

RESEARCH ARTICLE

Prioritizing the Preferences of Iranian Cancer Patients Regarding Acquisition of Health Information: Strategy for Patient Education

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Abstract

Recognizing cancer patients' preferences to obtain health information can help improve and reform the methods of communicating and providing proper services and consequently lead to effective patient education. The present cross-sectional study to prioritize the preferences of cancer patients regarding the acquisition of health information was conducted on cancer patients referred to hospitals affiliated to Semnan University of Medical Sciences in 2015. An anonymous self-administered questionnaire was developed. In the field of side effects of medications, 50 (46.7%) reported knowing about weight change, in the area of achieving relative health, 62 (57.9%) announced awareness about diet, and 45 (42.1%) reported physical complications as a first regarding information needs. In the area of obtaining information, 50 (46.7%) tended to take their information through means outside of the hospital setting. These results can help with design of clinical information systems, as they inform the most relevant and useful coverage designed for cancer patients. Providing useful information through healthcare providers, the media and clinical information systems can act as a major source of social support for cancer patients.

Keywords: Preferences - cancer patients - education - health information - Iran

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Introduction

Need is an innate feeling that comes in different shapes and degrees depending on individual characteristics. While some needs are common among people, the living environment and society tend to significantly affect the satisfaction of human needs. Taylor defines the need for information as an attempt to express a need and to find information for satisfying that need (Kahouei et al, 2014; Yeo 2016). Having information is similar to advising with someone for making a decision and can in turn abate fear and uncertainty (King et al., 2015; Mehdi et al., 2011).

Quality health information is essential for the greater participation of patients in their health care. Patients need timely, relevant, reliable and easily comprehensible general information. Such health information is an essential part of any strategy for the promotion of self-care, the power to choose, joint decision-making, chronic disease management and health literacy (Mahboobe et al., 2012; Mandl and Kohane 2016). Having information about the patients and their needs plays a major role in making decisions about their treatment process (Matsuyama et al., 2013; Kahouei et al., 2015).

Since the majority of cancer patients require a series of information about their personal needs and conditions, assessing their amount of perceived information is vital (Posma et al., 2009). Although the general public is less inclined nowadays to use the word "cancer", many of these patients actively seek to increase their information at different stages of their disease (Douma et al., 2012). After learning about the stages of their treatment and the side-effects of their medications, patients develop a need for information about rehabilitation (Bahous and Shadmi 2016). Considering the effect of surgery on health and quality of life in cancer patients, the postoperative information needs of these patients should be adequately addressed (Playdon et al., 2016). Physicians, nurses and other health care professionals are considered crucial sources of information for patients. During the course of diagnosis and treatment, patients tend to rely on newspapers, magazines and their physicians to satisfy some of their emerging information needs (Mozhgan et al., 2012; Bahous and Shadmi 2016).

Henselmans et al. (2012) conducted a study in the Netherlands to investigate the postoperative information needs of patients with esophageal cancer. They

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interviewed 20 patients and found that it is the physicians' responsibility to cooperate with their patients to satisfy their postoperative information needs and that patients require counseling after surgery. Posma et al. (2009) examined the relationship between age and information needs in patients through conducting five group interviews with 38 patients and concluded that older people have greater problems with processing and remembering information compared to younger individuals. They also found that, to help these patients, an educational setting should be developed that provides brief information on the topic and then repeats the bullet points of that information to the patients.

Assessing the information needs and expectations of cancer patients helps provide relevant information to them according to their own understanding, needs and wishes with the application of skills that help reduce the emotional impact of the disease on them and avoid subsequent isolation. Moreover, it helps develop a strategy for providing informational support to patients (Schmidt et al., 2016).

Studies conducted on the subject of informational support in Iran have failed to carry out a comprehensive examination of the information needs of cancer patients or understand these patients' priorities in the receiving of information and have not identified the patients' preferences regarding the form in which, the person from whom and the time when they receive this information. Providing cancer patients with the information they need has many benefits, including increased patient participation in decision-making, greater satisfaction with the selected treatment, improved ability to cope over the course of diagnosis, treatment and post-treatment, reduced anxiety and mood disorders, improved interaction with family members, better adjustment, realistic expectations, promotion of self-care and a sense of security (Kiesler and Auerbach, 2006). Recognizing health information needs can thus help improve and reform the methods of communicating information and providing proper services and consequently lead to effective patient education. The present study was therefore conducted to prioritize the preferences of cancer patients regarding the acquisition of health information.

Materials and Methods

Sample and setting

The study was a cross-sectional study which was conducted on cancer patients who referred to hospitals affiliated to Semnan University of medical sciences in 2015. Sample size was calculated based on similar studies (Matsuyama et al., 2013; , Playdon et al., 2016; , Henselmans et al., 2012) by using the Cochran formula. A total of 130 patients referred to the hospital during the six-month period of the study (from May to October 2015). Taking into account the confidence interval of 95% and using the formula for calculating the sample size, 97 subjects were recruited and finally 107 patients were enrolled in the study. Sampling was carried out using convenience sampling method. In this study, based on the inclusion criterion, we only recruited patients who

had been hospitalized for cancer in oncology department and their disease have been diagnosed at least 3 months.

Measures

The questionnaire used in this study was developed by the authors, after reviewing patients' seeking behavior literature. It was divided into three sections. The first section focused on demographic information (age, sex, education, kind of cancer, kind of therapeutic procedure, marriage status, income, disease duration, and treatment duration). The second section comprised a scale to measure the information needs about physical, psychological and drug side effects, a variety of therapeutic approaches and achieving the relative health. In this section, the subjects were asked to prioritize their expectations to obtain this information using the numbers 1 to 3. The third section measured the patients' preferences how to obtain this information inside or outside of the hospital.

The primary questionnaire was reviewed for content validity (through the content validity index (CVI)), and evaluated by 10 experts, who offered feedback in relation to the simplicity and clarity of questions, and the relationship between questions. The experts evaluated each question on a 4-point scale (1=low score; 4=high score), and the ratio of their response scores (3 and 4 to the total of 10 responses) were obtained. Items with

Table 1. Cancer Patient Demographic Characteristics

| Characteristics | Groups | N | % |
|---------------------------|--------------------------|-----|------|
| Age (Year) | 30< | 5 | 4.7 |
| | 30-50 | 24 | 22.4 |
| | 50-70 | 53 | 49.5 |
| Sex | >70 | 25 | 23.4 |
| | Male | 45 | 42.1 |
| Marital status | Female | 62 | 57.9 |
| | Single | 6 | 5.6 |
| | Marriage | 101 | 94.4 |
| Job | Employee | 7 | 6.5 |
| | Teacher | 5 | 4.7 |
| | Housewives | 53 | 49.5 |
| | Other | 42 | 39.3 |
| Education | Illiterate | 82 | 76.6 |
| | Diploma | 20 | 18.7 |
| | Bachelor degree | 4 | 3.8 |
| Income (million Rials) | Master degree | 1 | 0.9 |
| | <5 | 21 | 19.6 |
| Cancer region | 10-May | 78 | 72.9 |
| | 15-Oct | 8 | 7.5 |
| | Digestive system | 36 | 33.6 |
| | Genital system | 5 | 4.7 |
| | Urinary system | 5 | 4.7 |
| Treatment | Respiratory system | 8 | 7.5 |
| | Neural system | 2 | 1.8 |
| | Blood circulation system | 8 | 7.5 |
| | Glands | 43 | 40.2 |
| | Chemotherapy | 31 | 29 |
| | Surgery | 12 | 11.2 |
| | and Chemotherapy | 64 | 59.8 |
| Treatment duration (Year) | Surgery | 58 | 54.3 |
| | >2 | 58 | 54.3 |
| | 4-Feb | 34 | 31.8 |
| | 6-Apr | 7 | 6.5 |
| | 8-Jun | 4 | 3.7 |
| | 8< | 4 | 3.7 |

Table 2. Priority of Information Needs of the Cancer Patients

| Information needs | Groups | First Priority N(%) | Second Priority N(%) | Third Priority N(%) |
|-------------------------------|------------------------------|---------------------|----------------------|---------------------|
| Physical complications | Pain control | 66(61.7) | 41(38.3) | 0 |
| | physical fatigue | 41(38.3) | 66(61.7) | 0 |
| Mental complications | Stress | 69(64.5) | 38(35.5) | 0 |
| | Depression | 38(35.5) | 69(64.5) | 0 |
| Drug side effects | weight change | 50(46.7) | 31(29) | 26(24.3) |
| | Appetite reduction | 40(37.4) | 54(50.5) | 13(12.1) |
| | Sleep disorder | 17(15.9) | 22(20.6) | 68(63.3) |
| Achieving the relative health | Physical activity | 45(42.1) | 62(57.9) | 0 |
| | nutrition | 62(57.9) | 45(42.1) | 0 |
| other | Healthcare providers' duties | 63(58.9) | 43(40.2) | 1(0.9) |
| | Social problems | 1(0.9) | 8(7.5) | 98(91.6) |
| | Financial problems | 42(39.3) | 57(53.3) | 8(7.5) |

scores higher than 0.80 were considered suitable; items with scores of less than 0.80 were removed or revised as recommended by the experts, and then reevaluated. Of the original 30 items, 28 were selected to form the questionnaire for this research, which was then pilot tested on 26 patients, randomly selected. Based on their responses, further revisions were made and some items rephrased. Test and retest were used to check the reliability of scores on the individual items. Correlation coefficient was 0.81.

Procedure

The final version of the questionnaire was distributed among the patients. Those who had been included in the pilot testing of the instrument were excluded from the study. Questionnaires were self-administered, completed anonymously, and returned to the researcher within 72 hours.

Data analysis

Descriptive Statistics were calculated for individual items.

Ethical consideration

Ethics approval was obtained from the Semnan University of Medical Ethics Committee. A covering letter was prepared for distribution with the survey document, which described the purposes of the study and explained that a response to the survey would indicate the consent of the participant to take part in the research. It also assured participants of the confidentiality of their responses.

Results

Demographic characteristics of the data are outlined in Table 1. 53(49.5%) of the patients were between 50 and 70 years old. 101 (94.4%) were married. 62(57.9%) were female and 53(49.5%) were housewives. 82(76.6%) were illiterate. 78(79.9%) had income between 5 and 10 million Rials. 58(54.3 %) had started their treatment less than two years. In the field of physical complications 66 (61.7%) of patients, announced knowing the pain control and 41 patients (38.3%) reported the awareness of physical fatigue as first their information needs. As well as in the field of mental complications and 69 (64.5%) reported knowing stressors and 38 (35.5 %) announced the awareness of the depression as first their information needs. In the field of

Table 3. Cancer Patient Tendencies in Use of Information Resources

| Information Resources | Groups | N | % |
|-----------------------|---------------|----|------|
| Inside of hospital | Physician | 94 | 87.9 |
| | Nurse | 12 | 11.2 |
| | Social worker | 1 | 0.9 |
| Outside of hospital | Booklet | 50 | 46.7 |
| | media | 45 | 42.1 |
| | Internet | 12 | 11.2 |

side effects of medications 50 (46.7%) reported knowing weight change, in the area of achieving the relative health 62(57.9%) announced the awareness about feeding, and 45 (42.1%) reported knowing physical activity as first their information needs. In relation to other the information needs, 42 (39.3 %) reported the knowledge of financial issues, as first their information needs (Table 2). In the area of getting information inside of hospital, 94 (87.9%) had a tendency to get information from their doctor and 50 (46.7%) tended to put their information through the manual outside of the hospital (Table 3).

Discussion

The present study was conducted to prioritize the preferences of cancer patients regarding the acquisition of health information. The results obtained showed that the majority of cancer patients prefer to first receive information about pain management. The patients also paid great attention to information about pain-relief techniques and improving their life throughout all the stages of the disease. A study by Barrett et al. (2016) showed that pain has profound effects on quality of life and that the two are inversely related, so that an increase in one decreases the other, and also found that a direct relationship exists between the intensity of pain and the patient's concerns. Providing patients with information about the physical complications of their disease, especially pain management, increases their knowledge and awareness and prepares them for coping with the pain they have to endure throughout the stages of the disease and treatment.

The results of the present study showed that, with respect to physical complications, some patients wish to receive information about physical fatigue. Providing this type of information gives these patients the opportunity to use non-medicinal techniques to relieve physical

fatigue. The results also showed that some patients prefer to acquire information about physical activities first. Conley et al. (2016) also showed that regular exercise programs are the most effective methods for relieving fatigue, and that these programs should be individually designed for each patient based on his age, physical activity level and type and stage of cancer. Acquiring this type of information may enable the patients to control their anxiety, improve their mood and cope with the complications caused by the disease. The study by Liu et al. (2016) showed that regular physical activity moderates human behavior and relieves the pain and anxiety induced by treatment processes and thus improves their physical and mental health. Proper exercise programs carried out before, after and during the treatment may help patients feel better and remain stronger throughout the course of their treatment. Teaching cancer patients different fatigue-relief techniques appears to improve their understanding of fatigue and promote the assessment and provision of medical services.

As for the psychological complications of cancer, the present study found that some cancer patients prefer to first receive information about stress disorders. Many patients develop psychological complications such as anxiety and depression when they learn that they have cancer, and these complications are exacerbated by difficult therapies such as surgery and chemotherapy. The present study revealed that one group of the patients wish to first learn about the depression that accompanies them throughout the disease. A study by Beekers et al. (2015) showed a direct relationship between the severity of the disease and the patients' anxiety and depression, as the patients' stress increased with their debility. Providing cancer patients with such information appears to abate their concerns about the adverse effects of psychological disorders on their physical performance, life expectancy and personal and social relationships. Previous studies have shown that depression exacerbates physical symptoms, dysfunction and weakness in adherence to the medical regimen and thereby leads to a dramatic and prolonged reduction in the quality of life in patients (Husson et al., 2011; Jayadevappa et al., 2012). These results further demonstrate the importance of holding psycho-therapeutic programs for this group of patients so as to help their faster recovery.

As for the side-effects of medications, the results of the present study showed that most cancer patients prefer to obtain information about weight changes first. Weight loss can lead to joint and muscle pain, bedsore, weakness in the immune system and psychological disorders (Matsuyama et al., 2013; Bahous and Shadmi, 2016; Kenzik et al., 2015). The patients might have wished to receive this information first because the loss of body fat and weight is associated with an increased risk of certain chronic diseases and disabilities, and because weight loss is directly linked to health and longevity and is a major predictor of survival in certain critical diseases and malignancies (Innominato et al., 2013). Providing information about diet-therapy or improved diets and weight control plans can lead to a relative recovery and increased longevity in these patients. The results of this study also showed that more than half of the patients prefer

to receive information about nutrition first.

The results of the present study revealed that another group of the patients wish to receive information about financial matters. Obtaining this information appears to help the patients in finding the best option for making the least substantial payment for the treatments they received during the course of their disease. Previous studies have shown that the high costs of treatment and their unaffordability for some families have led to treatment delays and increased the patients' and their families' concerns and forced them to choose the most economical instead of the most helpful treatment protocol (Langius et al., 2016; Kourlaba et al., 2015; Kimman et al., 2015). Receiving this information may therefore help the patients be better able to afford their hospital costs.

The majority of the patients interviewed inside the hospital wished to fulfill their information needs through their physician. These results suggest that some patients believe that physicians have a greater responsibility toward the patients. A study by Beaver et al. (2010) showed that physicians have a greater knowledge of the individual needs of their patients and are more concerned about the reactions and responses of their patients. Nevertheless, in the study by Protiere et al. (2012), patients wished to receive information from nurses, which is inconsistent with the results of the present study. Overall, it appears that receiving information about the disease and the means of achieving relative recovery from the medical team leads to better patient satisfaction.

The majority of the patients interviewed outside the hospital wished to fulfill their information needs through instructional booklets; receiving information in this form may be a more lasting option. These results are consistent with those obtained by Nagler et al. (2010), who found that most patients wish to receive information in the form of a booklet. In their study, the patients argued that the likelihood of forgetting some instructions and the difficulty of working with a computer increased their motivation for using booklets.

The results of the present study showed that cancer patients have different priorities in receiving information, which may suggest that people's information needs are different from one another depending on characteristics such as the progress of the treatment and the time elapsed since the diagnosis of the disease, as cancer patients with longer history of cancer and duration of treatment are likely to have already received some information, and their information needs may therefore differ from patients with shorter history of disease and duration of treatment. Moreover, each different type of cancer necessitates its special information needs. The information needs of patients currently in the process of treatment may also be different from those receiving palliative care or those achieving relative recovery (King et al., 2015; Kent et al., 2013).

The majority of the cancer patients examined in this study did not have a high school diploma, which further highlights the importance of providing effective quality information to cancer patients, especially since it makes them feel supported.

These results can help with the design of clinical

information systems, as they inform of the most relevant and useful information that can be put into information systems designed for cancer patients. Providing useful information through healthcare providers, the media and clinical information systems acts as a source of social support for cancer patients.

In conclusion, the results of the present study showed the type of information that cancer patients needed most; that is, their unfulfilled learning needs and the perceived importance of this information for them. The study also showed that patients prioritize the acquisition of different types of information for achieving better self-care, including information on physical and psychological complications, the side-effects of medications, nutrition, physical activity and financial problems, and that they wish to receive this information over the course of their treatment through the medical team and in written form. It is therefore recommended to provide any disease-related information to the patients as according to their physicians' suggestions and with their cooperation and to also reform the methods of communicating this information. The findings of the present study can help clinical professionals learn more about the information needs of cancer patients and thus seek to help promote the quality of patient education and improve self-care in cancer patients.

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