Curr Pediatr Res 2016; 20 (1&2): 219-226

ISSN 0971-9032
www.currentpediatrics.com

Parental perceptions of their child's kidney disease.

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Abstract

Objective: To evaluate parental perceptions of their child's acute or chronic kidney disease, and to identify significant determinants of parental understanding among a sample of caregivers.

Method: This is a cross-sectional study, which was conducted over 4 month period from 1 February, 2014 to 30 May, 2014. The study involved structured face-to-face interviews for questionnaire completion with a convenience sample of 121 adult caregivers of children with acute or chronic kidney disease (aged 18–54 years) to explore their perceptions on their child's condition. Subjects were recruited from the Pediatric Nephrology clinic at King Abdul-Aziz University Hospital in Jeddah, Saudi Arabia.

Results: Perceived diagnosis awareness (77%), understanding of complex information such as the use of clean intermittent transurethral catheter (67%), and effects of medication (51%). There was an association between perceived knowledge and understanding of the condition with caregiver level of education (P value=<0.0001). Understanding of disease etiology is associated with education level (P value <0.05). Perceived knowledge and understanding of kidney disease was significantly positively associated with time-taken to explain the disease (P value <0.0001). Overall satisfaction levels with explanations were positively associated with caregiver age (P value<0.05). Caregivers favoured use of educational materials, particularly video (95%).

Conclusion: This study reveals existing patient-doctor communication can be improved through the establishment of standardized guidelines and practice on what, when, and how to elaborate on the condition with caregivers; and the efficacy of these practices to be measured and regularly reviewed.

Keywords: Renal diseases, Parents, Childhood, perception, Health Professional.

Accepted September 26, 2016

What is Already Known?

1. Parents would like more information on the disease at diagnosis and on the long-term outcomes for their children.
2. Caregivers who lack a social support network were found to be more prone to report and demonstrate depression-related symptoms.
3. Parental anxiety is strongly associated with psychological distress. This makes parents vulnerable to feelings of helplessness and actual cognitive disturbances.
4. Parents must also adopt a healthcare provider role, in addition to their expected parental responsibilities.

What this Study Adds?

1. It reveals existing effort among healthcare professionals to efficiently convey information to caregivers regarding their child's disease.
2. It reveals that healthcare professionals' approach to caregivers may be dependent on the diagnosis, educational background and age.
3. Caregiver's perceived knowledge and understanding of the disease was positively associated with the time taken to explain the disease.
4. The existing patient-doctor communication can be improved through the establishment of a standardized guidelines and practice.

Introduction

Studies on acute, chronic and life-threatening pediatric illnesses suggest that parental experiences of a child's severe illness are associated with heightened emotional distress, Post-Traumatic Stress Disorder (PTSD) and clinical depression [1-3]. This applies to parents whose children have acute or Chronic Kidney Disease (CKD); long-term conditions which result in life-long challenge and uncertainty. Treatment in such cases requires a coordinated multi-disciplinary approach, and involves numerous medications (delivery could include subcutaneous injections), invasive measures, 3-4 h of hemodialysis three times a week, or alternatively ongoing peritoneal dialysis, plus use of enteral tubes for nutritional augmentation [4].

A qualitative study of a group of 30 parents in Glasgow, Scotland in 2009, which explored parental concerns of children affected by Verocytotoxin-producing *Escherichia coli* – Haemolytic Uremic Syndrome (VTEC-HUS), showed that parents would like more information on the disease at diagnosis and on the long-term outcomes for their children [5]. This study found that such parental anxiety is strongly associated with psychological distress and makes parents vulnerable to feelings of helplessness and actual cognitive disturbances [5]. With CKD children, Health-Related Quality of Life (HRQoL) measurements are rather recent area of study, particularly in developing countries. Published results are inconclusive and relate only to small groups of patients at different CKD stages [6-8]. While Eijsermans et al. stated that the perceived QoL among children on dialysis and the general population were similar [9]; research by Gerson et al. [10] showed that compared to control subjects, patients with CKD (treated conservatively and undergoing renal replacement therapy) had lower overall satisfaction regarding their health. It is evident that given the complex nature of care required for all of these conditions, parents must also adopt a healthcare provider role, in addition to their expected parental responsibilities which makes it harder for them [11].

Tsai et al. in 2006 from Taiwan explored psychosocial factors impacting caregivers of those children diagnosed with peritoneal dialysis (PD) [12]. Similarly, Fielding and Brownbridge in 1999 in Leeds, UK carried out a survey of 60 caregivers of patients who were receiving chronic dialysis, which investigated psychosocial effects on caregivers of paediatric patients with End Stage Kidney Disease (ESKD) [13]. Both studies consistently identified the severity of the impact on the parents was greatest, the younger the child. These studies emphasized the consequences of the resultant isolation, which can occur whenever looking after those with a chronic condition. Additionally, caregivers who lack a social support network were found to be more prone to report and demonstrate depression-related symptoms.

In view of the need for parents to take on their unfamiliar roles of nurse, pharmacist and physician for their affected children and the psychosocial burden that this may impose on them, it is of paramount importance that parents receive effective education regarding their child's diagnosis and illness, and that communication with health-care professionals is open and effective. This means that parents must have sufficient information, time, educational materials, and effective parent-health professional communication provided to them for the benefit of the parent and ultimately the patient. Due to the particular importance of the caregiver role to those with CKD, researchers believe that parental perceptions on the quality and effectiveness of this educational and communication process play a major role in HRQoL. The aim of this study is to describe a snapshot of these current parental perceptions based on existing practices. To our knowledge this is the first study from Saudi Arabia evaluating perceptions of parents of children with renal disease. It has the potential for setting future recommendations for best practice.

Methodology

We conducted a cross-sectional study over 4 month period from 1 February, 2014 to 30 May, 2014. One hundred and twenty one adult caregivers (aged 18–54 years) were interviewed face-to-face to complete a questionnaire.

Patients were recruited from the Pediatric Nephrology clinic at King Abdul-Aziz University Hospital (KAUH) in Jeddah, Saudi Arabia. The sample included all subjects who were available and willing to participate in the study. Before the commencement of the study, the purpose, scope, nature and aims of the research were explained, and informed consent was obtained. 100% of parents approached agreed to participate. The participants were free to withdraw from the study at anytime, and this was explained before the study commenced.

A specially designed structured questionnaire was used to collect the data. This was constructed after a thorough review of the literature, and in the absence of a relevant pre-published validated questionnaire. It includes 25 questions, and took approximately 20 min to administer. The first section was concerned with socio-demographic data, including: age, gender, file number, caregiver name and education level; while the second part involving 20 out of 25 questions was related to parental perceptions and understanding of the diagnosis, the nature of the disease, prognosis, the treatment plan, medications, possible outcomes, educational materials and tools used to explain the disease. It was designed in English and translated into Arabic as appropriate during the structured interview. Piloting of the questionnaire was carried out with 10 patients from within the Nephrology clinic who were then excluded from the study.

After receiving approval from the Research Ethics Committee of the Faculty of Medicine in King Abdul-Aziz University, the study was carried out in two stages. Stage one was a medical chart review for those attending the pediatric nephrology clinic and whose parents had agreed to participate in the study. This review allowed access to relevant demographic data. Stage 2 involved the administering of the questionnaire in a face-to-face setting with researchers who were able to provide clarity and support within the interview. Both data collectors spoke Arabic and English fluently and could communicate in

English with non-Arabic speaking participants of diverse nationalities. This level of support also facilitated a high retention rate of 100%, and a high completion rate of 100% for the questionnaires.

Interviews were not recorded nor transcribed. For patient confidentiality, a data coding system was used during data entry to ensure patient anonymity. Data was kept secure to ensure patient confidentiality.

Statistical Analysis

Data was analyzed in two parts. Firstly, there was description of the data using frequency, cross tabulation, percentages and charts. Secondly, there was an examination of associations between variables and the statistical significance of such associations identified, using Chi square tests. All analyses were performed using the MINITAB statistical software package.

Results

Parental and Child Demographics

We recruited 121 subjects. Sixty-two percent of the children in the study were males. The age of the patients at diagnosis ranged from prenatal to 8 years old. The majority of kidney conditions were diagnosed at birth or antenatally (Table 1). The age of the patients at the time of this study ranged from 1 to 16 years, with a median of 6 years old (Table 1).

All the caregivers who responded to the questionnaire were patient mothers, and more than half of them were Saudi nationals. Most were educated, with about 9 out of 10 having attained at least secondary education. The age of the caregivers ranged from 18 to 54 years, with a median of 33 years (Table 2).

Perceived Knowledge of the Diagnosis and Condition

Perceived knowledge of their child's diagnosis (95%) and the nature of the disease (77%) among the caregivers were high. There were no associations by age (Figure 1) or nationality (Figure 2). The latter also indicates that overall satisfaction rates and time-spent on explanation was slightly reduced for Non-Saudis compared to Saudis. There was an association between perceived knowledge and understanding of the condition, but not diagnosis, with caregiver level of education (P value=<0.0001). Similarly, understanding of disease etiology was also associated with education level (P value <0.05), and also with the type of diagnosis (P value <0.05) (Table 3).

Perceived knowledge and understanding of the disease was significantly positively associated with time-taken to explain the disease (P value <0.0001)

Table 1. *Demographic characteristics of the pediatric patients*

Child		**N**	**%**
Gender	Male	73	62.0
	Female	45	38.0
Age at Diagnosis	Antenatal	9	7.0
	At birth	52	43.0
	Infancy	21	17.0
	1-4 years	30	26.0
	5-8 years	9	7.0
Current Age	1-5 years	49	41.0
	6-10 years	49	41.0
	11-16 years	22	18.0
Nationality	Saudi	67	55.0
	Non-Saudi	54	45.0

Table 2. *Socio-demographic characteristics of the caregivers*

Caregiver		**N**	**%**
Relationship	Mother	121	100.0
Nationality	Saudi	67	55.0
	Non-Saudi	54	45.0
Education Level	No education	2	2.0
	Primary (6-11 years)	11	9.0
	Intermediate (11-14 years)	31	27.0
	Secondary (14-18 years)	29	25.0
	Bachelor degree	33	29
	Professional/Diploma	3	3.0
	Postgraduates	6	5.0
Age	<=20	3	3.0
	21-30	46	40.0
	31-40	59	51.0
	41+	7	6.0

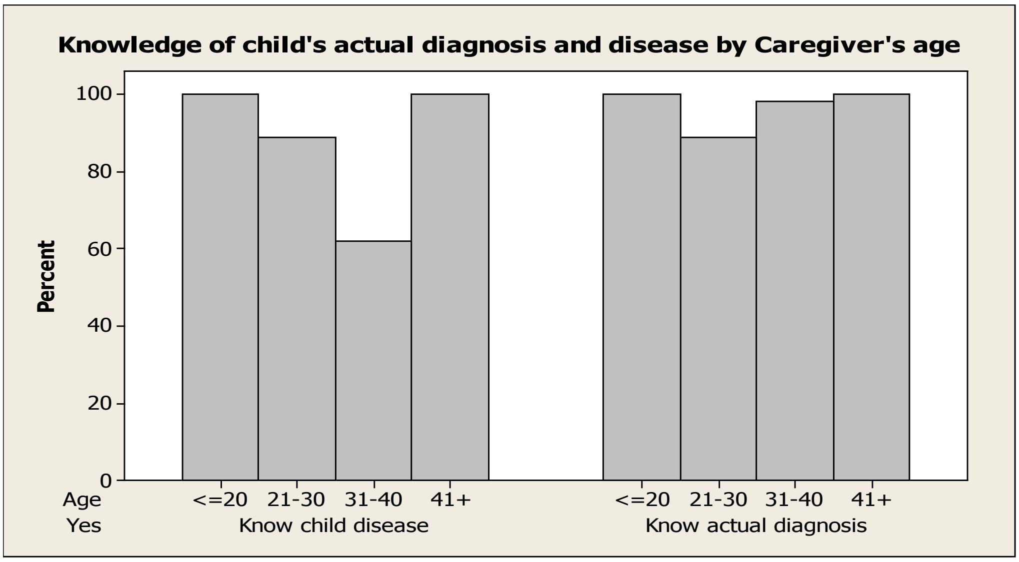

Figure 1. Perceived knowledge of diagnosis and condition by caregiver age

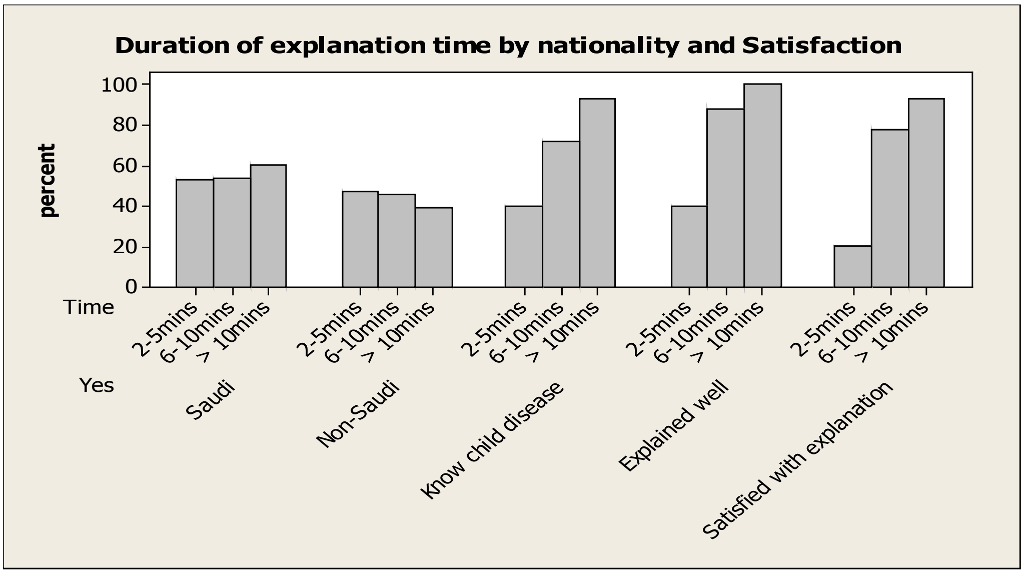

Figure 2. Duration of explanation time by nationality, perceived knowledge and satisfaction

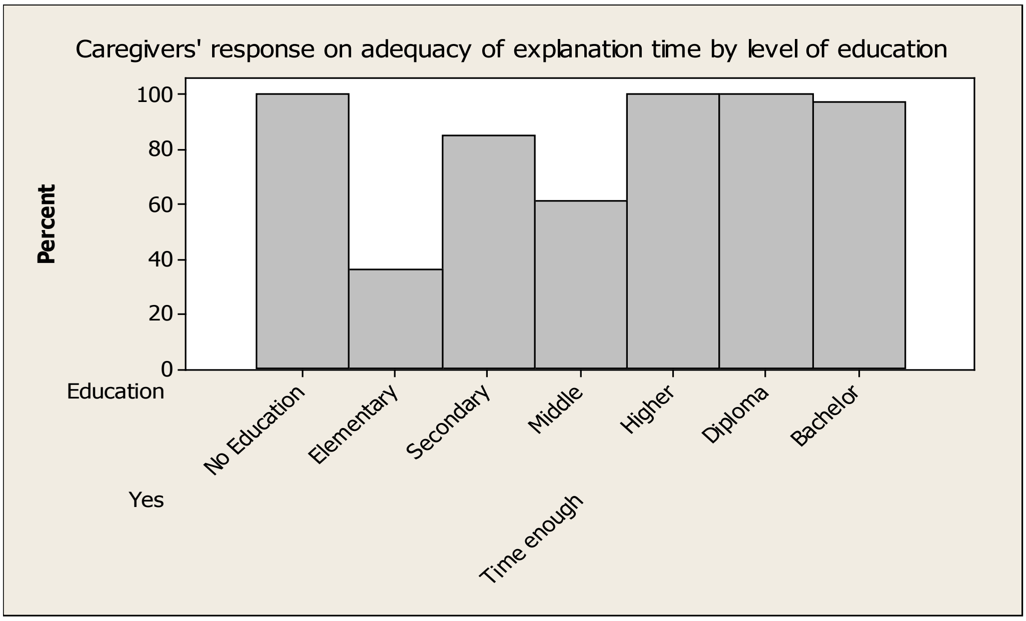

Figure 3. Caregiver satisfaction with duration by educational level

Table 3. *Summary of responses to questionnaire items*

Question Item	No (percentages)	Yes
Does the caregiver know the actual diagnosis?	6 (5.0)	109 (95.0)
Does the caregiver know about his child's disease?	27 (23.0)	88 (77.0)
Was the child's disease explained well?	15 (14.0)	93 (86.0)
Was the time taken to explain the child's disease enough?	24 (21.0)	88 (79.0)
Were complications of the disease explained to the caregiver?	46 (40.0)	69 (60.0)
Was the etiology of the disease explained to the caregiver?	45 (39.0)	70 (61.0)
Were the effects of the disease on growth & exercise explained?	33 (29.0)	82 (71.0)
Was the outcome of the disease explained to the caregiver?	30 (28.0)	76 (72.0)
Were the long-term prognosis explained to the caregiver?	39 (35.0)	73 (65.0)
Was he/she satisfied with the explanation of the child's disease?	27 (23.0)	88 (77.0)
Was the explanation of child's disease enough to alleviate his/her anxiety?	30 (27.0)	82 (73.0)
Was the use of educational materials to explain the child's disease sufficient?	6 (5.0)	109 (95.0)
Were the caregiver told about the nature of clean intermittent catheterization?	15 (50.0)	15 (50.0)
Were you told about the complications of the use of urinary catheter?	18 (67.0)	9 (33.0)
Was the effect of the medication explained to the caregiver?	93 (51.0)	90 (49.0)
Was the side effect of the medication explained to the caregiver?	48 (43.0)	64 (57.0)
Was the caregiver educated about long-term management?	39 (35.0)	73 (65.0)

(Figure 3). This shows that caregivers believed that the more time spent with them by health-care professionals on explaining the diagnosis and condition, the more they understood it. Those with an explanation time of 2-5 min were less likely to believe they understood the details of their child's disease compared with those who reported that health-care professionals had spent six or more minutes communicating with them on this (Figure 2). Of those parents who indicated that they were not satisfied with the explanations (Figure 2), about 80% believed that they lacked knowledge of their child's disease (Table 3).

Duration of Explanation and other Variables

Satisfaction rates were almost equivalent to time-spent on the explanations across nationalities and the majority (87%) of caregivers had at least 6 min of explanation of their child's disease spent with them (Figure 2). Distribution across age groups was similar; yet about two-thirds of those aged 20 years or less were of the opinion that the explanation time was inadequate (Table 3). Explanation was also associated with caregiver level of education (p-value <0.05). Those with an elementary education were more likely to have less time-spent (2-5 min) on explanations compared to those with higher levels of education (Figure 3).

The majority (79%) of the respondents were of the opinion that time used to explain their child's disease was sufficient (Figure 3). Almost two-thirds of all of those who indicated that the explanation time was insufficient, , stated that they had no knowledge about their child's disease (Table 3). Those who felt that time-spent on explanation was insufficient varied across nationality, level of education, age and disease type. Non-Saudis would like more time for explanation; and those with elementary and middle education also expressed a preference for extended time on explanation.

Explanation Satisfaction Rates and other Variables

Overall satisfaction levels with explanations were positively associated with caregiver age (P value <0.05) (Figure 4). Those most unhappy with the presentation of information on the disease were the 31-40 year age group that were least satisfied with the explanation. Those who indicated dissatisfaction with explanations given (23%) also stated they had no knowledge of the disease (Figure 4).

Diagnosis caregiver satisfaction rates seemed to vary by disease types, with some showing dissatisfaction higher than others. For example, caregivers of patients with obstructive uropathy, Steroid Sensitive Nephrotic Syndrome (SSNS) and renal anomalies were more likely to believe that they did not understand explanations of disease etiology than caregivers in other disease categories. About 90% of caregivers received all information from a consultant, and of these Saudis made up 60%. The majority (86%) of respondents believed diagnosis explanation itself was satisfactory (Table 3), but this varied by level of education (P value <0.01) and age (P value <0.01). About 73% of those with an elementary education expressed dissatisfaction with the explanation on diagnosis, and similarly lower satisfaction rates were expressed by respondents aged 31-40 years compared to other age groups (Figure 4).

In terms of age, about half were particularly dissatisfied with explanation of side effects, with dissatisfaction higher among the lower age groups (Table 3).

The etiology, long-term prognosis, effects and side effects of medication and long-term management of disease were among those areas that caregivers reported highest levels of dissatisfaction (Table 3). Saudis were more satisfied in general with explanations compared to other nationalities (Table 3). Nevertheless, about 50% of non-Saudis and 39% of Saudi nationals reported that disease etiology was not well explained. Also, about 58%

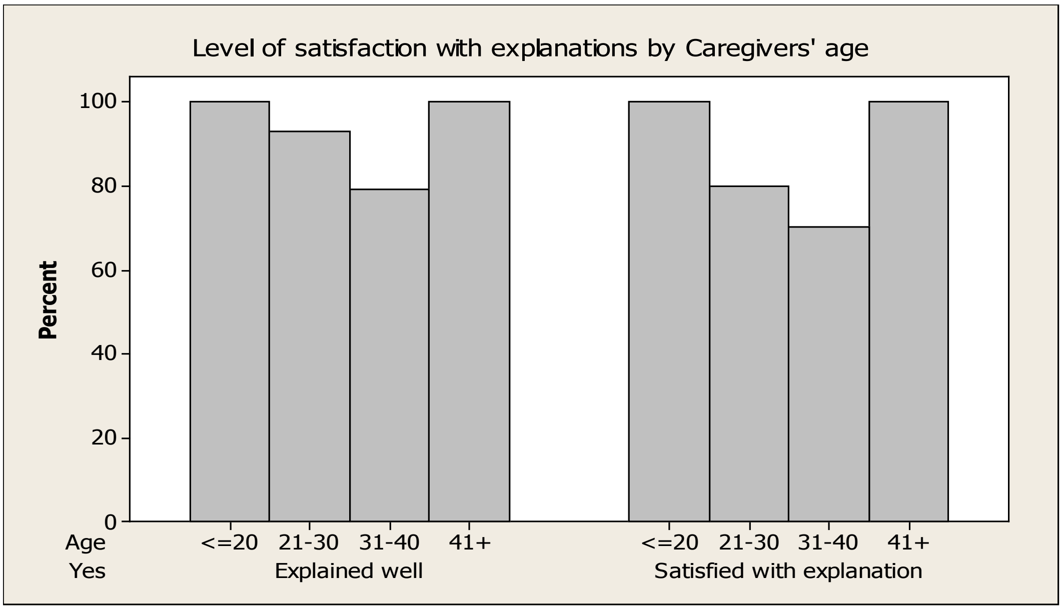

Figure 4. *Caregiver explanation satisfaction levels by age*

Table 4. *Actual versus preferred educational materials*

Educational Material Used			Preferred Education Material		
Material	**N**	**Percentage**		**Count**	**Percent**
Demonstration	40	40.0		24	22.6
Urine dipstick demonstration and record keeping	12	12.0		6	5.7
Drawing the mechanism of the illness	3	3.0		-	-
Video	12	12.0		73	68.9
None	21	21.0		-	-
Lecture/presentation	9	9.0		-	-
Conversation	3	3.0		-	-
Internet: Multimedia	-	-		3	2.8
N	100	100.0	N	106	100.0

and 48% of non-Saudis and Saudis respectively were of the opinion that the side-effects of medications were inadequately explained.

Educational Materials

Perceived knowledge was also related to the type of educational material used for explanation. Those who had no educational material used with them were less likely to state that they understood the nature of their child's disease. This depicts a large disparity between educational materials used and caregivers preferences. In existing practice, emphasis was placed on the use of demonstration as a mode of explaining disease information to the caregivers. In fact, 21% of caregivers actually received no explanation at all. Of those who did experience doctor-patient communication, caregivers overwhelmingly favoured using any form of supporting educational materials rather than none. Preferred educational materials varied by caregiver level of education. The majority above elementary education levels stated they would prefer video, while those with no education or elementary education only stated they would opt for demonstrations (Table 4).

Discussion

The results show that the majority of participants perceived that they were adequately informed by healthcare professionals in KAUH of their child's disease (77%). This can be significantly attributed to the high level of caregiver education as 29% of caregivers have a bachelor's degree. The areas of dissatisfaction revolved around more complex information, such as etiology, complications and side effects of medication, rather than the diagnosis/Dissatisfaction with the time taken explaining these areas was also significant. These findings echo those of a study conducted by Tong et al. [11] which reports a concern of some parents that they do not receive adequate information on illness and treatment. Results of their study similarly showed that there was a perceived lack of education provided to the participants regarding the effects of medication (51%) and the complications of long-term use of urinary catheter (67%). However, in both studies overall the role expected of healthcare practitioners in relation to patient/ parent education has been achieved due to the high percentage of satisfaction that was depicted by the results.

Nevertheless, the fact that those caregivers with lower education levels seemed to be less likely to understand the nature of their child's disease (9%), suggests a need to examine carefully the materials, communication strategies and level of understanding that healthcare practitioners may assume. It is unclear from this study to what extent language barriers may have inhibited communication as not all caregivers may have had fluency in either Arabic or English; or indeed if perceived differences in social status between consultants and caregivers could have resulted in higher levels of passivity and people pleasing behaviours resulting in a caregiver reluctance to initiate questioning.

Time spent on explanation as well as methods used need to reflect caregiver needs and preferences, and may also have to vary by diagnosis with some conditions meriting more allocated time than others. So, there may be a need to differentiate healthcare professionals approach to caregivers dependent on diagnosis, educational background and age. Equally as greatest dissatisfaction occurs in relation to the nature of the etiology of the disease, the treatment plan, medication side effects, complications and prognosis, this implies the need for ongoing communication that allows for discussion at the varying stages of the individual child's disease and in the face of different possible complications and prognosis rather than a one-off session at the diagnosis stage.

Historically, it is likely that during paediatric clinical care, efforts were focused on the provision of medical treatment, tests and the monitoring of the child's well-being rather than active consideration of parental needs. By understanding parent experiences, it would be ideal if healthcare providers could consistently demonstrate more supportive and empathetic care. The 'living worried' is most likely an appropriate term to describe parents of children affected by renal disease and studies provide strong evidence that systematic observation of parents may be necessary since their own well-being may be at risk [5].

Seventy three percent of our studied caregivers felt that the explanation of their child's disease was deemed enough to alleviate their anxiety. This is on line with evidence attained from the study made by Taanila et al. [14] which states that in other areas of pediatric medicine, intervention studies have shown that information and diagnosis management are keys in helping parents cope. Coordinated efforts between the general practitioner, pediatric nephrologists, social worker, psychologist and parent support groups may alleviate parental concerns. Increasingly, parent and patient support groups are seen as being very important for provision of information and advice with respect to a number of diseases including childhood kidney disease [15,16].

Conclusion

The role of the paediatric nephrologists is a challenging one as they are involved in diagnosis, clinical management and treatment of the patient as well as providing on-going pertinent information to the parents, at the right times. Verbal relay of information on diagnosis and likely prognosis are important but will not be fully absorbed or fully appreciated by parents during the initial stages of hospitalization or diagnosis of their children diseases

This study reveals existing effort among healthcare professionals to efficiently convey information to caregivers regarding their child's disease, yet scope for improvement is also evident. It is recommended that standardized guidelines and standardized practices to be established. These guidelines and practices need to take into consideration factors that influence doctor-caregiver communication. Measurement and review should occur on an annual basis to ensure mechanisms for maintaining or further improving this service. Further studies are recommended in this area.

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Special issue: Pediatric Research
Editor: Abdulla A Alharthi, Department of pediatric nephrology, Taif University, Saudi Arabia