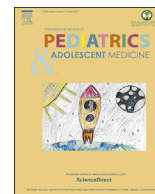


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Original article

Breaking bad news to children with chronic kidney disease: A questionnaire-based study and literature review

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ABSTRACT

Introduction: **Breaking bad news to caregivers of children with (CKD)** [I can't comment in the box] *Title says to breaking bad news to children but in here, breaking bad news to caregivers. Please clarify and edit accordingly.* is an important role of nephrologists. In our practice there has been a thought about parental dissatisfaction from breaking bad news to CKD patients. Caregiver's preferences on how to be told the bad news in CKD children has not been studied adequately. Our objective was to identify how much is the emotional and knowledge satisfaction of CKD caregivers and the relation of their socioeconomic and educational levels with their preferences in breaking bad news.

Methods: A questionnaire based study was conducted for caregivers of CKD children, in the outpatient clinics, and peritoneal dialysis and hemodialysis units at the King Faisal Specialist Hospital and Research Centre for three months.

Results: 83 questionnaires from caregivers of CKD patients age (1–14) years, mean age of 8.5 ± 3.9 years. (47.6%) were emotionally very satisfied, 29.5% were very satisfied about the knowledge they had.

Conclusion: Caregivers of CKD patients are satisfied emotionally more than the satisfaction about the amount of information they got. Different demographic data might affect their preferences in the way of receiving the bad news. The dissatisfaction suggesting that physicians' communication skills needs improvement.

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1. Introduction

Personal and family life is a sacred space that is protected by high walls and secure gates of beliefs, emotions, traditions, and attitudes. When these walls are lowered, the gates are opened to permit physicians into this sacred space in an ill patient's life. It is a great responsibility for physicians to maintain their trustworthiness via their appropriate conduct and practice, including the way in which they communicate with their patients.

Physicians send messages to their patients either directly or indirectly, verbally or via body language. All of those messages and

the way in which they are received might be influenced by many factors.

Breaking bad news is a challenging task for physicians, and it has to be done frequently in the clinical practice despite its unpleasantness. However, it appears that physicians struggle with delivering bad news. Gilbey et al. studied parents' perceptions and satisfaction with the physician with respect to their child's hearing loss at the time that they got the news. It was found that 50% of parents were dissatisfied with the process of breaking the news, and in most of these cases, the dissatisfaction was extreme. However, 21% of parents were happy with the way that the news was delivered to them [1].

This could be because of the lack of awareness about the way in which to define bad news. It has been commonly thought to be about life-threatening disease or death of a loved one but news can be bad depending on how much it means to different people. Bad news has been described by Buckman as any news seriously affecting a personal future expectations [2]. Bad news has also been

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described as news with a feeling of no hope, news affecting a person's mental or physical well-being, upsetting to their lifestyles, or news that conveys fewer choices in his or her life [3].

Breaking bad news to caregivers of children with chronic kidney disease (CKD) is an important task of pediatric nephrologists. In our opinion, it has a long-lasting effect due to the nature of CKD on the relationship between the doctors, their team members, the child, and his family. In our clinical experience we have noticed some degree of caregivers' dissatisfaction with the way in which they received the news about their child's CKD prognosis. To our knowledge, the preferences of Saudi caregivers for the way in which to receive the bad news about their children with CKD has not been adequately studied and investigated.

We aimed to identify a background for breaking bad news in the Saudi caregivers of children diagnosed with CKD and to be able to better understand the breaking of bad news dynamics. We tried to determine whether there were any differences among different segments of the Saudi population with respect to their preferences for the way in which they want to receive information about their child's condition and whether these differences can be explained by the factors we studied. Knowledge about the satisfaction of caregivers in breaking bad news can help to facilitate a change in doctors' communication abilities and skills and would improve the patients' and their families' psychological adaptation abilities.

2. Methods

We conducted a cross-sectional study over a 3-month period at King Faisal Specialist Hospital and Research Center in Riyadh in the pediatric nephrology clinics. Caregivers of pediatric patients diagnosed with CKD were recognized by the disease history from the hospital's patient data system. They were consecutively selected and met with interviewer before or after their regular appointments. Parents or caregivers answered a questionnaire regarding their preferences of the way they wish the bad news was delivered to them and what were the unsatisfactory points at the time of breaking bad news.

We included those patients who had CKD identified based on estimated glomerular filtration rate (eGFR) calculations by the modified Schwartz formula with <60 ml/min/1.73 and who were <14 years of age. We excluded the post renal transplant patients and new referrals with abnormal serum creatinine for only one occasion and those who have abnormal serum creatinine for <3 months duration.

The questionnaire was distributed through a pilot study consisting of 20 subjects and was modified according to their comments. The first and the modified drafts of the questionnaire were reviewed and approved by Research Center. It was anonymous and filled out individually or with help of the interviewer at the caregiver's request. A total of 84 questionnaires were answered and returned, and only one was excluded due to lack of data. No one refused to participate in the study. The questionnaire included the demographic data of the caregiver, his/her educational level, and his/her socioeconomic level (based on the latest household expenditure and income survey, published by the General Authority for Statistics, Kingdom of Saudi Arabia) [4]. The questionnaire studied two main outcomes with 22 items concerning general emotional and general knowledge satisfaction levels. Specific detailed questions were then included concerning the preferences of caregivers for breaking bad news.

The study was approved by KFSH Research Ethical Committee and Research Advisory Council with RAC no. 2151142.

Permission was asked from the patients' caregivers before filling out the questionnaire, and the caregivers were free to refuse to fill it out. All questionnaires are anonymous and confidential and related

research documents are kept in a safe closet. No one has access to those files other than the authors.

3. Statistical analysis

Data from the structured questionnaire were analyzed using categorical descriptive analysis. Frequencies, percentages and graphs were used to illustrate the responses. Statements that asked the participants about their preferences regarding breaking bad news were recorded using a Likert scale of five categories: (1) strongly agree; (2) agree; (3) neutral; (4) disagree; and (5) strongly disagree. Besides assessing the preferences, two outcome questions were added, which addressed emotional and knowledge satisfaction levels. Education and socioeconomic level variables were further grouped into binary variables when we test their association with the outcomes. Pearson's chi-squared test was used for an association analysis with a significance level of 0.05. SPSS 20 software was used to analyze and visualize this data.

4. Results

4.1. Demographic characteristics (Table 1)

We collected 83 questionnaires from caregivers (53.8% mothers, 43.6% fathers) of CKD children aged 1–14 years with a mean age 8.5 (3.9) years over a 3-month period of time. In terms of education levels, 47.6% of the caregivers had a university education, 41.5% had a general education, and 7.3% could not read or write. In terms of socioeconomic levels, 40.9% had a monthly income $>16,000$ Saudi Riyals (SAR), 15.2% had monthly income between 13,000 and 16,000 SAR, 15.2% between 11,000 and 12,999, and 28.8% earned $<11,000$ SAR monthly.

4.2. Primary outcomes (Fig. 1):

In term of the emotional satisfaction, we found that almost half (47.6%) of the caregivers were very satisfied, 30.2% showed some, but not much, satisfaction, and 22.2% were not satisfied emotionally. In terms of knowledge satisfaction, only one-third (29.5%) were very satisfied about the knowledge they had when they got the bad news, and 49.2% showed some but not much, satisfaction; however, 21.3% of the caregivers were not satisfied at all.

Interestingly we didn't find any statistically significant difference in the emotional satisfaction between caregivers who had high or low educational levels ($P = .57$). No statistically significant differences between those in the high or low socioeconomic groups ($P = .75$). No significant differences in knowledge satisfaction between the groups of high and low educational levels ($P = .3$) and no statistically significant differences between the high and low socioeconomic levels were observed ($P = .36$) as shown in Table 2.

4.3. Preferences of caregivers in breaking bad news

We found that all participants preferred to know about all the details of the disease and the investigations that has been done for their children. Also, they preferred to be informed about both good and bad news. More than half of them (63.3%) disagreed to know only about the information that they asked (strongly disagreed 36.7%, 26.6% disagreed, 5.1% neutral, 21.5% agreed, and 10.1% strongly agreed). More than half (66.7%) disagreed to be informed only about important information but not all of the information (43.2% strongly disagreed, 23.5% disagreed, 2.5% neutral, 17.3% agreed, and 13.6% strongly agreed) as shown in Fig. 4. We asked the caregivers about their preferences of being informed about the prognosis later rather than at the time of breaking the news, and we

Table 1
Responders' characteristics.

Characteristics of the responders			
Variable	Total		
Age mean(SD)	77	8.5	3.90%
Relation n(%)	78		
mother		42	53.80%
Father		34	43.50%
Other		2	2.50%
Education n(%)	82		
Cannot write & read		6	7.30%
General Education		34	41.40%
University Education		39	47.50%
Post-graduate		3	3.60%
Socioeconomic n(%)	66		
>16000 SR		27	40.90%
16000 - 13000 SR		10	15.10%
11000 - 12999 SR		10	15.10%
<11000 SR		19	28.70%
Emotional Satisfaction n (%)	83		
very satisfied		39	46.90%
some satisfied but not much		27	32.55%
not satisfied		17	20.40%
Knowledge satisfaction n(%)	81		
very satisfied		27	33.30%
some satisfied but not much		36	44.40%
not satisfied		18	22.20%

Table 2
Relationship of satisfaction with educational and socioeconomic levels.

Knowledge Satisfaction	Education		P value	Socioeconomic status		P value
	Low education	High education		High income	Low income	
Very satisfied	11 (13.8%)	16 (20%)	.3	10 (15.4%)	12 (18.5%)	.362
Some satisfied but not much	21 (26.2%)	15 (18.8%)		15 (23.1%)	12 (18.5%)	
Not Satisfied	7 (8.8%)	10 (12.5%)		11 (16.9%)	5 (7.7%)	
Emotional Satisfaction	Education		P value	Socioeconomic status		P value
	Low education	High education		High income	Low income	
Very satisfied	21 (25.6%)	18 (22%)	.574	17 (25.8%)	13 (19.7%)	.751
Some satisfied but not much	11 (13.4%)	16 (19.5%)		10 (15.2%)	10 (15.2%)	
Not Satisfied	8 (9.8%)	8 (9.8%)		10 (15.2%)	6 (9.1%)	

received variable answers (19.5% strongly disagreed, 24.7% disagreed, 11.7% neutral, 32.5% agreed, and 11.7% strongly agreed) as shown in Table 3. The results showed that 86.3% of the caregivers preferred to have an introduction to the bad news in a simplified scientific way (33.8% strongly agreed, 52.5% agreed, 7.5% neutral, 5% disagreed, and 1.3% strongly disagreed) (Fig. 2). Most of the caregivers (77.4%) preferred to have an introduction to the bad news in a religious and emotional way (41.2% strongly agreed, 36.2% agreed, 11.2% neutral, 7.5% disagreed, and 3.8% strongly agreed) as shown in Fig. 3. Seventy-six percent of caregivers preferred not to inform their child about condition (41.9% strongly disagreed, 33.9% disagreed, 4.8% neutral, 17.7% agreed, and 1.6% strongly agreed). Some caregivers (72.6%) preferred to have all the information at one single visit, and 55% preferred to receive it over several clinic visits

(Fig. 4). About 70% of the caregivers agreed to be informed by any member of the nephrology team, while 68% preferred to be informed by the consultant only without his/her team. Almost all of the caregivers refused to be informed of the bad news by a relative.

We gathered comments from caregivers concerning the main suggestions, which indicated the preference to be informed gradually and emotionally. Some suggested that physicians need to present a hopeful attitude although CKD is unlikely to be a hopeful condition. Some others suggested to talk about prognosis, early diagnosis, early treatment, and examples of recovered patients (Table 4).

Table 3
Caregivers' preferences in breaking bad news.

Item	Disagree %	Neutral %	Agree %
To be alone	25 (31.6%)	8 (10.1%)	46 (58.2%)
To be supported by a relative	18 (22.8%)	13 (16.5%)	48 (60.8%)
To be informed about all the details of the disease and the workup that has been done for my child.	0		81 (100%)
I prefer to know only about the information about which I asked	52 (64.2%)	4 (4.9%)	25 (30.9%)
To be informed about the prognosis at the time of breaking the news	19 (24.1%)	8 (10.1%)	52 (65.8%)
To be informed about the prognosis later, not at the time of breaking the news	34 (43.0%)	9 (11.4%)	36 (45.6%)

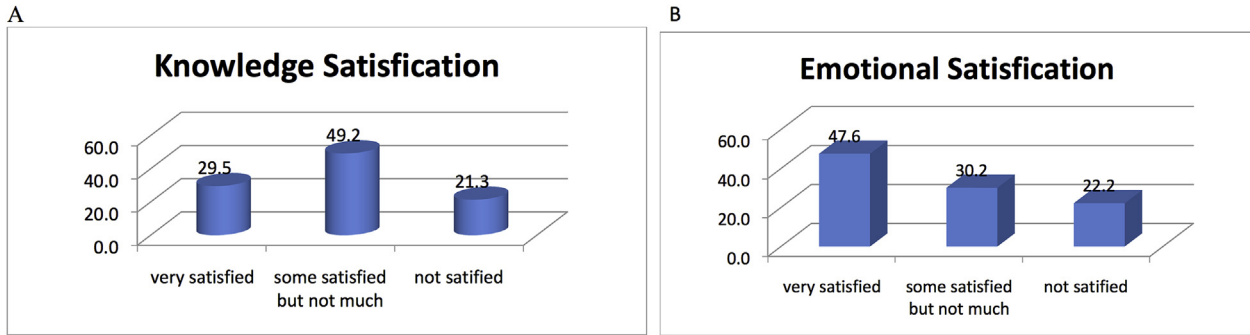


Fig. 1. Main outcome and emotional and knowledge satisfaction levels of caregivers.

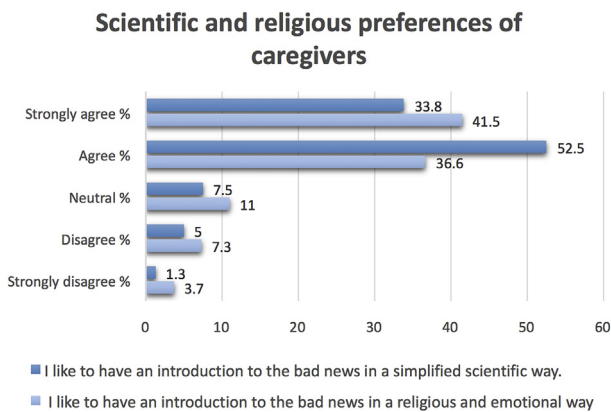


Fig. 2. Scientific and religious preferences of caregivers.

5. Discussion

Doctor–patient communication might be difficult because of the complexity of receiving bad news in conjunction with the many factors that play a major role in this situation. For instance, the health condition itself, psychological, social, cultural and spiritual considerations should also be considered. We need to understand the factors that help doctors in their communication with patients

and apply them in developing effective training programs in order to prepare trainees and making sure that they have an effective communication skills and then this will help in improving the quality of care and then the patients’ quality of life [5].

Hancock et al. in their study demonstrated that although most of healthcare providers are with the opinion that they should inform patients the prognosis as far as it can be predicted, many avoid talking about this topic or hide the information in actual practice [6].

Variations of preferences and needs of patients and relatives should be considered as they have different religious, cultural backgrounds, languages, cognitive levels, and ages. These differences put an additional demands on healthcare providers to adjust the way of breaking bad news accordingly, this may influence the abilities to deliver the bad news in an effective way [7,8].

There are many factors considered to be facilitators of the ideal bad news breaking at both the patient and physician levels. At the patient level, the personal characteristics (older age and a longer life expectancy) and some patient’s opinions (such as the patients prefer their physicians to be honest) are important. At the physician level, physician availability is an important factor (particularly taking the necessary time to explain the situation), certain physician’s characteristics (such as long-standing relationship between physicians and their patients, experience, and good training) and certain physician’s opinions (such as that patients must be informed of the prognosis and have the right to know all the detailed information). Physicians should know the difference

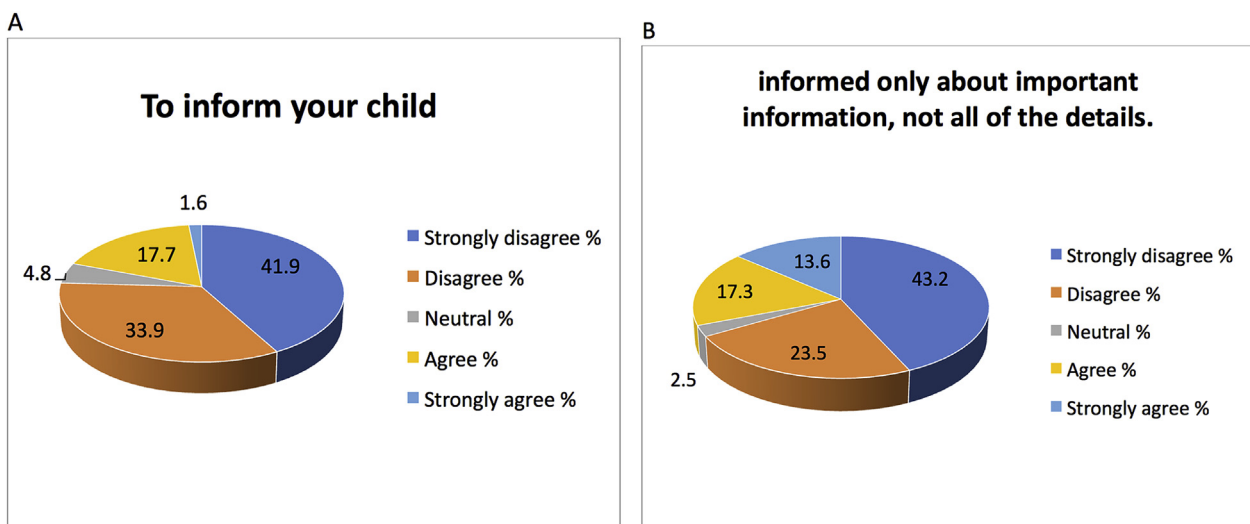


Fig. 3. Preferences of the way to be informed.

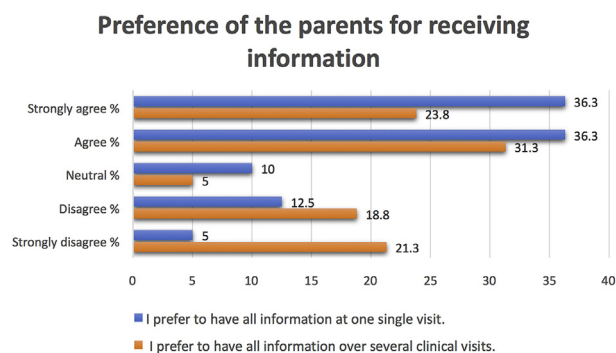


Fig. 4. Preferences of receiving the information in single visit versus several visits.

Table 4

Special comments from caregivers.

Special Comments:	NO.
Recommend informing Gradually	11
Recommend informing slowly and Emotionally:	15
1- Especially for mothers	4/15
2- Social worker attending	4/15
Recommend the physicians to give hope	6
Recommend the right to know about financial aid	2
Recommend giving examples of recovered patients	2
Recommend early diagnosis/early treatment	4
Recommend talking about prognosis	5

between their patients' problems and their perceived needs; patients sometimes may wish not to talk or not to be supported with all of their health related issues [7,8].

Physicians need to re-evaluate the patients and their families' preferences since changes might happen over time with the progression of disease. It has been found that giving a chance to the patient to talk about his own story, expressing the feeling of empathy, digging deeply in patients' emotions, talking about diagnoses and prognoses, sharing the decisions together, and the alternative options can help in forming a good relationship and facilitating the right way to break the bad news. Physicians need to develop a strategic technique in the form of a management plan with the patient's cooperation by gathering information from the patient in order to understand the patient's level of knowledge and their expectations and being ready to be informed about the bad news. Providing intelligible information according to the patient's needs and desires should be done next with the aim of supporting the patient and reducing the emotional impact of receiving the bad news [9]. "If breaking bad news is done in bad way, patients and their families may never forgive us; by contrast, if we get it right they will never forget us" [10].

Breaking bad news is an important and unpleasant task for physicians, and it has to be delivered in a proper way. In our practice as pediatric nephrologists, we sometimes ask ourselves: "Was the news I wanted to deliver to the caregivers were in an empathic and accurate way? Most importantly, were they perceived in a proper way? Was the receiver satisfied from my way, and were they satisfied with the news they received?"

In this study we tested the amount of satisfaction of breaking bad news among caregivers of children diagnosed with CKD in a tertiary care hospital in Riyadh, Saudi Arabia. The study revealed that around 22% of the caregivers were unsatisfied emotionally, and 21% were not satisfied about the knowledge they received when they got the news. These findings are different than what Gilbey found in studying the amount of satisfaction from parents experience receiving news of their child's hearing loss. Gilbey found that

50% were dissatisfied about the news [1]. In our study, we found that the socioeconomic and education levels did not affect emotional levels or knowledge satisfaction. This means that the assumption of emotional stability with a high socioeconomic level can be misleading to the communicator. It also showed that physicians' skills and empathy are needed during communication in order to produce better emotional satisfaction, and more details about the disease and its prognosis should be delivered to the caregivers in order to yield more knowledge satisfaction.

Clayton et al. showed that the balance between giving hope and being honest is an important communication skill for healthcare providers and that patients mostly prefer honest and accurate information and to be told with empathy [11].

Rodin et al. noted the variabilities and patients preferences and at the same time aimed to develop general communication approaches [12].

With respect to clinician's communication skills, it has been mentioned in the literature that many of the patients comments about the communication skills of staff at the time of breaking news about a diagnosis and prognosis, many patients mentioned that they wish if clinician communication be more empathetic and compassionate. A large number of patients are still not satisfied with the amount of information they received and the way of delivery. Maguire and colleagues demonstrated that effective communication skills are beneficial for both doctors and patients. Moreover, in 26% of cases, information which was not effectively delivered was found to be the reason that influence individuals to file a claim of malpractice. There are many factors considered to be barriers of ideal bad news breaking. The barriers can be classified into three: (1) Barriers related to doctor; (2) Barriers related to the patients themselves and their relatives or caregivers; and (3) Barriers related to institutions. At the doctor level, the challenges were the doctor's difficult availability and level of knowledge and the disease complexity (such as the complexity of information and being unsure about of the prognosis). Lack of physician training in this area leads to unsatisfactory skills. Physicians should get training in the approach of breaking bad news correctly. Physicians should also be ready to take their time when delivering the news in order to minimize many problems later. Ideally, this training should be started in medical school. This medical school training can provide the basic or simulation cases for example role-playing scenarios. Higher level of knowledge will be subsequently gained at the early years of the medical career, observation of senior physicians, trainers and instructors delivering bad news. More advanced stage of training should include real performance of trainees in real life under supervision. By training, trainees also will learn how to manage their time to be able to face the challenging limited time. Doctors need to find the most suitable time to be able to communicate effectively. Human failings include being busy and exhausted from very long on-call hours. Which may cause tiredness, which can decrease the doctors' ability of proper communication in delivering the bad news. Language competence includes language courses, which are beneficial to overcome this challenge. At the patient level, the patient characteristics (such as the patient's medical problem, and his/her personality, language, and religious and cultural differences), the characteristics of the patient's health condition (such as unpredictable disease course) and the role of the patient's social supporters. Organization-related barriers include the communication environment and the availabilities of the co-health services (such as social workers) to support the patients and their families [7,8].

Training in communication skills in the general pediatric residency programs in Saudi Arabia have gradually become more focused. However, they still may need to be more integrated into the training program in the pediatric nephrology fellowship with

particular focus on breaking bad news skills as this is a very common nephrologist responsibility. It is well-known that teaching communication skills to the trainees is a very effective way to improve their skills. In an online cross-sectional survey done among second year nephrology trainees in the United States, Combs et al. demonstrated that 25% of fellows were never observed for their performance at the time of family meetings about goals of management for end stage patients. More than half (51%) of the fellows who attended those family meetings never received any feedback from the attending physicians about their performance during the meeting [13]. In an educational quality improvement report, Cohen et al. reported participation in a full-day workshop for nephrology trainees, which was done via didactics and simulation case scenarios. The workshop focused on communication skills for multiple aspects, including breaking bad news and discussing the care goals, that could improve the trainees' communication skills. Their progress was measured using a self-reported survey for the fellows who attended the workshop [14].

Empathy is the key for effective communication, and in the breaking bad news approach, a study by Baile and colleagues who organized suggestions and instructions for approach with empathy. They organized it into the mnemonic (SPIKES) setting up, perception, invitation, knowledge, emotions, strategy, and summary. Setting up involves making sure about the patient privacy and preparing a comfortable environment during breaking bad news. Only the members of medical team, the patient, his/her support or loved ones should be there in the meeting. Making eye contact is good, and some may use emotional body language with touching hands if acceptable with the patient's culture. Making sure to provide enough time for questions and to take the time to answer them. Interruptions (such as phone calls) should not be allowed. Patient perceptions should include: "Asking the patient what do they know about their disease" and "Are they understanding why the investigations were done?" in order to know if they correctly understand the circumstances or not, and then explaining the news to the patient's comprehension level and the way in which much he is prepared to receive the news. Invitation to break news includes bringing the patient into your conversation and letting him/her know that you will explain the news you have to him/her. Knowledge entails explaining the news you have, but before you do that, it's important to understand the patient's education level, how much he know about the disease, and also his cultural background. Emotions involves explaining the news in an empathetic and polite way and giving the patient his chance to express his feelings about what you told him. Strategy and summary indicate it is always important to summarize the conversation for the patients, give them a strategic plan and follow-up, and to give them a full supportive approach (such as phone numbers for any questions or social supportive groups for some diseases) [15].

The ask-tell-ask technique is an important guide for communication between a physician and a patient in order to avoid overwhelmingly extensive news that is done by asking about how much knowledge patient had expected to or actually received followed by giving a small amount of information and then asking questions in order to check the patient's understanding of the news [16].

In this study, we demonstrated many factors and demographic data that can affect the preferences of breaking bad news and could be a guide for physicians to help in showing empathy and respect for the caregivers' the preferences at the time of breaking the news (Table 3). Mothers tend to prefer to be supported by a relative during breaking of bad news (73% agreed), while fathers tend to prefer to be alone (79% agreed). Both mothers and fathers tend to prefer not being informed by a relative (67% of mothers and 88% of fathers disagreed). The majority of caregivers preferred to know about good and bad news (95% of mothers and 87% of fathers

agreed), and they preferred to have an introduction to the bad news in a religious and emotional way (83% of mothers and around 80% of fathers agreed).

If the caregivers were highly educated, they do not prefer to know only about the important information (83% disagreed) and they will not prefer to know only the information they asked about (83% disagreed); they tended to want to know all of the details, while in the low educated category, 45% disagreed, and 47% agreed. In both the low and high educated groups, the majority of them prefer to be informed about good and bad news (84% of low educational level and 100% of high educational level agreed). The group who had low educational levels tended to prefer to be informed with sympathy more than the highly educated group (82% of the low-level and 48% of the high-level groups agreed). Both low and high educated groups preferred to have an introduction in a simplified scientific way (82% of the low level and 90% of the high level groups agreed), and both categories preferred to have an introduction in a religious and emotional way (82% of the low level and 74% of the high level agreed).

Interestingly the socioeconomic level did not yield significant differences in the preferences between the high and low socioeconomic levels except that around one-third of the low-level groups did not prefer to be informed in a gradual way (31% of low-level and 7% of the high-level groups disagreed; $P = .033$).

This study can help us and pediatric nephrologists in general to understand the structure of the society with which we are dealing (particularly the caregivers of CKD pediatric patients' society) and can guide us to understand what they prefer during the breaking of bad news. Some study limitations were conducting the study in a single center and in a very specialized hospital that may not represent totally the picture of Saudi Arabian society and might be different in the general hospitals and in the peripheral centers around the country. A multicenter study is needed in order to provide a better understanding of the Saudi society in general.

6. Conclusion

In our center, caregivers of CKD patients appeared to be very emotionally satisfied, which was higher than the satisfaction about the amount of information that they received. Preferences in receiving the bad news were different between mothers and fathers and high and low educational levels. Socioeconomic levels did not affect most of their preferences. A multicenter study needs to be conducted. Some caregivers (21.3%) were not satisfied by the knowledge they received, and 22.2% were not satisfied emotionally, suggesting that physicians' communication skills need to be improved.

Declaration of competing interest

The authors of this paper have no financial disclosure or conflict of interest to declare. The Authors are declaring that the results presented in this paper have not been published previously in whole or part, except in abstract format.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijpam.2020.03.002>.

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