar scarce and contradictory results<Table 2>. The table presents a review of literature conducted by the writer against selected criteria. Mills and Sullivan(1999) identified age, gender, education, time since diagnosis, type of cancer, treatment, and stage of disease as possible influential factors on amount of information,

<Table 2> Possible influencing factors on educational needs and preferences: The supporting and opposing literature

Possible influential factors	Amount of information		Kinds of information		Preferred learning methods	
	Significant relationship found	No significant relationship found	Significant relationship found	No significant relationship found	Significant relationship found	No significant relationship found
Age	Fukui (2002) Galloway et al. (1997) Kim & Hur (2002) Meredith et al. (1996)	Choi (1999) Hileman et al. (1992)		Luker et al. (1996)	Chelf et al. (2002)	
Gender	Fukui (2002) Meredith et al. (1996)	Choi (1999) Kim & Hur (2002)	Fukui (2002)		Chelf et al. (2002)	
Education	Fukui (2002) Kim (1998)	Choi (1999) Galloway et al. (1997) Kim & Hur (2002)	Fukui (2002)	Luker et al. (1996)	Chelf et al. (2002)	
Socio-economic status	Meredith et al. (1996) Hileman et al. (1992)	Choi (1999) Galloway et al. (1997) Kim & Hur (2002)		Luker et al. (1996)		
Site of cancer		Choi (1999) Fukui (2002)	Kim & Hur (2002)	Hughes et al. (2000)		
Time since diagnosis			Luker et al. (1996)	Kim & Hur (2002)	Luker et al. (1996)	
Type of treatment	Fukui (2002) Meredith et al. (1996)	Choi (1999)	Fukui (2002) Meredith et al. (1996)			
Employment status	Choi (1999)	Fukui (2002)		Fukui (2002)		

kinds of information, and kinds of preferred learning methods cancer patients and their families had. However, Knowles(1980) contends, in adult education, educational interest that can be defined as the expressed preference varies greatly according to socioeconomic level. Therefore, the analysis presented in this study has added socio-economic status and employment status to Mills' and Sullivan's indicators.

There is, unfortunately, no agreement in the literature on factors influencing informational needs and preferences of patients and their families. However, this may support diversity of informational needs and preferences of patients and their families. The above analysis implies that the amount and kinds of information patients and their families want are variable and very individual, and thus cannot be assumed based on those influential factors. In addition, more studies are certainly required to identify or confirm factors influencing preferred learning methods of patients and their families. Only two studies found that age, gender, education (Chelf et al., 2002), and time since diagnosis (Luker, Beaver, Leinster, & Owens, 1996) are related to patients' preferred learning methods. Moreover, several studies appear to be problematic with respect to generalization due to flaws in research methodology or sampling from a highly specific population. For example, in analysing kinds of patients' informational needs according to the time since diagnosis, a cross-sectional study may have not correctly reflected patients' phase-specific informational needs(Kim & Hur, 2002). Also, indirect examination of patients' informational needs through patient notes may have had the possibility of contamination of other variables, such as nurses' perspectives(Hughes, Hodgson, Muller, Robinson, & McCorkle, 2000), and too

specific subjects of research, such as research on patients with breast cancer, may not have represented patients in the context of cancer (Galloway et al., 1997; Luker et al., 1996). In spite of such limitations of those studies, if any one conclusion is to be drawn, it is that patient education need not necessarily to be designed based on those influential factors. Rather, as Mills and Sullivan(1999) concluded, healthcare professionals' individual approach to informational needs and preferences of patients and their families is desirable.

In short, such inconsistent results among the studies reviewed confirm that patients' and their families' informational needs and preferences vary considerably. Healthcare professionals will be challenged in designing an educational program which considers amount of information, kinds of information, and preferred learning methods according to those possible influential factors analysed in this study. Rather than designing patient education specific to those unconfirmed influential factors, it can be suggested that when providing patient education, healthcare professionals individually approach patients and their families, but need to have some knowledge of general issues of those possible influential factors. Also, insufficient sound research on those possible influential factors calls for more rigorous research.

Educational Readiness of Patients and Their Families

Educational readiness, that is, preparation to learn is characterized as learners' interest, motivation, and physiologic maturity(Lee, 1998). Adult learners' readiness to learn develops with life's tasks and problems (Knowles, 1980). In the context of oncology care, patients' educational readiness emerges

from the patients' illness experiences(van der Molen, 2000). Van der Molen(2000) describes educational readiness of cancer patients as the stage of their cancer experiences at which individual patients accept that they are living with cancer. By exploring the lived experiences reported by six cancer patients, van der Molen found that patients with cancer are unlikely to process information effectively unless they reach this acceptance. Furthermore, it was revealed that the stage of this acceptance in the patients' cancer experiences considerably varied among individuals. Fredette(1990) believes that understanding the progression of cancer patients' psychosocial adjustment provides an opportunity to ensure those patients' educational motivation, and ultimately educational readiness. Fredette identifies cancer patients' six adaptation stages, from the time of diagnosis of cancer to the stage of dying, according to cancer patients' psychosocial adjustment to their cancer experiences. Based on this idea, the author suggests an educational model that considers patients' educational readiness. Educational approaches that consider patients' psychosocial responses or adaptation to illness will assist in providing patient education consistent with individual patients' educational readiness.

When examining patients' educational readiness, the assessment of their desire for information may allow healthcare professionals to gauge patients' readiness to learn. In general, patients and their families have a great desire for information, and often want as much information as possible(Choi, 1999; Meredith et al., 1996; Stetz et al., 1996). Meredith et al.(1996) examined information needs of 250 patients diagnosed cancer within the previous nine weeks, and found that 79% of patients wanted information as much as

possible. Similarly, from interviews with family caregivers of BMT patients, Stetz et al.(1996) discovered that patients and their families spent considerable effort seeking information and even evaluating the validity of the information. High desire for information was also seen in patients with hematological malignancies who underwent BMT. Choi(1999) found that the total mean score of those patients' overall learning needs was 3.11 out of 4.0, indicating that their learning needs were relatively high. Assessment of how much patients and their families desire information provides useful information to develop patient education fitted to their educational readiness.

However, when the above results are applied to practice, there must be careful consideration of patients' individuality. In research on the perspectives of information needs of 20 patients who underwent autologous BMT, Tarzian et al.(1999) ascertained that the range of information needs of BMT patients varied from minimal to comprehensive. The researchers interviewed ten patients before a clinical pathway that included a teaching protocol for autologous BMT, and ten patients after the implementation of the clinical pathway. Whilst several prepathway patients showed a high desire for information, some postpathway patients appeared to fear knowing details about autologous BMT. Such information-avoiding behaviors were often seen in patients with cancer as well. Researchers who explored information needs of patients with cancer(Leydon, Boulton, Moynihan, & Jones, 2000; Mills & Sullivan, 1999) found that patients avoided detailed specific information on their own illness until they were able to absorb basic general information on cancer. This result may indicate that patients' readiness to learn or to absorb information requires an individual ongoing

assessment, and information giving inconsistent with patients' educational readiness creates patients' psychological distress.

It is interesting to note why some patients do not seek further information after receiving general information. In a qualitative study, from interviews with 17 patients with cancer in outpatient oncology clinics, Leydon et al. (2000) uncovered the main reasons for patients' limited desire for information. Patients believed that because doctors would do their best, patients did not need further information: medical knowledge was difficult to understand; and because being a good patient meant doing as doctors said, information seeking might be perceived as a behavior beyond patients' compliant roles. Also, because of contradictory and negative information, information seeking was considered to be threatening and fearful. Consequently, to maintain their hope, patients did not want further information. They also thought that occupying too much of their doctors' time to ask further information could reduce the time for others. This study implies that healthcare professionals must consider patients' concealed intentions behind their poor educational readiness.

In general, educational readiness of patients and their families appears to be closely associated with their psychosocial adaptation to illness experiences. Although many patients and their families in the context of oncology and hematoncolgy care are highly motivated to gain health information related to the patients, information inconsistent with their educational readiness causes psychological distress. Therefore, to ensure the provision of information congruent with the educational readiness of individual patients and their families, ongoing assessment of their

psychological adaptation to illness and psychological response to the information provided will be required. Furthermore, since educational readiness can be covered by individuals' personal belief or psychological state, or environmental variables, the process of assessing educational readiness should include consideration for those influential variables in educational readiness.

Conclusion

Through a comprehensive review of the literature, informational preferences and educational readiness of patients and their families, and associated factors have been examined in the contexts of oncology and hematoncolgy care. It appeared that patients and their families preferred receiving information from a variety of learning methods, particularly verbal communication with physicians. This finding gives rise to the need for diverse teaching methods and physicians' participation in patient education. Moreover, considering that when patients and their families got information, their emotions could be negatively as well as positively influenced by the information provided, their emotional states should be carefully and constantly assessed. Furthermore, there remained a number of assumptions regarding influential factors in patients' and their families' informational needs and preferences. Accordingly, designing patient education based on those related factors appears to be unwarranted. Rather, it is suggested that healthcare professionals need to individually approach patients and their families. Also, since patients' and their families' educational readiness is influenced by their psychological adjustment to illness, ongoing assessment of their psychological adjustment and responses to illness is required to provide patient

education consistent with their educational readiness.

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- 국문초록 -

암환자 및 가족의 교육 선호 문헌고찰

윤 수 진¹⁾

1) 제주한라대학 간호과 전임강사

목적: 종양환자 및 가족을 위한 환자교육의 필요성은 건강 돌봄의 중심이 완치의 개념에서 삶의 질 개념으로 바뀌어 감에 따라 더욱 대두되고 있다. 이들을 위한 환자교육이 성공적으로 이루어지기 위해서는 환자와 가족들의 교육선호 양상과 일치하는 교육적 전략이 필요하다. 본 연구는 종양환자와 가족들의 교육선호와 일치하는 효과적인 교육적 전략의 기초를 제공하기 위해 시도되었다. **방법:** 본 문헌고찰은 컴퓨터 데이터베이스

주요용어 : 정보요구, 정보 선호도, 암환자

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에 수록된 1990년에서 2002년에 출간된 선행연구 결과를 토대로 분석하였다. 결과: 종양환자와 그 가족은 의료전문인과의 대화, 책자, 시청각 및 인터넷 매체 등의 다양한 방법을 통해 정보를 구하였으며, 이러한 교육 요구 및 선호 양상은 다양한 요인에 따라 매우 개별적이었다. 또한 이들의 교육 준비상태는 질병 경험의

정신·사회적 수용 상태와 밀접하게 연관되어 있었다. 결론: 다양한 교육 방법을 활용한 개별적 접근이 종양환자와 가족을 위한 환자교육에 적절할 것이며, 이들의 교육 준비상태와 일치하는 환자교육을 제공하기 위해 질병에 대한 정신적 적응과 수용상태를 지속적으로 사정하는 것이 필요하다.