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Patients' Information Needs in Affiliated Hospitals of Tehran University of Medical Sciences

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Introduction

Information seeking theories often refer to the concept of information needs, a presumed cognitive state wherein an individual's need state triggers the search behavior characteristic of information seeking in a given context. With the growth of electronic information and the increasing availability of health information, the idea of the 'informed patient' has become prominent. On the one hand, this has resulted in concerns about associated changes in the doctor-patient relationship and health outcomes [1]; on the other, it has given rise to visions of timely, high quality, accessible, understandable, reliable, and relevant information for patients and care-providers [2] Certainly, a kind of shift is occurring in access to knowledge and, with it, access to power [3].

Over recent years, communication and information have been considered increasingly important in helping people cope with cancer [48]. Understanding what cancer patients need to know and from whom they receive information during the course of care is essential to ensuring quality care [9, 10]. However, it is also recognised that patients vary in how much information they want and that this may change during their illness. These attitudes are reflected in the efforts that patients make to obtain further information or to resist information that is offered to them [11]. It is essential to identify the information topics that are important to patients to provide information that will increase their knowledge, promote independence and persuade them to self-manage their illness. An integral part of quality health care provision is that patients are given information that addresses their needs [12].

Salient issues include information and education, coordination of care, respect for preferences, emotional support, physical comfort, involvement of family and friends, and continuity and transitions in care [13]. Many studies of people diagnosed with life-threatening illnesses reveal that the way in which they are told information and involved in decision-making are important determinants of satisfaction with care. A large American cohort study of seriously ill patients recently confirmed that these factors were also important for families [14].

Patient information is an important part of health care. It is important to evaluate fulfillment of expectations in order to achieve this [15]. The advent of Internet-based information systems has provided an opportunity for the widespread access to medical information [16].

An integral part of quality health care provision is that patients are given information that addresses their needs [17]. Changing roles in health care call for patients to share responsibility for managing their health. Patients may need additional health-related information to participate in healthcare decisions. Providers who understand and address these needs will be in a better position to engage patients' active participation in their healthcare [18]. Patient-centered information is oriented to their needs. The main objective of such information is coping with everyday life and learning to live with the chronic disease [19]. Truth-telling in medicine is a broad area and often encompasses several ethical issues. These issues include the right of patients or their families to receive information about their diagnosis and illness [20]. Any conversation between a health professional and a patient will involve the exchange of information. No longer is the clinician the sole decider of a treatment management plan [21]. Good information provision needs to be accessible, timely, reliable and accurate. Information can help patients and care givers with a variety of different needs, from information to support decision-making (clinical information), to information to help with living with cancer (supportive information) [22].

The experiences and knowledge of patients can complement those of clinicians, health professionals, and researchers [23]. With the increased availability of health information, the idea of the informed patient has become more prominent. Concerns about the associated changes in the doctor-patient relationship and health outcomes [24], contrast with visions of timely, high quality, accessible, understandable, reliable and relevant information for patients and caregivers [25]. Certainly, a shift is occurring in access to knowledge, and with it access to power [26].

There is a considerable interest amongst gastroenterology patients concerning their diagnosis and the management of their disease. The provision of simplified letters about their outpatient management does not seem to have any advantage over simply providing copies of all relevant correspondence sent to GPs[27].

Previous research has highlighted the importance of understanding users' changing information needs [28]. No sooner have users' needs been identified and supported than they change. This paper evaluates the changing information requirements of users through their information journey in two different domains (health and academia). In-depth analysis of findings from interviews, focus groups and observations of 150 users have identified three stages to this journey: information initiation, facilitation (or gathering), and interpretation. The study shows that, although digital libraries are supporting aspects of users' information facilitation, there are still requirements for them to better support users' overall information work in context. Users are poorly supported in the initiation phase, as they recognize their information needs, especially with regard to resource awareness; in this context, interactive press-alerts are discussed. Some users (especially clinicians and patients) also require support in the interpretation of information, both satisfying themselves that the information is trustworthy and understanding what it means for a particular individual [29].

Patients with low literacy are less likely to use the Internet to acquire additional medical knowledge, whether they have access or not. Unfortunately, because these individuals are more likely to have worse health, their needs for health education are greater,

especially for those with chronic illnesses [30]. This issue affects their relationship with physicians; studies have shown that patients' acceptance of diagnoses and treatment plans depends on education [31]. Hence, additional efforts are required to assist persons with lower literacy skills. With adaptive technologies supplying touchscreen input and audio output, kiosks can be made available for patients motivated to learn, independent of their literacy or education level [32, 33]. Physician offices with health information kiosks may be an alternative method for browsing health-related information, being temporally linked to clinician interactions. However, additional issues, such as cost, complexity of use, and potentiality for misinformation, then arise [34]. Still, additional research is necessary to determine the possible benefits and effects on the patient-physician relationship.

Statement of the Problem

Information is important in any activity. It is necessary for the implementation of any plan or project. The first agent of information processing is the recognition of the exact needs of information users. A survey of the information needs of patients is one of the most important tasks of information specialists and librarians.

Significance of the Study

Innovative studies identify and measure the information needs of patients and highlight priorities and preferences with regard to what information they need [35]. It is essential to identify topics that are important to patients to provide information that will improve their knowledge, promote independence, and encourage them to self-manage their illness [36].

When patients assume a greater role in acquiring knowledge, there must be a corresponding change in the physician's role as decision-maker. Surveys and observational studies are needed to elicit physicians' attitudes toward Internet health information and their corresponding patient-physician relationships. In addition, research is needed to evaluate the barriers to physicians' implementation of information technology. In Canada, researchers have administered a new survey instrument to stratify primary care physicians into different levels of information technology usage. This research tested a new instrument on 101 family physicians, and placed physicians in high, intermediate, and low information technology (IT) usage groups [37].

Objectives of the Study

The present study seeks to meet the following objectives:

- Studying the Information needs of the patients in hospitals affiliated to Tehran University of Medical Sciences
- Determining the needed information about the disease among patients in affiliated hospital of Tehran University of Medical Sciences
- Determining the needed information about the treatment process among patients in affiliated hospital of Tehran University of Medical Sciences
- Determining the required information on the treatment courses of the hospitals affiliated to Tehran University of Medical patients
- Determining the Information needs of the patients in hospitals affiliated to Tehran University of Medical Sciences
- Determining the information needs of the patients about treatment courses in affiliated hospital of Tehran University of Medical Sciences
- Determining the information needs of patients about Laboratory tests in affiliated hospital of Tehran University of Medical Sciences
- Determining the helping needs of patients in affiliated hospital of Tehran University of Medical Sciences
- Determining the needed information about the other patients' services in affiliated hospital of Tehran University of Medical Sciences

- Determining the patients' level of satisfaction with information received from affiliated hospital of Tehran University of Medical Sciences
- Determining the access method on patients' information in affiliated hospital of Tehran University of Medical Sciences

Research Questions

The survey consisted of three sets of questionnaires with covering letters explaining the project and the participant's part in it. Regarding the abovementioned points, the study seeks to answer the following questions:

1. What is the needed information about the disease among patients in affiliated Hospital of Tehran University of Medical Sciences?
2. What is the needed information about the treatment process among patients in affiliated Hospital of Tehran University of Medical Sciences?
3. What is the required information on the treatment courses of the hospitals affiliated to Tehran University of Medical patients?
4. What are the Information needs of the patients in hospitals affiliated to Tehran University of Medical Sciences?
5. What are the information needs of the patients about treatment courses in affiliated Hospital of Tehran University of Medical Sciences?
6. What are the information needs of patients about Laboratory tests in affiliated Hospital of Tehran University of Medical Sciences?
7. Are the patients in the affiliated hospital of Tehran University of Medical Sciences inclined to receive help?
8. What is the needed information about the other patients' services in affiliated Hospital of Tehran University of Medical Sciences?
9. How much are the patients' levels of satisfaction with information received from affiliated Hospital of Tehran University of Medical Sciences?
10. What are the access methods on patients' information in affiliated Hospital of Tehran University of Medical Sciences?

Background to the Study

In information behaviour research, there has been a growing recognition of the information user's context as constituting a vital frame of reference [38]. Information behaviour does not occur in a vacuum, but arises from and is conditioned by circumstances. Consequently, the context for information-seeking behaviour provides an explanatory framework for meaningful interpretation and also for generalization. It locates the role of information seeking within an unfolding personal and social history, and provides a framework for generalization by suggesting prior circumstances which may be predictive. As Vakkari, Savolainen, and Dervin have argued, context provides the necessary conditions for understanding information needs and behaviours [39].

Iconomou, et al. (2002) assessed the information needs of Greek cancer patients and examined whether awareness of diagnosis had any impact on the patients. One hundred patients were interviewed on the overall and specific information needs, satisfaction, emotional distress, and quality of life. Patients exhibited a great desire for information in general. The need to have more information was high especially regarding the aftermath of chemotherapy, prognosis, chemotherapy quality, and diagnosis. Patients were more satisfied with care but less satisfied with the information that they received. Only 37% knew they had cancer, especially the younger, the better educated, and those with breast cancer. Awareness was not related to satisfaction, emotional distress, or quality of life. Our findings suggest that Greek cancer patients need more factual information about their condition and management. Greek oncologists may feel freer to inform their patients about the diagnosis and other issues following their judgment, rather than employing the policy of concealing the truth [40].

Cassileth, Volckmar, Goodman, R.L. (1980) concluded that information giving and

seeking were explored among 160 cancer patients who were receiving or about to receive radiation therapy. Eighty-two new patients and 78 experienced patients completed a questionnaire designed to elicit their knowledge of diagnosis and radiation therapy, expectations about treatment, self-assessment of the adequacy of their knowledge, and desire for additional information. Detailed knowledge of diagnoses was reported by 92 percent. Patients were optimistic about treatment; only one person thought that radiation might not be helpful; one-third of patients who were receiving palliative therapy and 50 percent of those who were treated radically thought that radiation therapy might cure their disease. Although experience with radiation therapy increased patients' knowledge, it barely diminished the desire for information. Most experienced patients had accurate information, but many did not feel well informed. The radiation oncologist was the preferred source of further information. The desire among knowledgeable patients for more information may express patients' uncertainty and unmet needs for confirmation and support of their beliefs [41].

Herma (2001) examines the transition to the electronic information era in academia, seeks to establish, from the published literature, to what extent university researchers have accepted, and adapted to, the changes wrought in information activity by seemingly endless technological developments. Within the wider context of the impact of the changing information environment on each of the three clearly discernible components of academic research (the creation of knowledge and standards, the preservation of information, and the communication of knowledge and information to others), disciplinary-rooted differences in the conduct of research and their influence on information needs are identified, and the resulting inter and intra-individual variations in researchers' information seeking behaviour are explored. Reviewing a large number of studies investigating the integration of electronic media into academic work, an attempt is made to paint the picture of academics' progressively harnessing the new technologies to scholarly information gathering endeavors, with the expressed hope of affording some insight into the directions and basic trends characterizing the information activity of university faculty in an increasingly electronic environment [42].

Marouf and Anwar, (2010) found that respondents heavily depend on books and journals for teaching and on a larger variety of materials for research purposes. Their use of informal sources is comparatively less than formal sources. Journals and books are considered as the most important sources to meet their needs. Among the informal sources and conferences, the subject experts and colleagues are given higher importance than librarians and government officials. Journals and books are used more frequently than raw data, technical reports, and manuscripts and primary materials. Their satisfaction level with all the sources is positive but higher for journals and books. The level of satisfaction with informal sources is slightly higher than formal sources. Their library use is very low with complaints about the quality of staff, resources, especially in Arabic, and access to international resources [43].

Francis (2005) examined how 26 social science faculty use library resources. Findings revealed that participants demonstrated similar behavior patterns to their colleagues both in the developed and developing world. They strongly relied on textbooks to support their teaching and on journal literature to support their research and current awareness activities. However, findings also showed that over one-half of the social scientists expressed a preference for access to journal articles in electronic format, which are a new development and a reflection of the increase in orientation to electronic products. Further findings are presented [44].

Attfield, Adams, and Blandford (2006) presented findings from a study of information-seeking behaviour by National Health Service patients which explored motivational triggers for information needs. Previous research has highlighted the importance of contextual elements in users' changing information needs. This paper highlights how those needs may centre on specific events: in particular, a patient's consultation with their doctor. Patients initiate information seeking to assess whether they need clinical intervention, in preparation for the patient-doctor consultation and to verify the diagnosis or treatment stemming from that consultation. The study has revealed that having confidence in health practitioners is one key motivation for information seeking.

Another is a desire to use health service resources judiciously, efficiently, and effectively. [45]

Wallis (2006) found that faculty regularly sought out information to support their research, teaching, and service, though they did not tend to ask librarians for assistance. Faculty who had been at the UIC SPH ten years or more were significantly more likely (P = 0.02; chi square test) to sometimes contact a librarian (56.3%) than faculty who had been at the institution less than 10 years (20.0%). This finding demonstrated a clear shift in the self-sufficiency of library users over time. [46, 47]. Rather than developing workshops for faculty, the liaison should instead publicize contact information, as faculty members indicated they would prefer to ask for assistance as questions arise. As a relationship develops between the faculty members and the liaison librarian, opportunities for education and training can increase. These findings may help libraries identify opportunities for outreaching to public health faculty, whose needs differ from public health students and practitioners [48]

Wilson, (2006) finds that the problem seems to lie with a failure to use a definition appropriate to the level and purpose of the investigation [49]. Liao, Finn, and Lu (2007) identified the starting point of the information-seeking process for each student. This study discussed both similarities and differences of the information-seeking behaviors of the two groups [50].

Andruccioli, et al. (2009) described the results of a semi-structured interview to assess the illness-awareness of cancer patients in Hospice. The results of this study were based on the interviews made in Rimini and Savignano sul Rubicone Hospices (n = 51). Psychologists evaluated illness-awareness of the participants interviewed independently from the code system that was provided for the interview. According to the psychologists, 18 patients (35%) were aware, 11 patients (22%) were unaware, and 22 patients (43%) were aware with defense mechanisms. According to the code system of the interview, the results were as follows: 18 patients (35%) were aware, 2 patients (4%) were unaware, and 29 patients (57%) were aware with defense mechanisms. Two participants had to be reassessed because of inconsistency in some factors. In conclusion, the data analysis underlined that the congruence of the 2 assessment methods was found in 33 of the 51 patients examined (65%) and that the degree of concordance was rather low.

Methods

Sample

The study encompasses all outpatients who went for a treatment to 15 hospitals affiliated to Tehran University of Medical Sciences including (Arash Hospital, Imam Khomeini Hospital, Amir A'lam Hospital, Cancer Institute, Baharloo Hospital, Bahrami Hospital, Razi Hospital, Roozbeh Hospital, Women's Hospital, Sinai Hospital, Shariati Hospital, Ziaian Hospital, Farabi Hospital, ValiAsr Children's Medical Center and Hospital)

Method

The study was a survey and the random sampling method, a nonprobability sampling, was conducted. Data collected through the distributing researcher made questionnaires using specialized texts written in Persian and foreign language.

The survey consisted of ten sets of questionnaires with covering letters explaining the project and the participant's part in it. One set was made available to patients visiting the same-day outpatient facility or arriving for preadmission workup at the hospital. Participation was voluntary. No attempt was made to identify any patient. It was made clear in the covering letter that the survey was not connected to the patient's reason for visiting the hospital or to his or her own diagnosis. Surveys were used in the study

only if they had been completely filled out.

Results

157 (44.9 %) females and 193 (55.1 %) of males answered the forms in this research. The maximum numbers of the participants were 232 patients (66.3 %) in the age range of 21-40 years, and the minimum numbers were 15 patients (4.3%) in the age range of 61–80 years. The majority of the patients, 121persons (34.6%), were Turkish and the fewest were Arab and Mazndaranian races each of whom was about 7 (2%) persons. In educational aspect, 193 persons have diploma (55.1%), in majority, and one person (0.3%) who had the doctorate degree was in minority. The most accessible methods to seek information about disease was through physician, which was about 121 persons (34.6%), and the least possible way was through radio and TV which was about 15 persons (4.3%).
The vast majority of patients tend to have information about the disease, treatment, treatment duration, information treatment and the information about the laboratory tests. This was accepted in theoretical texts and research studies in previous researches abroad.

In order to answer the questions, we used the frequency distribution and percentage to analyze the results the questions of which can be recapped as follows:

Considering the first question "What is the needed information about the disease among patients in affiliated Hospital of Tehran University of Medical Sciences?", it can be clearly seen from the table that 248 people (70.9%) of the patients wanted to know the name of their disease but there are also some patients about 193 persons (55.1%) who were not motivated to be familiar with their diseases. 213 people (60.9%) were not willing to know the spread of their diseases and 200 people (57.1%) didn't want to find their diseases cause. 196 (56%) of the patients did not try to get the information on how to control their disease. Based on the given table, it can be stated that most of these patients don't want to acquire the least possible information about their disease. It is necessary to say that citizens need to achieve some information for avoiding the spread of disease.

Regarding the second question on "What is the needed information about the treatment process among patients in affiliated Hospital of Tehran University of Medical Sciences? ", it can be seen from the table that most of the patient during the treatment process were about 148 persons, 42.3%, who wanted the information while being treated and the minimum number of the patients during the treatment process was 39 persons, 11.1%, for those who wanted information on their previous treatment. It can be said that the majority of the people need information to prevent the disease before its occurrence.

Results on the second question showed that most of the patients were in their treatment process, but as they finished their process and felt better, they were not interested to follow their previous problem and didn't try to find any information on the reasons and causes and behave as if they did not need the information.

Following the third question on "What is the required information on the treatment courses of the hospitals affiliated to Tehran University of Medical patients?" it should be mentioned that most of the information was for the caring information which was about 158 (45.1%) and the minimum number was for the hormonal treatment which was about 9 persons (2.6%).

The third question states that most of the patients said 'no' to this question, but they needed this information for their health care. Also, they just said "yes" for having an active role in their remedy and they mentioned that they needed a lot of information about their disease for this. This above mentioned items showed that patients believed that medical information is not important for their disease.

Pointing to the fourth question on "What are the Information needs of the patients in

hospitals affiliated to Tehran University of Medical Sciences?", it can be seen from the table that the majority of the patients said "no" when they were asked for the "information need" for their treatment process which shows the fact that patient don't consider the medical information as important for their own treatment, but they were positive on the decision-making aspect of their treatment.

As speaks for the fourth question, it becomes clear that most of the patients wanted to have an active role in their remedy (208 persons) and only 96 0f them wanted to have information about other remedy models.

Summarizing the fifth question on "What are the information needs of the patients about treatment courses in affiliated Hospital of Tehran University of Medical Sciences?", it can be stated that most of the patient when asked to respond the " treatment course information" said "no" for their own treatment which reveals the fact that they are afraid to be informed on their information about their disease.

Considering the fifth question, most of the patients wanted to fully participate in their remedy process and only 96 of them wanted to have information about other remedy models.

Considering the sixth question on "What are the information needs of patients about Laboratory tests in affiliated Hospital of Tehran University of Medical Sciences?" it can be seen that most of the patients were willing to find information of the objective of their laboratory tests, but were negative for the process and also the results of such tests.

The results of the sixth question state that most of the patients (136 persons) wanted to know what the purpose of librarian tests is and some of them (104 persons) wanted to have information about their librarian tests levels.

The seventh question on" Are the patients in the affiliated hospital of Tehran University of Medical Sciences inclined to receive help?" holds the fact that most of the patients were not willing and inclined to receive help for their disease and were negative about it and they were positive to receive help out of the hospital.

Regarding the seventh question, most of the patients were inclined to receive psychological support and the minimum number were desired to receive rehabilitation services

Regarding the eighth questions on "What is the needed information about the other patients' services in affiliated Hospital of Tehran University of Medical Sciences?", it should be said that most of the patients were positive on the caring location, patient's recovery and written information for the patients but they were not inclined to receive information through new mediums of information transfer.

Question eighth states that most of the patients (295, 84.3%) wanted to receive information on the caring location and some of them wanted to find some information about their diseases from the internet.

Considering the ninth question on "How much are the patients' levels of satisfaction with information received from affiliated Hospital of Tehran University of Medical Sciences?" most of the patients expected to receive more information about their disease and they were completely satisfied with it.

Regarding the ninth question, most of the patients (309 persons, 88%) wanted to just know the good news about their diseases and the minimum number (65 persons, 18.6%) wanted to have as little information as possible.

Regarding the last question on "What are the access methods on patients' information in affiliated Hospital of Tehran University of Medical Sciences?", it must be stated that most of the patients (121 persons, 34.6%) received information on their disease from their attending physicians and (15 persons, 4.3%) received the least amount of information from the media namely television and radio, and the minimum number (17

persons, 11.7%) received the information from the internet

Discussion and Conclusion

Disease diagnosis is considered a hazardous experience for patients. Patients should have some information about it to make decision for the remedy and adjust themselves with disease results. The researchers showed that having some information about the disease not only helped them to recognize the disease, but also helped them to make a good decision for their disease. This recent research is similar with [13, 41, 51, 52]. It means that if somebody has more tendencies to know about his/her disease, he will have a more active role in his/her disease and compatibility with the disease.

Recommendations

- Informational needs should be surveyed on each group of special patients.
- Hygienic and mental supporting condition should be surveyed on each group of special patients.
- The effect of the issues should be surveyed on patient's residency and patient's residency reduction.
- The access methods and barriers should be surveyed on each group of special patients.

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