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The Survey of the Patients' Willingness and Awareness on the Disclosure of Medical and Social Information

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Abstract: People referring to the health centers should always be aware of the consequences of the misuse of their information and medical records. In view to the importance of the patient's right on the information disclosure and due to the lack of such studies, researchers aimed to study the patient's awareness and willingness to disclose personal medical information. It is a cross-sectional study aimed to assess the inpatients' willingness and knowledge of their medical information conducted in the affiliated hospitals of Semnan University of Medical Sciences in 2014. The 253 patients were selected as the statistical society. The results showed that patients had little information about the ways of transferring their medical information. On the other hand, they were reluctant to transfer their information outside the hospital. It seems that the cooperation of media is essential to increase public awareness. Also, training medical staff to increase their knowledge about the rights of the patients and also increasing the patients' awareness with the brochure on admission and the patient's justification of its contents may be necessary.

Key words: Health centers, patient's awareness, reluctant, cooperation, brochure

INTRODUCTION

If we notice to the information contained in the medical records, we understand that in addition to the diagnostic and laboratory data, there is some information about family history, genetic testing, history of diseases and their treatments, history of drugs and drug abuse, tests for sexually transmitted diseases and information about the patients' personality and mental health in their files (Tavakoli *et al.*, 2010; Kahouei *et al.*, 2015).

People referring to the health centers should always be aware of the consequences of the misuse of their information and medical records. The most important misuses are the wrong treatment, loss of job, loss of trust and confidence, unwillingness to continue treatment because of the disclosure of certain information and also threatening the people's financial well-being. Apart from the fact that the patient himself should be cautious for confidentiality of the records, the providers of health services at different levels involving the patient's confidential information, depending on the type of services offering and their access to the patients' confidential information should be responsible for the confidentiality of the records (Arab *et al.*, 2011; Kahouei *et al.*, 2014a, b).

Information confidentiality is one of the patient's rights in the health centers. Medical Records Department is responsible for organizing, storing, producing and disseminating the information and the guarantee of safety, integrity and availability of data, so that this information can only be provided to the competent authority (Zadeh *et al.*, 2007; Kahouei *et al.*, 2014b). Hence, laws for transferring the data in the health centers should be written and it should be determined that no records can be transferred without a written request except in the emergency cases and for the evaluation of medical care, research and education in the certain institution, the court's decision in the legal centers and courts and health care personnel for the patients' care and treatment (Tavakoli *et al.*, 2010; kahouei *et al.*, 2013).

One of the main responsibilities of health care workers is the management and practical application of the rules and procedures of the institution to maintain the confidentiality, security and disclosure (Hajavi *et al.*, 2005; Kahouei *et al.*, 2013) of the documents.

It seems that due to lack of clear guidelines regarding confidentiality of patient information, the personnel of the medical records departments in the health centers work according to their own desires leading to the violation

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of patients' rights. In the majority of cases, there are no rules in our country for accessing, using and disclosing the patients' records (Farzandipour *et al*., 2008; Mahboobe *et al*., 2012).

Whiddett *et al.* (2006)'s study showed that the attitude of the patients to share their information depended on the patient's identity, the level of anonymity and the type of information.

Mohseni *et al*. (2012)'s research indicated that in the case of informed consent of patients, there was 58/3% incompatibility between the standards of hospitals of the Ministry of Health and the international standards. As it is known, several studies have been conducted on the disclosure of information in Iran (Jozi *et al*., 2010; Mehdi *et al*., 2012). However, most studies have just examined the information dissemination process but no studies have been conducted in Iran to survey the inpatients views on the willingness and awareness about the disclosure of their medical information.

Such studies would lead to evaluate the patients' interest and knowledge about the disclosure of their information. On the other hand, the patients' expectations in relation to the disclosure of specific information will be identified and the process leads to improved disclosure of the patient's health information.

In view to the importance of the patient's right on the information disclosure and due to the lack of such studies, researchers aimed to study the patient's awareness and willingness to disclose personal medical information.

MATERIALS AND METHODS

It is a cross-sectional study aimed to assess the inpatients' willingness and knowledge of their medical information conducted in the affiliated hospitals of Semnan University of Medical Sciences in 2014. In this study like other similar ones (Whiddett *et al*., 2006; Mohseni *et al*., 2012) and according to the sample size of Kogran formula, 253 patients were selected as the statistical society. So that the number of inpatients in the 3 months period (from January to April 2014) was calculated as 730. Then, taking into account the confidence level of 95% and also on the basis of the sample size formula, 251.9 sample sizes were determined and eventually 253 patients were chosen. In this study, an anonymous questionnaire designed by researchers was used for collecting the data. Following the literature review related to the patients' rights in the case of medical information, a questionnaire was designed. The questionnaire consisted of two parts: the first section included demographic information such as age, sex, educational level and occupation. The second part consisted of 8 questions related to the patients' perspectives towards the disclosure of information such as: sharing the patients' information (identity and clinical), the patients' access to their own records, the patients' awareness of legal rights of dissemination and transfer of information, using consent to disclose medical information and the role of health professionals in informing the patients about their legal rights. The second question was designed as a priority, so that the patients were asked to grade the options of each question from 1-3. The patients were asked to express their opinions on the questions 3-8 as low, medium and high. The patients' responses were scored as at all = 1 and a lot = 4. The surface and content fluency of the questionnaire was reviewed by a team of specialists in the field of health information management. Then, based on experts' opinion, the questionnaire was revised and amended. The initial questionnaire consisted of 15 items, however, 3 items due to conflict with the aims of the study and 4 items because of overlapping were deleted. To measure the reliability of the questionnaires, they were distributed randomly among the 30 patients as the pilot. Cronbach's alpha coefficient was 80.8. Testing and retesting were used for the priority questions. The correlation coefficient obtained was 82.8%. The descriptive statistics, Man Winnie and Kruskal-Wallis tests were used for the analysis of data. In this study, following the permission to collect information and regarding the ethics such as notifying the target population about the purpose of study, explaining the fact that the target population were free to participate in the study and ensuring the patients that their identity information will remain confidential, the questionnaires were distributed to the entire target population.

RESULTS AND DISCUSSION

In this study, the findings showed that 164 patients (65.9%) were 20-40 years old, 170 patients (67.7%) were female and 182 individuals (73.1) had diploma degree (Table 1). The 134 individuals (54%) of the target population were willing to disclose non-personal information (Fig. 1). The results showed that 217 (88.2%) of the statistical population considered the physicians as their highest priority to disclose their own information, 25 (10.5%) chose the researchers and 6 (6.2%) the organizations out of hospitals (Table 2). The 84 (34.1%) of the statistical population reported their access to their medical information as average (Fig. 2) and 74 (33.6%) of individuals claimed that their awareness of the rights of

Table 1: Demographic characteristics and its relationship with the awareness of information disclosure

Demographic characteristics	Groups	N (%)	Mean±SD	p-values
Age	>20	24 (9.6)	2.07±0.49	0.326
	21-40	164 (65.9)	2.14±0.71	
	41-60	46 (18.5)	2.06±0.66	
	<60	15 (6.0)	1.8±0.59	
Sex	Male	81 (32.3)	2.1±0.66	0.183
	Female	170 (67.7)	2.06±0.69	
Education	Uneducated	182 (72.2)	2.10±0.98	0.095
	Diploma	17 (3.2)	2.07±0.66	
	Bachelor	53 (21)	2.07±0.68	
Job	Unemployed	15 (6.1)	2.26±0.61	0.815
	Housekeeper	129 (52.4)	2.07±0.69	
	Employee	42 (17.1)	2.10±0.66	
	Other	60 (24.4)	2.13±0.70	

Table 2: Prioritizing patients' preference towards disclosure of information of medical records

Priorities preferences	First N (%)	Second N (%)	Third N (%)
Medical staffs	217 (88.2)	27 (11)	2 (0.8)
Researchers	25 (10.5)	141 (59.5)	71 (30)
Other organizations outside the hospital	6 (6.2)	67 (28.8)	160 (68.8)

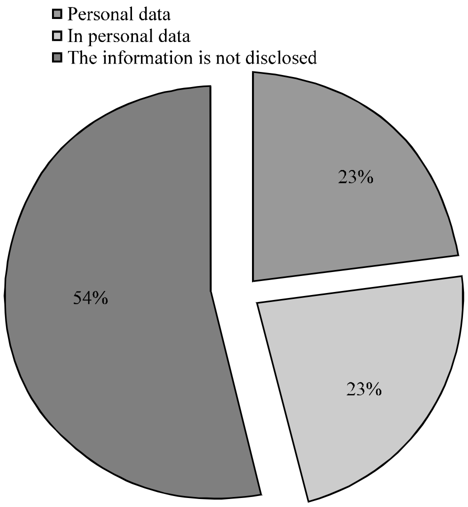

Fig. 1: Patients' preference in the sharing types of information

patients was inadequate and 80 (32.1%) of the target population were not aware of the distribution of the distribution of their medical information (Table 3).

This study was performed to determine the patients' level of awareness and willingness to disclose the information, the results indicated that there was no significant relationship between the patients' education and their awareness of their clinical rights. While in the Mohseni *et al.* (2012)'s study entitled "to survey the points of view of the patients' admitted to Hamedan teaching hospital on their rights were quite opposite that is the patients with higher levels of education were more aware of their rights".

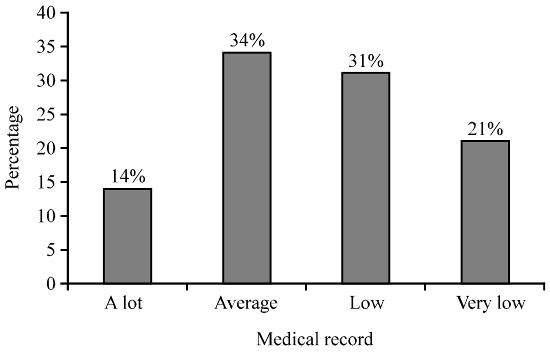

Fig. 2: The patients access to their medical records

The results indicated that the target population was very sensitive to reveal their identity information and they had some limits for the disclosure of their identity information. And more than half of the target population was very willing to disclose information (physical and therapeutic) not related to their identity. Whiddett *et al.* (2006)'s study aimed on the patients' perspective to share their clinical information found that the patients regarded some limits for the disclosure of their personal (identity) information. Westin (1991)'s study also found that more than half of the target population refused giving the correct identity information to the private companies because of the confidentiality of the information.

Approximately, the majority of the population were willing to give their personal and general information to the doctor. It seems that the target population had self confidence to the physician's (medical staff) confidentiality. So that, in Jozi *et al.* (2010)'s study performed with the purpose of surveying the nurses and the patients' viewpoints to regard the patients' rights in the teaching hospitals of Iran University of Medical Sciences in 2011, showed that the target population agreed with the confidentiality of the doctors and nurses. Whiddett *et al.* (2006)'s study also showed that target population gave their general information (personal and non-personal) to the doctor and medical staff.

The results indicated that the patients may not have sufficient knowledge of the use of information in the field of research, so that a small percentage of the target population were willing to give their information to researchers. The patients' lack of awareness of the objectives of the research studies and the results leads to the decrease of patient participation in the research studies (Mehdi *et al.*, 2012). On the other hand, it seems that the patients are concerned with the confidentiality and security of the information by researchers, so that in the study performed by Ahmadi and Motevallizadeh (2011) entitled "conflict and balance in

Table 3: Patients' awareness of their rights

Awareness charter of patient's rights	Very low N (%)	Low N (%)	Average N (%)	A lot N (%)	Mean±SD
Patient's knowledge about the disclosure of information	82 (32.8)	84 (33.6)	66 (26.4)	18 (7.2)	2.08±0.93
Knowledge of how to transfer patient's records	80 (32.1)	75 (30.1)	76 (30.5)	18 (7.2)	2.12±0.95
Awareness of consent application in the disclosure of data	99 (39.9)	67 (27)	63 (25.4)	19 (7.7)	2±0.98
The duties of the medical team to inform patients of their rights	78 (31.6)	69 (27.9)	78 (31.6)	22 (8.9)	2.17±0.97

preserving the privacy and disclosure of genetic information", the results showed that the violation and disregarding the patients' privacy by the researchers, leads to the loss of confidence and unwillingness of the patients' to participate in the research.

The results showed that a very small percentage of the target population were willing to give their information to the research team not related to the hospital. The population appears to be very sensitive to their confidentiality of the information. Westin (1991) found that 82% of participants in the study were very sensitive to the confidentiality of the information.

The results showed that less than half of the target population had access to the information contained in their medical records. This can be due to the lack of the determined policy in the clinical centers (Farzaneh *et al*., 2011). So that, the studies have shown that there is no written and determined policy on the patients' access to information regarding different legal aspects and patients often have no access to their health information (Farzandipour *et al*., 2008; Whiddett *et al*., 2006; Kahouei *et al*., 2011). It seems that a scheduled policy should be developed in the health care institutions regarding the patients' access to their information and confidentiality aspects.

The results showed that less than half of the statistical society had little knowledge of the details of the charter of their rights such as information disclosure of their medical records. This finding may be due to insufficient information given by the medical staff to the patients on admission and hospitalization in the medical center. As the study of Mohseni *et al*. (2012)'s indicated that lack of patients' awareness of their rights was due to the lack of information provided by nurses and other members of health care team. The results of the descriptive research performed by Olsen *et al*. (2005) showed that some of patients were unaware of their rights including the right to disclose their medical information.

The results showed that less than half of the statistical society had little information about transferring their medical records. Perhaps, it is due to the lack of policy and procedure in information transfer. The results of the review study conducted by Nansa *et al*. (2011)'s in Iran, Malaysia and Australia showed that in these countries there was not sufficient policy for this case. The study by Bokaei showed that more than half of the patients were unaware the sixth principle of their rights charter about "the patient's right for the confidentiality of the information in their medical file, clinical examinations and consultations".

The results showed that less than half of the target population had no knowledge of consent for disclosure of information perhaps they were unaware of the rules of professional secrecy. Many studies have noted the patients' low awareness of their rights regarding confidentiality of medical information (Mohseni *et al*., 2012; Ahmadi and Motevallizadeh, 2011; Kahouei *et al*., 2013). On the other hand, probably there is no policy or statute to consent the disclosure of information in medical centers, so that Farzandipour *et al*. (2008) conducting a review study, found that there is no determined (compiled and approved) policy in Iran for the collection of information with the patient's consent.

CONCLUSION

The results showed that patients had little information about the ways of transferring their medical information. On the other hand, they were reluctant to transfer their information outside the hospital. It seems that the cooperation of media is essential to increase public awareness. Also, training medical staff to increase their knowledge about the rights of the patients and also increasing the patients' awareness with the brochure on admission and the patient's justification of its contents may be necessary.

LIMITATIONS

It should be noted that the results of this study should be interpreted with caution because this study has been conducted using a questionnaire designed by the researcher and maybe the potential problems such as poor understanding of the questions threatens the results.

However, with regard to the validity and reliability of the questionnaire, its impact on the study has been little. Secondly, the limitations of this study is that it cannot be generalized because it was conducted just in one city.

However, some of the results of this study are compatible with the results of other studies. It seems that it is required to conduct more comprehensive studies in this field, so that it can be generalized to the entire population.

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