Assessment of Patients' Knowledge and Awareness about their Rights and Duties

تقييم معارف ووعي المرضى لحقوقهم وواجباتهم

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الخلاصة

خلفية البحث: ان حق المريض احد المفاهيم الاساسية في مجال الرعاية الصحية. يهدف تنفيذ قانون حقوق المريض الى تأمين ممارسة طبية جيدة ويمكن أن يحسن العلاقة بين الطبيب والمريض إذا كان كل منهما على علم بذلك.

الهدف: تقييم معارف ووعي المرضى لحقوقهم وواجباتهم

المنهجية: اجريت هذه الدراسة المقطعية العرضية على مراجعي 16 مركزا من مراكز الرعاية الصحية الاولية في مركز مدينة البصرة باستخدام الاستبانة

أجريت الدراسة للفترة من 1 كانون الاول 2013 ولغاية 28 شباط 2014 وشملت 886 مراجعا من كلا الجنسين من مجموع 1010 مراجعا تمت دعوتهم للمشاركة في البحث، وبهذا تكون نسبة الاستجابة 87.7% .

تم استخدام برنامج SPSS لاجراء التحليل الاحصائي للنتائج المستخلصة، تم تحليل البيانات من خلال التحليل الاحصائي الوصفي (التكرار، النسبة المئوية) والاحصاء الاستدلالي (الوسط والانحراف المعياري ومربع كاي للمقارنة)

النتائج: تراوحت أعمارالمشاركين بين 17 الى 71 سنة ومتوسط العمر39.3 ± 13.8 سنة،537 مريضا (60.6%) كانوا من الاناث و349 مريضا (39.4%) من الذكور. معظم المرضى (77.2٪) ليس لديهم معارف بوجود لائحة بحقوق المرضى، ورغم ذلك لوحظ أن لديهم وعيا جيدا لبعض حقوقهم حيث وجد أن 72.4٪ منهم لا يوافقون على منعهم من الوصول الى المعلومات الخاصة بحالتهم الصحية و 76.6٪ منهم ليهم وعي بضرورة احترام خصوصية هذه المعلومات.

اظهرت الدراسة ايضا أن غالبية المرضى (73.5%) لا يوافقون على حجب بعض المعلومات المتعلقة بحالتهم الصحية عن الاطباء و83.2% يوافقون على اخبار المركز الصحي عند تغيير محل سكنهم.

الاستنتاج: أظهرت النتائج ضعفا واضحا في معرفة المرضى لحقوقهم

التوصيات: توصي الدراسة باجراء برامج تثقيفية من خلال وسائل الاعلام المختلفة لتعريف المرضى بحقوقهم مع ضرورة تشريع قانون حقوق المرضى.

مفتاح الكلمات: حقوق المريض، المعرفة، مراكز الرعاية الصحية الاولية، البصرة

ABSTRACT

Background: patient's right is the one of the basic issues in health care. Implementation of patient's rights law is intended to secure good medical practice and can improve the doctor-patient relationship if both of them are aware of it.

Objectives: To assess the level of knowledge and awareness of patients about their rights and duties.

Subjects and methods: A cross-sectional survey was conducted for the period from 1st December 2013 to 28th February 2014 among patients of both sexes aged 17 years and more attending 16 primary health care centers in Basra city using a self-administered questionnaire. The study included 886 out of 1010 patients invited to participate in the study giving a response rate of 87.7%.

Data analysis was done using SPSS version 19. Chi-square test was used to compare the proportions among the various groups and a P-value of <0.05 was considered to be statistically significant.

Results: Eight hundred and eighty six (886) patients were included in the study aged 17-71 years with a mean age of 39.3 ± 13.8 years. Of them, 537 patients (60.6%) were females and 349 patients (39.4%) were males. Most patients (77.2%) didn't know about the existence of patients' list of rights, even though they were aware about some of their rights, 72.4% of them disagreed to be prevented from access to information related to their health status, and 76.6% of them were aware about the privacy of such information. Most of

the patients (73.5%) disagreed to withhold some information relevant to their health conditions, and 83.2% of them agreed to notify the PHC Center if they change their residential address.
Conclusion: There was a lack of patients' knowledge regarding the patients' rights.
Recommendation: Extensive education of patients about their rights through mass media and legislation of such rights are recommended.
Key words: Patient's rights, knowledge, PHC centers, Basrah

INTRODUCTION

For any developing country to step high in the development of the quality of health care it should take over the essential part of the human rights, which is the patient rights. Even the patient right is not so well to do practically but it is accepted worldwide. The patient right charter differs from one country to another but there are main principles agreed upon universally and can be found in most of the countries [1-3] that have the legislation of patient rights declared, which are; the right to access information recorded in his/her medical records and to be fully informed about the health status, the right to care and treatment, the patient has the right to make free decision, and the patient has the right to privacy and confidentiality of information and socio medical data. However, cultural and socio-economic differences creating differences in barriers and facilitators may play an important role in individual attitudes and perceptions of rights in general and patients' rights in particular [4].

At the same time the patient has some responsibilities or duties that he/she needs to be aware of them and implements them practically, duties toward themselves, other patients and relatives, health care personnel and society [5].

Of these, the patient must provide all information related to his/her health, the patient must inform the health center when he/she changes the residential address [5].

In Iraq the new constitution 2005, in article31 has guarantee the health care to every Iraqi citizen [6] and for good quality of health care it needs to quick implementation of the national statement of patient rights that has been adopted by the ministry of health in collaboration with USAID/Iraq. This statement in its way for legislation in the Iraqi Parliament [7] but this statement has been already seen attached to the walls of the Primary Health (PHC) Centers in Basrah whether the people aware of it or not. There is a paucity of information about the knowledge and awareness of the patients attending the PHC centers for treatment or health promotion related to their rights.

It is so illuminating to assess the patient knowledge, awareness of their rights and responsibilities in Basrah. There are no researches done in Basrah about the patients' awareness of their rights and responsibilities.

This study is designed to determine the levels of patients' awareness, knowledge of their rights and responsibilities and to identify the regress in operation, which may help to improve quality of health care and improve the doctor patient relationship.

METHODOLOGY

A cross–sectional analytic survey was conducted during the period from 1st December 2013 to 28th February 2014 aiming to assess the patients' awareness of their rights and responsibilities. A convenience sample of 1010 patients of both sexes attending 16 PHC centers in Basrah was invited to participate in the study. Of those invited, 886 patients accepted to participate in the study giving a response rate of 87.7%. Approximately equal numbers of patients from each center were simple randomly

selected. The inclusion criteria for patients' enrollment into the study were fully conscious, age above 16years,able to give consent. The participants were aware about the aim of the study and they were informed that the participation is voluntary and the data would be confidential. Verbal consent was taken before data collection. The patients were informed that the data would be anonymous and confidential and the information is for scientific research only. The ethical committee of College of Medicine, Basrah University, approved the study.

An interview questionnaire was designed to collect data for this study. It consists of two parts. The first part includes information on the patient's demographic parameters such as age, gender, education, and occupation. The second part consists of questions about the patients' rights knowledge and awareness including the 10 items listed in the national statement of patient rights in PHC centers. The 10 patients' rights were grouped into four main rights; the right to access information recorded in any his/her medical records and to be fully informed about the health status, the right to care and treatment, the patient has the right to make free decision, and the patient has the right to privacy and confidentiality of information and socio medical data. The responsibilities of the patient which were asked for were; the patient should not hide information related to his health status from his doctor, and the patient should inform the PHC center when he changes his residential address.

Statistical analysis was done using the SPSS version19. Data were presented using descriptive statistics in form of frequencies and percentages. Chi-square test was used to compare the proportions among the various groups and a P-value of <0.05 was considered statistically significant.

RESULTS

Table 1: Clients Responses about their knowledge and awareness, about their rights and responsibilities

Items	Disagree No. (%)	I do not know No. (%)	Agree No. (%)	Total No. (%)
The patient has to be prevented from access to some information about his health status	641 (72.4)	33 (3.7)	212 (23.9)	886 (100)
The administration decides the health service provider and the patient is not allowed to chose another one	376 (42.5)	33 (3.7)	477 (53.8)	886 (100)
The doctor is the one who decides the investigations and treatment and the patient is not allowed to share his opinion	320 (36.1)	44 (5.0)	522 (58.9)	886 (100)
The patient's information is the property of the PHCC and it can be disclosed without any restriction	679 (76.6)	22 (2.5)	185 (20.9)	886 (100)
The patient has to withhold some information relevant to his health condition	651 (73.5)	35 (4.0)	200 (22.5)	886 (100)
The patient has to notify the PHCC when s/he changes his residential address	115 (13.0)	34 (3.8)	737 (83.2)	886 (100)

The majority of the respondents were females 537(60.6%). The mean age of the study population was 39.3±13.8 years (a range of 17-71 yeas) and those who were aged less than 50 years constituted more three quarters 666 (75.2%) of the study population. Of the total studied persons, 678 (76.5%) were literate and 413 (46.6%) were housewives.

More than three quarters of the patients (77.2%) did not know that there is a list of patients rights and duties, and more than half (54.2%) of those who knew the existence of such list, correctly identified only one right, and only 0.5% correctly knew three rights. Among the majority who knew that there is a list (64.6%), hearing was the source of such knowledge. Only 24.9% of the participants have been informed about the type and reasons behind the disease and side effects of medication, while 75.1% of them were informed about different therapeutic alternatives. More than three quarters (76%) of the patients reported that they were seen or heard by another person while they were consulting their doctors.

Table 1 shows the answers of the respondents to questions specific to the rights and duties that were documented in the national statement of patient's rights and responsibilities, which had been adopted by the Iraqi ministry of health. The majority (72.4%) of the respondents disagreed with preventing them from access to some information about their health status, while 53.8% of them agreed that "the administration decides the service provider and the patient is not allowed to choose another one". Of the patients, 58.9% agreed with the statement "the doctor is the one who decided the treatment and investigation and the patient not allowed to share his opinion". Only 20.9% agreed that the PHC center could disclose their information to any one without restriction. Most of the patients (73.5%) disagreed to withhold some information relevant to their health conditions, and83.2% of them agreed to notify the PHC Center if they change their address.

Table 2: Comparison Differences Between Clients' Knowledge and awareness regarding their Gender

Items	Gender		X^2; P-value
	Male No. (%)	Female No. (%)	
The patient has to be prevented from access to some information about his health status:			
Disagree	270 (77.4)	371 (69.1)	15.187;
I do not know	18 (5.1)	15 (2.8)	0.001
Agree	61 (17.5)	151 (28.1)	
The administration decides the health service provider and the patient is not allowed to chose another one			
Disagree	165 (47.3)	211 (39.3)	5.523;
I do not know	12 (3.4)	21 (3.9)	0.063
Agree	172 (49.3)	305 (56.8)	
The doctor is the one who decides the investigations and treatment and the patient is not allowed to share his opinion			
Disagree	122 (35.0)	198 (36.9)	
I do not know	21 (6.0)	23 (4.3)	1.497;
Agree	206 (59.0)	316 (58.8)	0.473
The patient's information is the property of the PHCC and it can be disclosed without any restriction:			
Disagree	284 (81.4)	395 (73.6)	8.154;
I do not know	9 (2.6)	13 (2.4)	0.017

Agree	56 (16.0)	129 (24.0)	
The patient has to withhold some information relevant to his health condition			
Disagree	244 (69.9)	407 (75.8)	4.010
I do not know	17 (4.9)	18 (3.4)	0.135
Agree	88 (25.2)	112 (20.9)	
The patient has to notify the PHCC when s/he changes this residential address			
Disagree	46 (13.2)	69 (12.8)	2.793;
I do not know	18 (5.2)	16 (3.0)	0.247
Agree	285 (81.7)	452 (84.2)	

Table 2 shows the differences between males and females in awareness about their rights and responsibilities. More men than women were aware about their right to share information about their health status (77.4% Vs 69.1%) with a highly significant difference. The same trend was also noticed regarding the privacy of their information. Of men, 81.4% disagreed that their information can be disclosed by the PHC center without restriction compared with 73.6% of women. No significant differences between men and women in awareness about the other rights. The majority of both men and women were aware about their duty not to withhold information relevant to their health status from their doctors (69.9% of men Vs 75.8% of women) but the difference was not significant. The same pattern was also noticed regarding their duties regarding informing the PHC center when they change their residential address.

Table 3 Comparison Differences Between Clients' Knowledge and awareness regarding their age

Items	Age		X^2; P-value
	< 50 years No. (%)	≥ 50 years No. (%)	
The patient has to be prevented from access to some information about his health status:			
Disagree	499 (74.9)	142 (64.5)	12.695;
I do not know	18 (2.7)	15 (6.9)	0.002
Agree	149 (22.4)	63 (28.6)	
The administration decides the health service provider and the patient is not allowed to chose another one			
Disagree	273 (41)	103 (46.8)	3.323;
I do not know	23 (3.4)	10 (4.6)	0.190
Agree	370 (55.6)	107 (48.6)	
The doctor is the one who decides the investigations and treatment and the patient is not allowed to share his opinion			
Disagree	241 (36.2)	79 (35.9)	
I do not know	30 (4.5)	14 (6.4)	1.225;
Agree	395 (59.3)	127 (57.7)	0.542
The patient's information is the property of the PHCC and it can be disclosed without any restriction:			
Disagree	516 (77.5)	163 (74.1)	3.607;
I do not know	19 (2.8)	3 (1.4)	0.165

Agree	131 (19.7)	54 (24.5)	
The patient has the right to withhold some information relevant to his health condition Disagree I do not know Agree	 505 (75.8) 25 (3.8) 136 (20.4)	 146 (66.4) 10 (4.5) 64 (29.1)	 7.785; 0.020
The patient has to notify the PHCC when s/he changes his residential address Disagree I do not know Agree	 85 (12.8) 21 (3.1) 560 (84.1)	 30 (13.6) 13 (5.9) 177 (80.5)	 3.632; 0.163

As shown in Tables 3, more patients aged <50 years (74.9%) disagreed to be prevented from access to information related to their health status than those aged ≥ 50 years (64.5%) with a highly significant difference (P= 0.002). No significant difference was noticed in awareness about the other rights between patients according to their age. Younger age group patients (<50 years) significantly (P= 020) disagreed to withhold information relevant to their health status from their physicians (75.8%) compared with those age ≥ 50 years (66.4%). No significant difference was noted between the two age groups regarding notifying the PHC center when they changed their residential address.

Table 4 Comparison Differences Between Clients' Knowledge and awareness regarding education level

Items	Education level			X^2; P-value
	Illiterate No. (%)	Pre-university No. (%)	University No. (%)	
The patient has to be prevented from access to his health status information: Disagree I do not know Agree	 150 (72.1) 4 (1.9) 54 (26.0)	 402 (71.7) 23 (4.1) 136 (24.2)	 89 (76.1) 6 (5.1) 22 (18.8)	 4.572; 0.334
The patient is not allowed to chose another one Disagree I do not know Agree	 79(38.0) 9 (4.3) 120 (57.7)	 238 (42.4) 19 (3.4) 304 (54.2)	 59 (50.4) 5 (4.3) 53 (45.3)	 5.374; 0.251
The patient is not allowed to share opinion in diagnosis and treatment Disagree I do not know Agree	 68 (32.7) 10 (4.8) 130 (62.5)	 213 (38.0) 24 (4.3) 324 (57.8)	 39 (33.3) 10 (8.5) 68 (58.2)	 5.620; 0.229
The patient's information can be disclosed without any restriction: Disagree I do not know Agree	 154 (74.0) 4 (1.9) 50 (24.0)	 438 (78.0) 11 (2) 112 (20)	 87 (74.4) 7 (6.0) 23 (19.6)	 8.367); 0.079

The patient has the right to with hold some information relevant to his health condition				
Disagree	154 (74.0)	423 (75.4)	74 (63.2)	11.393
I do not know	6 (2.9)	19 (3.4)	10 (8.5)	0.022
Agree	48 (23.1)	119 (21.2)	33 (28.2)	
The patient has to notify the PHCC when s/he changes his residential address:				
Disagree	35 (16.8)	55 (9.8)	25 (21.4)	16.278;
I do not know	9 (4.3)	23 (4.1)	2 (1.7)	0.003
Agree	164 (78.9)	483 (86.1)	90 (76.9)	

Although there was a slight increase in awareness of the patients about their rights (in access to information related to their health status, sharing decision in investigation and treatment, and restriction of disclosing their information) with increasing level of education, the difference was not significant. Unexpectedly, illiterate patients were more aware and tend to disagree on withholding information related to their health more than those who were highly educated with a significant difference (P <0.05). Also they agreed more to notify the change in their residential address than highly educated people with a highly significant difference (P <0.01). (Table 4)

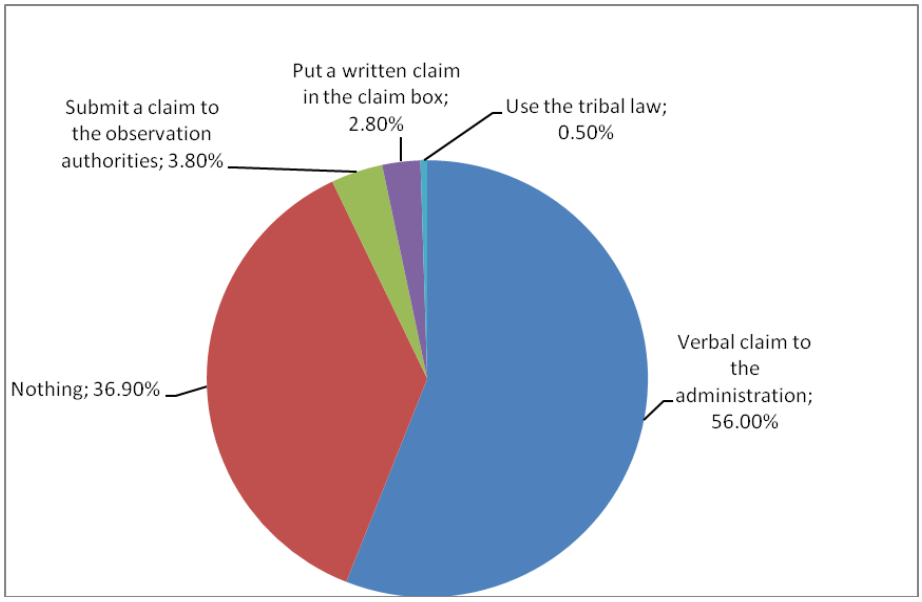

Figure 1 Action of participants when their rights are exposed to bereavement

The response of the participants to the question "What will you do when your rights are exposed to bereavement?" is shown in Figure 1. Most of them (56%) answered that they would submit verbal claim to the administration of the PHC center and more than one third of them (36.9%) answered they would do nothing. While 3.8% answered that they would submit a claim to the observation authorities, 2.8% would put a written claim in the claim box, and only 0.5% reported that they would use the tribal law.

DISCUSSION

This study showed that only 22.8% of the participants know the national statement of the patient's rights that had been adopted by the Iraqi ministry of health, a result that is in agreement with that of Zulfikar et al in Turkey who reported that only 23% of the respondents know the patients' rights [8].

Also, Alghanim in Saudi Arabia reported that 75% of the patients attending the primary health care centers did not know about the presence of patients right [9]. In Turkey also another study done by Kuzu et al showed only 9% of the patients were aware of the list of patients' rights[10].

Whereas a study in Lithuania showed that 56% of the patients had heard or read about the law on patients' right [11]. This difference may be due to socio-cultural differences. Of those who knew that there is a list of patients' rights, the majority identified only one right while only 0.5% of them identified 3 rights. A result which is similar to that reported by others [1,12] necessitating a need for awareness rising among patients to improve the practical implementation of the Patient's Rights [11].

In this study, meeting the caring needs is the core concept for the meaning of patients' rights, a result that had been documented by Al-Bishi (2004) in Saudi Arabia [13] and Joolaee et al in Iran (2010) [14].

Although most patients did not know about the patients' bill of rights, even though they were aware about their rights, 72.3% of them disagreed to be prevented from access to information related to their health status, and 76.6% of them were aware about the privacy of the information related to their health status. However, many patients (53.8%) agreed that decision making is to be done by the health care provider and the patient is not allowed to chose another one, a result which is in agreement with that of a study in Greece where the right to confidentiality was not considered as a right of privacy and many patients allowed their doctors to make decisions [15], and also in agreement with that reported by Habib FM et al in Saudi Arabia [12] who found that only 51.2% of the sample knew that they have the right to have a second opinion consultation.

Of the studied patients, only 24.9% were informed by their doctors about diagnosis and complications of medication, a result which is comparable to that reported by Razavi et al who showed that 65.2% of patients stated that physicians did not explain enough about the therapy, drugs and complications [16].

The low level of knowledge and awareness of the patients about their rights in choosing the health care providers and sharing their opinion in decision making about investigations and treatment may be an indication of submissive behavior on the patient's part, related to the low knowledge of the Law of Patient's Rights [17], and may reflect the paternalistic relationship between the doctors and the patients in Iraq. This finding is in agreement with that of Merakou et al who reported that many patients permit doctors to make decision [15].

There was a positive association between awareness and education, and there was a negative association between awareness and age. A result, which had also been reported by others [12,18].Given the fact that knowledge can improve the awareness of people about their rights [18].Patients with university level of education are better informed because they are more active in asking for such information, and they are more actively tell about their wishes to the physicians [19]. On the other hand, highly educated people tend more to withhold information related to their health conditions than illiterate people and they

disagreed more to inform the PHC center when they changed their residential address. Disclosure may be mediated by a variety of individual and interpersonal factors [20]. Highly educated people may consider withholding of some information as some sort of privacy.

Statistically significant higher percentages of males were aware of their rights than females. This could be explained by that men were more educated than women in this study [16.3%] of men were highly educated vs . 11.2% of women ($p< 0.001$).

More than (60%) of patients in this study reported that they will submit some sort of claim when their rights are violated. The expanding patient population is becoming more knowledgeable and aware of their rights, consequently taking action by contacting the consumer forum to lodge their complaints [21]. A substantial proportion of patients (36.9%) did nothing when their rights are violated and more than half of them reported that they would submit a verbal claim to the administration, a result which is similar to that reported by Merakou et al [15], probably due to more than half of the participants (52.2%) were either illiterate or with primary educational level.

CONCLUSION

There was a lack of patients' knowledge regarding their rights.

RECOMMENDATIONS

1. Appropriate measures have to be taken from a national perspective in order to legislate and promote implementation of patients' rights.
2. Education of the patients about their rights.

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