

## Assessment of Awareness and Source of Information of Patients' Rights: a Cross-sectional Survey in Riyadh Saudi Arabia

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### Abstract

**Background:** In the rapidly changing atmosphere of health care, many factors have affected how health care is practiced. The rights of the patient have also been affected. Patient rights have recently become the center of national attention in the practice of medicine. **Objective:** This study was designed to assess the patients' awareness of their rights in Saudi Arabia to identify the source of their awareness. **Design:** A cross-sectional descriptive design was used to collect data for this study aiming. Convenience sample of 625 subjects were recruited from the public places as malls, and restaurants. All subjects recruited into the study were fully conscious, able to give consent and were admitted to the hospital at least once before. An Interview questionnaire which consisted of three parts: the first part was the patients' demographic parameters. The second part was the patients' rights listed in National Patients and their families' Rights and Responsibilities' booklet The third part included subject's medical history and the source of the subject's information about their rights. **Results:** The mean age of the sample was  $35.75 \pm 11.8$ . About 51% of the sample was males while 49% was females. Fifty percent of the sample was married. The majority of the sample (87.4%) knew that they should be informed about their right in the medical care sittings. Almost all the sample (97.3%) did not know that they have the right to know the name of their health care provider. Sixty seven point five percent knew that they have the right to be provided with interpreters to communicate with health care providers. Only 51.2% of the sample knew that they have the right to have a second opinion consultation. The majority (73.76) of the subjects get their information about their right from nurses Conclusion: More emphasis from health care providers should be placed on increasing the patient awareness about their rights as patients need to be involved in making decisions regarding their treatment.

**Key Words:** informed consent, patient-centered care, patients' rights.

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### Introduction

Today, concerns about the patients' choice, respect for their values and preferences, and access to nursing care are becoming more complex. Patients' expectations are getting higher and they always want the best. They want to

actively participate in decision-making, proposed procedures or treatments and their various alternatives. General awareness of human rights has been on the rise. Cultural differences play an important role in individual attitudes and perceptions of rights in general and patients' rights in particular (1,2).

World Health Organization research group on patients' rights and citizens' empowerment suggested that each country should articulate its concerns and priorities according to its own cultural and social needs to promote and protect patients' rights (3).

Assuring that the rights of patients are protected requires more than educating policy makers and health providers; it requires educating citizens about what they should expect from their governments and their health care providers about the kind of treatment and respect they are owed (4,5). Citizens, then, can have an important part to play in elevating the standard of care when their own expectations of that care are raised. Some countries have recognized this, and have advanced their knowledge of genomics in public, academic and scientific spheres. Some follow democratic procedures to vote on resolutions pertaining to genomics (6). This knowledge and active engagement empowers lay individuals to make informed decisions about the future of genomics, both at the personal and at the policy level (7).

Most patients' bills of rights, are concerned with informed consent, confidentiality, privacy, autonomy, safety, respect, treatment choice, refuse the treatment and participating in the treatment plan. These rights are derived from the values and ethics of the medical profession (8). Patients must be competent to understand the relevant information and the decision at hand and must not be coerced into accepting treatment against their wishes (9, 10).

In the study carried out by **Al Bishi (11)**, he studied the Saudi patients', physicians' and nurses' perception of and lived experiences with patients' rights. He found that meeting the patients' caring needs is core concept patient's rights and educate the public about their rights in Saudi Arabia. He also found the lack of knowledge about the rights, lack of standard of practice among the hospitals and the impact of service pressure and subsequent lack of holistic care, are barriers to patients' rights practice in Saudi Arabia

In King Saudi Arabia, the ministry of health was published the National Patients and their families' Rights and Responsibilities' booklet which all patients receive upon hospital admission. The patient bill of rights is a written document which is available in most Saudi health care organizations, but many patients and their families may not be aware of their rights that have been granted by the Saudi government through policies and regulations of the Ministry of health (12, 13, 14). In the current study awareness was defined as a patient's ability to perceive, to be conscious and to understand their rights.

It was highly informative to assess the patient's awareness of their rights in Saudi Arabia. There was no comprehensive research done in KSA about patient awareness and their rights. This study was designed to assess the patients; awareness of their rights in Saudi Arabia and also to assess the source of their information to identify important lapses in performance, which may help to improve patient safety

## Methodology

A cross-sectional descriptive design was in this study aiming to assess the patients' awareness of their rights in Saudi Arabia. A convenience sample of 625 subjects was recruited for this study. The subjects were recruited from public places as Malls, Mosques, and Restaurants. The inclusion criteria for subjects' recruitment into the study were fully conscious, more than 18 years old, able to give consent, were admitted to the hospital at least once in the last six months and not part of healthcare providers' team. Participants were aware about the aim of the study and they were informed that the participation is voluntary. Verbal consents were taken before data collection. Subjects were informed that the data will be anonymous and confidential

Using the sample size calculator with the confidence level of 95% and confidence interval 4, the sample size was calculated to be 600 subjects and it was increased to 625 subjects to ensure the sample representativeness.

An Interview questionnaire was designed to collect data for this study. It consisted of three parts: The first part was the patients' demographic parameters, such as age, gender, education, and income. The second part was the patients' rights awareness questionnaire. The questionnaire included the items listed in National Patients and their families' Rights and Responsibilities' booklet which included 14 questions to assess patient awareness about different aspects of their rights such as the right to have the health care staff introduce themselves and to appropriately display their Identification (ID) badges, the right to accept or refuse to participate in any medical research, the right to receive full explanation of any unanticipated outcomes of care and treatments, and the right to obtain a second opinion consultation from another specialist. The questionnaire was scored and the total score was computed for each subject. The score for each question was either 0 if the subject was not aware about this specific right and 1 if the subject was aware about the right. The lowest score would be 0 point while the highest score would be 14 points. The third part included subject's medical history and the source of the subject's information about their rights.

The content validity of the questionnaire was assessed by a group of experts who examined the tools and approved it. Test retest method was used to determine the reliability of the tool, by applying this tool twice on 5 subjects who were excluded from the study. The reliability was 0.84. Subjects needed 15 -20 minutes to complete the questionnaire. A pilot study was conducted to test the feasibility and applicability of the tools, and identified the most suitable time to collect data. The pilot study was carried out on five subjects. The result of the pilot study was helped in refining the interview questionnaire form.

Data was coded for entry and analysis using SPSS statistical software package version 18. Data was presented using descriptive statistics in the form of frequencies and percentages. Interval and ratio variables were presented in the form of means and standard deviations, and tested by Student t-test. Nominal and ordinal variables were compared using chi-square test. The association between variables was examined using persons correlation test. The significance level was chosen as  $p < 0.05$ .

## Results

The study aimed to assess the patients; awareness of their rights in Saudi Arabia and also to assess the source of their information. An Interview questionnaire which consisted of three parts was used to collect the data for this study. The first part was the patients' demographic parameters. The second part was the patients' rights awareness questionnaire. The third part included subject's medical history and the source of the subject's information about their rights.

Socio-demographic characteristics were demonstrated in table 1. The age of the participants ranged between 18 – 80 years old. The mean age of the sample was  $35.75 \pm 11.819$  years. About two thirds of the subjects (66.4) were under 40 years of age. Only 4.16 percent of the subjects were over 60 years old. About half of the sample (50.9%) were males while 49.1% were females. There was statistically significant difference between the males and females regarding age. The mean age of the males was 37.4, while it was 34 for female ( $p = 0.000$ )

There was statistically significant difference between the males and females regarding marital status ( $p = 0.002$ ). There were higher percentages of divorced and widow female than males. About half of the sample was married. More than two thirds of the sample (76.8%) had education of high school or higher. There was no statistically significant difference between the males and females regarding education ( $p = 0.118$ )

The number of family members of the sample ranged between 2 – 18 members. The mean number of family members was  $7.8 \pm 1.794$ . The majority of the sample (87.04%) had family income more than 10000 Saudi Riyal (SR) per month. The majority of the sample had family members ranged between 5 – 9 members.

**Table (1): Frequency Distribution of Sociodemographic Characteristics of the Sample**

<b>Variables</b>	<b>Number n = 625</b>	<b>Percent</b>
<b>Age</b>		
Less than 30	246	39.36
30 – 39	169	27.04
40 – 49	113	18.08
50 – 59	71	11.36
60 and up	26	4.16
Mean	35.75	
SD	11.819	
<b>Gender</b>		
Male	318	50.9
Female	307	49.1
<b>Marital Status</b>		
Single	153	24.5
Married	317	50.7
Divorced	121	19.4
Widow	34	5.4
<b>Level of Education</b>		
Illiterate	61	9.8
Elementary	22	3.5
Intermediate	55	8.8
High school	230	36.8
College	250	40
Graduate	7	1.2
<b>Family income</b>		
Under 5000SR	48	7.68
5000– 10000	33	5.28
10000- 15000	272	43.52
15000 – 20000	133	21.28
20000- 30000	89	14.24
More than 30000	50	8
<b>Number of Family Members</b>		
Less than 5	6	0.96
5-9	522	83.52
10 and up	79	12.64
Mean	7.8	
SD	1.794	

Medical history of the subjects in the sample showed that 13.78% had diabetes mellitus either type I or type II, 7.4% had hypertension and 4.16% had heart diseases. The number of hospital admission ranged between 1-24 times. The mean number of admissions was  $3.568 \pm 3.135$ . More than half of the sample (62.08) was admitted 1 – 3 times while only 14 % were admitted more than 6 times (table 2).

Only 0.6% of the subjects were aware of only one patient right. On the other hand only 1% of the subjects were aware of all the 14 rights. About one third of the sample 32.1% was aware of ten or more rights. Thirty point six percent were aware of only 6 or less rights out of the 14 rights. More than one third of the sample (37.1%) were aware of 6 – 9 of their right (Figure 1).

**Table (2): Frequency Distribution of the Medical History and Number of Hospital Admission of the Sample**

<b>Variables</b>	<b>Number N = 625</b>	<b>Percent</b>
<b>Medical History</b>		
Diabetes	86	13.76
Hypertension	44	7.04
Heart Disease	26	4.16
Respiratory Disease	7	1.12
Cancer	2	0.32
<b>Number of Hospital Admissions</b>		
1-3	388	62.08
4-6	147	23.52
More than 6	90	14.4
Mean	3.58	
SD	3.136	

Table 3 showed that females awareness was statistically significant higher than males in eight items out of the fourteen. The eight items were: The right to be informed about your rights and responsibilities in a manner you can understand, the right to submit suggestions, or/and complaints and to be informed with the results of such complaints, the right to be provided with interpreters to communicate with health care staff, the right to obtain a second opinion consultation from another specialist. the right to be provided with appropriate medical services available in hospital facilities, the right to participate in care decisions to the extent you wishes to, and in choosing the treatment plan upon signing the general consent form, the right to refuse or discontinue treatment after a thorough explanation by your physician about the consequences and or outcomes of your decision, and the right to request an appropriate assessment and management of pain ( $p = 0.000, 0.001, 0.000, 0.000, 0.000, 0.000, 0.000, 0.000$  respectively). While there were no statistical difference between males and females in the rest of items

There was a significant negative correlation between total awareness score and age. The increase of age was associated with decreased total awareness score ( $p = 0.000$ ). There was also a significant negative correlation between total awareness score and number of family members. The increase of number of family members was associated with decreased of total awareness score ( $p = 0.000$ ). There was a significant positive correlation between awareness score and education. The higher education level was associated with increase of total awareness score ( $p=0.000$ ). There was also a significant positive correlation between total awareness score and family income ( $p=0.000$ ). There was no association between awareness score and number of hospital admissions (table 4).

A large percentage of the sample got their information about patient right from nurses and doctors (73.76%, 62.08% respectively). Forty one percent of the sample got information from other health care provider, while 35.36% of the subjects got information from National Patients and their families' Rights and Responsibilities' booklet, while about one third of the subjects (34.4%) got information from family and friends. The percentages in this table do not add up to one hundred as the alternatives are not exclusive as most of the subjects in the sample indicated that they got their information about patient rights from more than one source.

## Discussion

Patient rights have recently become the center of national attention in the practice of medicine. Patients' rights vary in different countries and in different jurisdictions, often depending upon prevailing cultural and social norms. Patients have certain rights concerning their personal and private information relevant to their medical care. It was highly informative to assess the level of Patients' Awareness of their Rights and the Source of their Awareness:

A total 625 previously admitted individuals were interviewed to assess their awareness about their rights. The majority of the subjects were young with a mean and standard deviation of  $35.75 = 11.819$  year, and a range of 18-

**Table (3): Comparison between Males and Females regarding their Awareness about each Individual Patient Rights item**

Variables	Total	Male	Female	P
	Number (%)	Number (%)	Number (%)	
	n ==624	n = 318	n = 307	
The right to have your valuables collected and secured according to hospital procedures.	557 (89.1)	278 (49.9)	279 (50.1)	0.165
The right to be informed about your rights and responsibilities in a manner you can understand.	546 (87.4)	213 (46.3)	247 (53.7)	0.000
The right to be respected by hospital staff in a way that takes into consideration the patient's cultural and religious values and beliefs?	531 (85.0)	269 (50.7)	262 (49.3)	0.793
The right to submit suggestions, or/and complaints and to be informed with the results of such complaints.	446 (73.6)	264 (48.4)	282 (51.6)	0.001
The right to be provided with interpreters to communicate with health care staff?	422 (67.5)	194 (46.0)	228 (54.0)	0.000
The right to be informed the necessary directives and procedures,.	376 (60.2)	191 (50.8)	185 (49.2)	0.960
The right to obtain a second opinion consultation from another specialist .	320 (51.2)	121 (37.8)	199 (62.2)	0.000
The right to be provided with appropriate medical services available in hospital facilities.	318 (50.9)	126 (39.6)	192 (60.4)	0.000
The right to receive full explanation of any unanticipated outcomes of care and treatments	314 (50.2)	166 (52.9)	148 (47.1)	0.318
The right to accept or refuse to participate in any medical research and your refusal decision will not negatively affect the medical services provided.	241 (38.6)	127 (52.7)	114 (47.3)	0.472
The right to participate in care decisions to the extent you wishes to, and in choosing the treatment plan upon signing the general consent form.	233 (37.3)	55 (23.6)	178 (76.4)	0.000
The right to refuse or discontinue treatment after a thorough explanation by your physician about the consequences and or outcomes of your decision,	231 (37)	62 (26.8)	169 (73.2)	0.000
The right to request an appropriate assessment and management of pain.	157 (25.1)	52 (33.1)	105 (66.9)	0.000
The right to have the health care staff introduce themselves and to appropriately display their ID padres.	17 (2.7)	10 (58.8)	7 (41.2)	0,507

Figure (1): Number of Rights which were known by the Subjects in the Sample

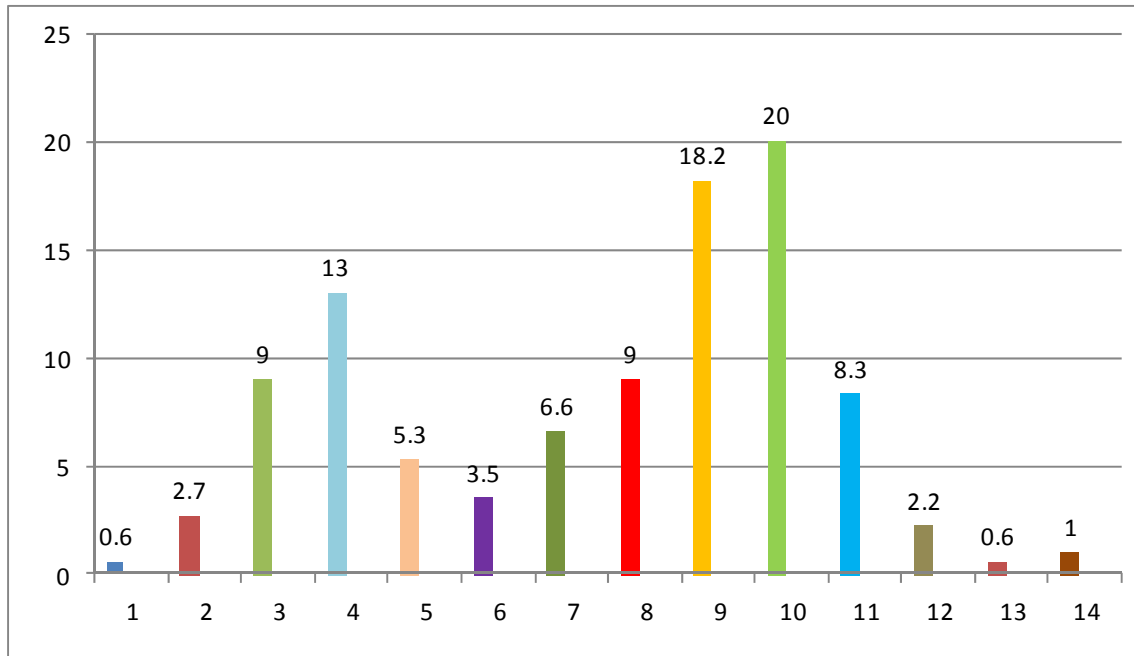


Table (4): Correlation between the Total Awareness Score and Age, Education, Family Income, Number of Family Members, and Number of Hospital Admissions

Variables	Total awareness score	
	R	P
Age	-0.47	0.000
Education	0.673	0.000
Family income	0.470	0.000
Number of family members	-0.422	0.000
Number of hospital admission	-0.33	0.412

Table (5): The Frequency Distribution of the Source of Sample Information about Patients Rights

Source of information about patients rights	Number	Percent
Doctor	388	62.08
Nurse	461	73.76
Other health care providers	257	41.12
National Patients and their families' Rights and Responsibilities' booklet	221	35.36
Family and friend	215	34.4
Hospital board	137	21.92

74 years. The literacy rate was 91.2%. Similar findings by Yousouf et al (1), they studied Hospitalized patients' awareness of their rights: a cross-sectional survey from a tertiary care hospital on the east coast of Peninsular

Malaysia A total of 250 patients was surveyed. The majority of the respondents were young; with a mean  $\pm$  standard deviation age of  $45 \pm 16$  years, and a range of 13–84 years. The literacy rate was 86% (primary through tertiary education).

The number of hospital admission ranged between 1-18 times. The mean number of admissions was  $3.568 \pm 3.135$ . More than half of the sample (62.08) was admitted 1 – 3 times while only 14 % were admitted more than 6 times. Surprisingly there was no statistically significant association between the total awareness score and number of hospital admission. There was a positive association between awareness score and education as well as income. There was a negative association between awareness score and age as well as number of family members.

The three rights that more than 80% of the subjects were aware of are: The right to have your valuables collected and secured according to hospital procedures, the right to be informed about your rights and responsibilities in a manner they you can understand, and the right to be respected by hospital staff in a way that takes into consideration. Statistically significant higher percentage of females were aware of their rights than men. This could be explained by the fact that female also admitted with their children and they are more often to ask questions related to their own and their family health Yousouf et al (1) found that Patients were reasonably informed about their illness. Their privacy and religious beliefs were duly respected. Treatment options and the duration of treatment were not discussed with all patients.

Only 1% of the subjects were aware of all the 14 rights. About one third of the sample 32.1% was aware of ten or more rights. Similar findings by Almoajel (12) who carried a study about patients rights at King Saud Medical City in the middle province in Saudi Arabia and found that there was a lack of patients' awareness regarding the patients' rights. Danute (14) studied Awareness and practice of patient's rights law in Lithuania and get a similar results that there is a need for awareness-raising among patients to improve the practical implementation of the Patient's Rights Law in Lithuania.

There were some limitations to this study that need to be mentioned: first data was collected from subjects who were admitted at least one time to the hospital within the last six months but they are not currently hospitalized which might affect their recalling for their rights. Second, there is potential for information bias towards giving whatever the respondents thought would be an acceptable response to the researcher, rather than revealing the whole truth.

Doctors and nurses were the main source of information about patient rights for the majority of the subjects. As about 10 % of the subjects in the sample were illiterate they mostly relay on nurses and doctors as source for their information. Most of the patients do not have time to read the booklet of patients' rights during hospitalization as they mostly concerned about their diagnosis and prognosis.

Almost 22% of the subjects got their information about patient right by reading it from the hospital board. In contrast with these results Changole (15) found that half of the patients who participated in the study had never heard of any patients rights anywhere. This finding may indicate how the health care system has neglected such an important legal issue. No single poster on patients rights was available on walls of the unit and no lesson were given to patients concerning their rights

Farther studies to assess the health care provider's awareness and application of patient's right needs to be conducted in Saudi Arabia to assure that the health care providers understand the up to date approach and sophisticated importance of health care quality assurance, patient's rights and how to solve any problem out of respect of patient. Also programs to enhance patient's awareness must be conducted to be able to improve the practical implication of patient rights.

**Conflicting Interest:** There was no conflict of interest.



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