## Level of health awareness of Saudi patients on renal replacement therapy

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## **ABSTRACT**

**Objective:** To assess health awareness in patients on renal replacement therapy (RRT) in Saudi Arabia.

Methods: This is a cross-sectional survey using a 22-item questionnaire in 143 randomly selected adult RRT patients [40 on hemodialysis (HD), 61 on peritoneal dialysis (PD) and 42 with renal transplant (TX)]. The study was carried out at King Abdul-Aziz Medical City, Riyadh in April 2006. The questionnaire was designed to evaluate patients' knowledge in 5 areas: 1. causes of renal failure, 2. biology of the kidneys, 3. symptoms of kidney disease, 4. therapeutic options available, 5. national kidney patients support facilities. The association between the level of awareness (the percentage of correct answers) to different demographic factors was assessed.

Results: Three fifths of the patients had less than secondary education. The average mark for correct responses of all patients was 45.9% with a highest (58%) for the category on "biology of the kidney" and lowest (36.8%) for "national kidney patients support facilities". The PD group had the highest score (54.4%) followed by HD (44.3%) and finally TX (35.1%).

Conclusions: The level of our patients' health awareness is lower than satisfactory. Level of education seems to be a contributory factor.

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The prevalence of chronic renal failure (CRF) is high in the Kingdom of Saudi Arabia. There are currently almost 8000 patients on dialysis. In addition, the incidence of CRF is rising due to the expanding group of the elderly and the massive epidemic of diabetic nephropathy (DN). The number of kidney transplants does not match this growth in the number of patients. In Saudi Arabia and over a 20-year period, the prevalence of endstage renal disease (ESRD) has increased from 20-25 to 270 per million population (PMP) per year (11-fold increase) and the incidence rose from 4.6 to 38.6 PMP (8-fold increase).

The other highly noticeable trend in Saudi Arabia is the rise in the mean age of patients on dialysis. This rose from 37.9 years in early 80s to 51.3 years by the end of the 20th century. Similar trends of increasing incidence of ESRD and higher age of patients have been seen in other countries.

Renal replacement therapy in any given country is highly correlated to its Gross National Product. The spending on dialysis in USA in 1991 was approximately \$8 billion. In 2001, it rose to staggering \$22.8 billion of which \$15.4 billion was from Medicare budget. This amounts to 6.4% of the total Medicare budget. Erythropoietin (which costs \$440/month per patient) accounts for a substantial part of the cost in the treatment of patients on dialysis. The cost of providing dialysis is horrendous. In Saudi Arabia where 8000 patients are currently on dialysis, the annual cost is 700 million Saudi Riyals (equivalent of 185 million US \$).3

The patient on renal replacement therapy needs to be aware of factors that can affect his/her health and well being. These include compliance with treatment, knowledge of diet to avoid, amount and type of fluids to take or avoid, and awareness of possible complications that can accompany the condition.

Over the last decade there have been attempts at educating Saudi kidney patients on renal replacement therapy. This was carried out through the efforts of both our institution and the Saudi Center for Organ Transplantation. It is known that an aware patient is an empowered patient,

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especially in chronic disease settings. An aware patient is more likely to share effectively and usefully in his/her own care and ask for and get more optimal care.

In this study, we investigate the awareness of Saudi patients on renal replacement therapy regarding a number of issues related to their healthcare.

**Methods.** This is a cross-sectional survey carried out in April 2006 using a 22-item questionnaire in 143 randomly selected renal replacement therapy patients [40 on hemodialysis (HD), 61 on peritoneal dialysis (PD) and 42 with working renal transplant (TX)]. We excluded children and those who did not consent.

The questionnaire was pre-tested and written in simple Arabic to evaluate patients' knowledge in 5 well-thought areas evaluating knowledge of: 1. causes of renal failure, 2. biology of the kidneys, 3. symptoms of kidney disease, 4. therapeutic options available, and 5. national renal scene. Moreover, we collected demographic information such as age, gender, education, region of residence, and having children.

The overall awareness score was calculated as a percentage of correct answers. The impact of type of the renal replacement therapy (HD, PD or TX) on the overall awareness score as well as any of the 5 different categories was assessed. Additionally, we analyzed the impact of any of the demographic characteristic on the scores. A point was given for each correct response, whereas no point was given for each wrong or missing response. No score was given for the demographic data.

Table 1 - Demographic characteristics of the studied subjects.

Demographic Characteristics	Details of characteristics	N	(%)
Gender	Male	78	(54.5)
	Female	65	(45.5)
Place of residence	Central province	128	(89.5)
	Other provinces	15	(10.5)
Age	Less than 40 years	84	(58.7)
	More than 40 years	59	(41.3)
Group of patients	Hemodialysis	40	(28.0)
	Peritoneal dialysis	61	(42.7)
	Renal transplant	42	(29.3)
Parents	Yes	108	(75.5)
	No	35	(24.5)
Education	Below secondary	86	(60.1)
	Above secondary	57	(39.9)

The maximum score possible for the whole questionnaire was the total correct points of 56, which were denoted as 100%. Additionally, each of the 5 awareness categories was marked separately.

Statistical analyses. The total scores were calculated for the sample as a whole and then compared between the 3 patient groups (HD, PD, and TX) to find any significant differences using Analysis of Variance testing. A p-values <0.05 were considered statistically significant. Moreover, scores were compared according to the different demographic information such as education status (above or below secondary education), age (above or below 40 years of age), gender, and place of residence (Central region versus other regions) using chi-squared testing. Similarly, the scores were calculated and analyzed separately according to each of the 5 categories and the effect of the same factors (modality of the patient, education, age gender, and area of residence). Data management and analyses were carried out using the Statistical Analysis System version 8.02 (SAS Institute, North Carolina).

**Results.** The vast majority of the responders filled out the questionnaire on their own; a few needed the questions to be read to them by the health educator.

Table 1 describes the demographic characteristics of the 143 respondents. There were 54.5% males and the vast majority 89.5% were from the Central region of the Kingdom. There were slightly more patients over the age of 40 years compared to those aged less than 40 years of age. Approximately three fifths of the patients had secondary education or less and just under two fifths had either attended secondary or university education.

**Table 2** shows the overall scores (expressed as percentages) by the 3 groups of patients pooled together (N=143) broken down into the 5 question categories. It can be seen that the best score was for "biology of the kidney" set of questions and the worst mark was for the set of questions regarding "national kidney patients support facilities".

**Table 2** - Average scoring of the subjects, categorized by the different categories as well as the inter-quartile range.

Question category	Awareness score (%)	Inter-quartile range (%)
All categories combined	(45.9)	(33.9)
Causes of renal failure	(43.1)	(25)
Biology of the kidneys	(58)	(43)
Symptoms of kidney disease	(51.1)	(40)
Therapeutic options available	(43.2)	(43.8)
National kidney patients support facilities	(36.8)	(42.9)

**Table 3** shows that when the scores were broken into the 3 patient groups (HD, PD and TX) separately, it was apparent that the PD group had the highest mean score (54.4%) followed by HD group (44.3%) and finally the renal transplant group (35.1%) (p=0.005). Indeed the PD group scored highest in all 5 question categories and this was statistically significant.

**Table 4** shows that there was no significant impact by gender, educational level and parenthood on the overall scores or scores according to awareness categories.

**Discussion.** This study revealed that the mean overall score for correct responses in all the patients pooled together was 45.9%. This is a disappointing result suggesting that we are not doing a good job at raising the awareness of our patients.

**Table 3** - Correct response rates in each question category in the 3 patient groups.

Question category	Group 1 HD	Group 2 PD	Group 3 TX	P-value
All categories combined	(44.3)	(54.4)	(35.1)	< 0.0001
Causes of renal failure	(40.8)	(51.3)	(33.3)	< 0.0001
Biology of the kidneys	(57.5)	(66)	(47)	< 0.0001
Symptoms of kidney disease	(49.3)	(60.7)	(39)	0.0002
Therapeutic options available	(42.5)	(51.7)	(31.5)	<0.0001
National kidney patients support facilities	(33.9)	(44.7)	(27.9)	0.003

HD - hemodialysis, PD - peritoneal dialysis, TX - renal transplant

The highest mark of 58% was achieved in the category on "biology of the kidney". This may be related to the fact that 40% had secondary or university education and the questions in this category had to do with simple queries on kidney anatomy and physiology. The second highest score by category was seen in response to questions on symptoms of kidney disease. This may not be surprising as these patients suffered from these symptoms (51.1%). The low score in the "therapeutic options available" category (43.2%) would suggest that we as health care givers do not explain the treatment options to the patients. This, however, may be related to the fact that over 70% of our patients had their first medical encounter when an immediate renal therapy was required in one way or another.<sup>1</sup>

It is particularly disappointing that the lowest score was seen for the "national kidney patients support facilities category (36.8%), despite concerted efforts by the Saudi Center for Organ Transplantation to spread awareness among the public generally and renal patients in particular.

When the scores were broken down according to the 3 patient groups (HD, PD, and TX), it was apparent that the PD group had the highest mean score 54.4% followed by HD group 44.3% (44.7%) and finally the renal transplant group 35.1% (*p*<0.0001). This trend was seen in all question categories and at statistically significant levels. One possible explanation is that patients accepted for PD tend to be younger, more educated and professional than those receiving hemodialysis. Another possible explanation is that PD patients carry out their own treatment and receive continuous training in this respect. These 2 explanations are likely to raise health awareness among patients.

**Table 4 -** Distribution of scores according to demographic data.

Demographic Characteristics	All categories combined	Causes of renal failure	Biology of the kidneys	Symptoms of kidney disease	Therapeutic options available	National rena scene
Education						
< secondary	(44.6)	(41.1)	(56.7)	(50.1)	(42)	(35.6)
> secondary	(48.8)	(46.4)	(61.2)	(53.6)	(45.9)	(39.3)
<i>p</i> -value	0.2	0.2	0.2	0.5	0.4	0.9
Gender						
Males	(46.6)	(42.3)	(59.9)	(52.2)	(43.9)	(39)
Females	(45.7)	(44.7)	(56.6)	(50.6)	(43.1)	(34.6)
<i>p</i> -value	0.8	0.5	0.3	0.7	0.8	0.3
Parents						
Yes	(46.5)	(42.8)	(58.3)	(51.5)	(44.6)	(37.7)
No	(46.8)	(45.5)	(59.6)	(52.6)	(42.3)	(37.1)
p-value	0.9	0.5	0.7	0.8	0.6	0.9

No significant differences were found in the overall score or in the scores by category due to gender or parenthood. There was a minor trend towards higher scores in patients with secondary education or higher but this did not reach statistical significance.

There is very little resources in the literature considering health awareness amongst patients on renal replacement therapy although there are some reports assessing awareness among the public and among those with other diseases.

In a study to assess awareness of terminal cancer patients, the authors found that only one third of the patients and caregivers understood that the treatment was curative. The awareness regarding the actual goals of treatment improved with time and specially 6 months before death and the authors concluded that awareness is a dynamic process, which improves with time and communication skills.<sup>4</sup>

There are also ethnic differences in awareness regarding the diseases. As an example, it appears that hypertensive African Americans are more aware of the definition of hypertension and that it can lead to renal failure compared to their Hispanic and white counterparts. On the other hand, they were more likely to believe that medications are the only way to control blood pressure.<sup>5</sup>

A recent survey in Canada<sup>6</sup> showed that both hypertensive patients and the public have very poor awareness regarding the complications of hypertension and its serious prognosis.

There are reports showing evidence that patient empowerment and education improve outcome in a number of disease processes. One such study showed that a structured patient education by adults with type 2 diabetes resulted at 14 months to improved glycemic control, reduced total cholesterol level, body weight, body mass index and waist circumference, reduced requirement diabetes medication.<sup>7</sup> In a randomized multicenter study based in Munich it was shown that within a 2-year period such a program was related to a significant reduction in rehospitalization rates from 58-41% and also a shortening of intermittent days spent in hospital from 78 to 39 days.<sup>8</sup> Patient education in elderly patients with hypertension has also been shown to enhance BP control significantly.<sup>9</sup>

It is possible that any positive effects of health education has more to do with motivation and changes in behavior and attitudes rather than with expansion of knowledge.<sup>10</sup>

In another study on the effect of education in asthmatic patients, it was found that in the intervention group, there were less visits with acute asthma as compared to the reference group; and this positive influence was more prominent in children.<sup>11</sup>

In a study designed to assess awareness of 9 major risk factors for heart disease among American Indians it was reported that the percentage of correct answers ranged from 70-90%. It is interesting in this study that unlike our study, the responders with hypertension or diabetes scored higher than the others. Furthermore, and again unlike our study, females and advanced education, were significantly associated with heart disease awareness.<sup>12</sup>

In a controlled study in diabetic patients using patient empowerment education program, it was shown that intervention group had a significant reduction in glycated hemoglobin levels.<sup>13</sup>

In a survey carried out on the public in Singapore to investigate the public's awareness on diabetes mellitus, the correct response rate was high but as the authors point out this may be related to the high percentage of secondary and tertiary education among respondents (86.3%). It is interesting to note that in this study, the respondents' awareness of diabetic support groups in Singapore was low despite apparently effective media campaigns over a long period of time.<sup>14</sup>

Patient empowerment in their own care is becoming essential in managing patients especially in chronic illnesses as the above references show. This has been shown to improve prognosis in diabetic patients. This process requires awareness of the diseases, their complications and treatment options. This study suggests that we need to improve our health education of our patients particularly in making them aware of the treatment options available to them and the national scene in renal services. This could be enhanced in a number of ways including increasing the input from trained health educationalists, developing website and internet discussion groups for the various diseases and establishing chronic kidney diseases clinics.

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## **Related topics**

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