Clinical use of patient decision-making aids for stone patients

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LIM AH, STREEPER NM, BEST SL, PENNISTON KL, NAKADA SY. Clinical use of patient decision-making aids for stone patients. *Can J Urol* 2017;24(4): 8890-8894.

Introduction: *Patient decision-making aids (PDMAs) help patients make informed healthcare decisions and improve patient satisfaction. The utility of PDMAs for patients considering treatments for urolithiasis has not yet been published. We report our experience using PDMAs developed at our institution in the outpatient clinical setting in patients considering a variety of treatment options for stones.*

Materials and methods: *Patients with radiographically confirmed urolithiasis were given PDMAs regarding treatment options for their stone(s) based on their clinical profile. We assessed patients' satisfaction, involvedness, and feeling of making a more informed decision with utilization of the PDMAs using a Likert Scale Questionnaire. Information was also collected regarding previous stone passage, history and type of surgical intervention for urolithiasis, and level of education.*

Results: *Patients (n = 43; 18 males, 23 females and two unknown) 53 ± 14years old were included. Patients reported that they understood the advantages and disadvantages outlined in the PDMAs (97%), that the PDMAs helped them make a more informed decision (83%) and felt more involved in the decision making process (88%). Patients reported that the aids were presented in a balanced manner and used up-to-date scientific information (100%, 84% respectively). Finally, a majority of the patients prefer an expert's opinion when making a treatment decision (98%) with 73% of patients preferring to form their own opinion based on available information. Previous stone surgery was associated with patients feeling more involved with the decision making process (p = 0.0465).*

Conclusions: *PDMAs have a promising role in shared decision-making in the setting of treatment options for nephrolithiasis.*

Key Words: patient decision making aids (PDMA), shared decision-making (SDM), nephrolithiasis, kidney stones

Introduction

The physician-patient relationship has evolved from a paternalistic "physician knows best" to one that encourages and values patient involvement in the decision-making process. We have moved on from an era where withholding poor prognoses from patients was acceptable, and even incorporated into the American Medical Association Code of Ethics in 1847,[1] to a time where patients have full access to and legal ownership of their medical records. A central consequence of this shift is the implementation of shared decision-making (SDM) and the use of patient decision-making aids (PDMAs).

The Picker Institute, formerly the Picker Commonwealth Program for Patient-Centered Care, first coined the term, "patient-centered care" in 1988. "Patient-centered care" is a term used to encompass ways to keep patients informed and involved while also focusing on considering their personal preferences, values, family situations, lifestyles and cultural traditions when making healthcare decisions.[2]

Accepted for publication May 2017

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In 2001, the Institute of Medicine published a report, Crossing the Quality Chasm, which declared "patient-centered care" as one way to improve the safety and quality of patient care healthcare in the setting of an increasingly complex healthcare system.[3]

At the heart of patient-centered care is SDM.[4] SDM is the collaborative effort between the healthcare provider and the patient in choosing a treatment based on up-to-date scientific information while taking into consideration patient values and preferences.[5] PDMAs are evidence-based tools used to facilitate SDM by helping patients make more informed decisions and feel more involved in the decision-making process when more than one reasonable treatment option is available.[6] PDMAs are informational resources that can be presented in a variety of formats including a handout, audio recording, video, or interactive website used to educate patients and facilitate SDM.[7] Important components of well-designed PDMAs are that they are easy to understand, explain the advantages/disadvantages, provide up-to-date scientific information and present information in a balanced manner.[8,9]

A 2014 Cochrane review including 115 studies involving 34,444 participants showed that PDMAs improve patients' knowledge, satisfaction with their care, help them feel more informed, improve communication between patients and their healthcare practitioners and do not worsen health outcomes.[10,11] PDMAs have become so widespread that a group of practitioners, researchers and stakeholders have developed the International Patient Decision Aid Standards (IPDAS) Collaboration in an effort to set criteria for the design of PDMAs to ensure quality and effectiveness.[12]

Previously, we developed and tested PDMAs for patients in hypothetical stone settings. Compared to when PDMAs were not used, patients reported improvement in understanding of surgical options for ureteral stone removal. We concluded that the use of a PDMA for surgical SDM was valued by stone-formers.[13] The aim of the present study was to evaluate the use of PDMAs in actual stone patients in the outpatient clinical setting considering surgical treatment for urolithiasis. We assessed the patients' understanding of the material in the PDMAs and their sense of involvement and preferences in the decision-making process.

Materials and methods

Adult patients (> 18 years) with confirmed urolithiasis on imaging (computed tomography scan, ultrasound or abdominal film) were recruited from September 2014-May 2015. Patients were excluded from the study if the stone was infected, they had a solitary kidney, or if only one treatment option was acceptable as determined by the urologist. PDMAs were developed for the following treatments: observation, medical expulsive therapy, ureteroscopy, shock wave lithotripsy and percutaneous nephrolithotomy. Urologists educated each patient on his/her treatment options utilizing the appropriate PDMAs (e.g., medical expulsion, ureteroscopy, etc.) to guide the discussion. The patient and urologist then made a treatment decision. Following the clinic visit, patients completed a questionnaire regarding their experience using the PDMAs.

We developed the PDMAs according to the principles of the IPDAS Collaboration and modified them based on patient feedback from a previous study at our stone center.[13] Patients were given a diagram with a graphic depiction of the kidneys, ureters and bladder to show the location and size of their stone (s). The appropriate PDMAs were administered to facilitate explanations of the treatment options. Information was presented in a balanced manner. Each PDMA described the suggested treatment on a single sheet of paper with the following headings: "surgery consists of" (if applicable), "what to expect post procedure", "possible advantages include", and "possible disadvantages include". Diagrams were included on the aid to help patients visualize the relevant anatomy and surgical procedure.

An investigator-designed Likert Scale questionnaire was administered to assess patients' experience with the PDMAs, Figure 1. The questions addressed

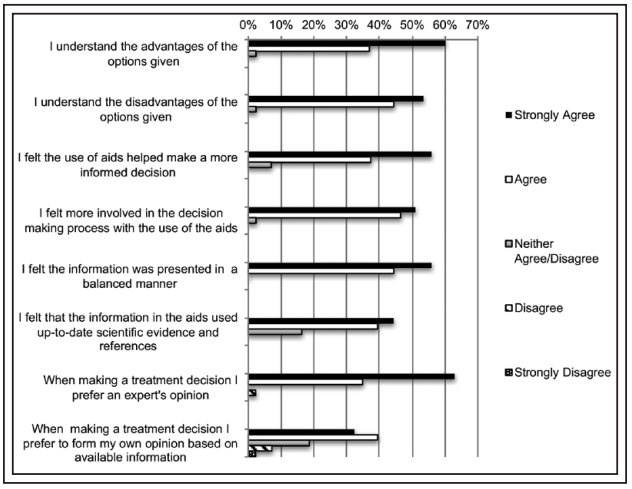

Figure 1. Patient responses to Likert Scale Questionaire regarding their experience with PDMAs.

the patients' understanding of the advantages and disadvantages of each treatment approach, and whether they felt they had made an informed decision, felt involved, the information was balanced, up-to-date scientific information was presented, and whether patients preferred an expert's opinion or preferred to make their own decision based on the available information. Patients also provided information regarding prior stone passage, previous surgical intervention for a stone and, if applicable, which type of surgical intervention, and highest level of education completed, Table 1. A Fisher's exact test was performed by a University of Wisconsin biostatistician to determine if there was a relationship between patient demographics/stone history and their responses to the questionnaire. The responses were divided into three different categories for statistical analysis: strongly agree and agree, neither agree or disagree and disagree/strongly disagree. Finally, patients were encouraged to write comments regarding how to improve the decision aid.

TABLE 1. **Patient demographics and stone history**

Characteristic	
	43
Age (yrs)	
Mean	53
Range	± 14
Sex, n (%)	
Male	18 (42)
Female	23 (53)
Did not report	2 (5)
Previously passed a stone, n (%)	
Never	2 (5)
1 prior stone episode	20 (47)
10 or more	5 (12)
Previous surgical intervention for stone, n (%)	
Yes	16 (37)
No	37 (63)
Type of intervention for stone, n (%)	
Shock wave lithotripsy	10 (24)
Ureteroscopy	9 (22)
Percutaneous nephrolithotomy	5 (12)
Open/laparoscopic procedure	2 (5)
Highest level of education, n (%)	
Graduate	7 (16)
College	19 (44)
High school	16 (37)
Junior high	1 (2)

Results

There were a total of 43 patients (n = 43, 18 males, 23 females, 2 did not provide this information) with a mean age of 53 ± 14years. Data regarding patients' stone history and educational background are shown in Table 1.

The majority of patients reported that they understood the advantages outlined in the PDMAs presented to them (60% strongly agreed, 37% agreed, 2% neither agreed/disagreed, with no patients reporting that they disagreed or strongly disagreed). Similarly, the majority of patients reported that they understood the disadvantages (53% strongly agreed, 44% agreed, 2% neither agreed/disagreed, with no patients reporting that they disagreed or strongly disagreed). Most patients felt the PDMAs helped them make a more informed decision (56% strongly agreed, 37% agreed, 7% neither agreed or disagreed, with no patients reporting they disagreed or strongly disagreed). In addition, the majority of the patients felt more involved in the decision making process with the use of the PDMAs (51% strongly agreed, 47% agreed, 2% neither agreed/disagreed with no patients reporting they disagreed or strongly disagreed). Patients felt the information in the aids was presented in a balanced manner (56% strongly agreed, 44% agreed, with no patients reporting they neither agreed/disagreed, disagreed or strongly disagreed) and that the PDMAs used up-to-date scientific information (44% strongly agreed, 40% agreed, 16% neither agreed/disagreed, with no patients reporting they disagreed or strongly disagreed). A majority of the patients said they would prefer an expert's opinion when making a treatment decision (63% strongly agreed, 33% agreed, 2 % disagreed with no patients reporting they strongly disagreed). Finally, a majority of the patients said they would prefer to form their own opinion based on available information (33% strongly agree, 40% agree, 19% neither agreed/disagreed, 7% disagreed and 2% strongly disagreed, Figure 1. Patients who had previous stone surgery were significantly more likely to strongly agree or agree that they felt more involved in the decision-making process with the use of our decision aids than those who did not have previous stone surgery ($p < 0.05$). Seven of 43 patients chose to leave favorable comments on the decision aids.

Discussion

Although there is often more than one acceptable treatment option for most urolithiasis cases, the use of PDMAs to assist with SDM in urolithiasis is relatively new. Our study demonstrated that the PDMAs we developed were easy to understand across a variety

of educational backgrounds, that information was presented in a balanced manner, that patients felt like they made a more informed decision and felt more involved. Most of the patients stated that they preferred to make their own decision based on the available information presented in the PDMA while at the same time stating that they preferred an expert opinion. Thus, we concluded that most but not all patients' prefer SDM vs. physician-only decision which is in line with what has been shown previously.[14] Unfortunately, while the majority of patients appear to prefer SDM, healthcare providers often do not engage patients in SDM. A study by the Institute of Medicine reported that fewer than half of patients were asked by the healthcare provider about their goals and preferences.[15] A PDMA can be used in SDM to provide standardized information to patients and to facilitate a discussion about patients' healthcare goals and preferences. Incorporating patient preferences in the decision-making process is an important component to improving our relationships with patients.

Our PDMAs helped patients feel like they made an informed decision. An underemphasized role of healthcare providers is to educate patients. Patients are often overwhelmed by medical terminology or misled by information presented on the Internet, in advertisements, or by friends and/or family. Further, physicians often overestimate patients' understanding of their disease processes and the impact on their long term health, which may limit patients' ability to make informed decisions.[16] For example, studies have shown that up to three-fourths of patients with metastatic disease believe that they can be cured with chemotherapy.[17] PDMAs help improve patients' understanding of their disease and the rationale underlying treatment options, which enables more effective SDM.[18]

Patients who had previous stone surgery were significantly more likely to strongly agree or agree that they felt more involved in the decision making process with the use of our decision aids than those who did not have previous stone surgery. We do not have data to determine if decision aids were used in the clinic visit for their previous stone surgery. In order to determine whether or not this data truly reflects a difference in patients feeling more involved due to use of a decision aid, a randomized control study must be conducted comparing those who receive decision aids compared to those who do not. Age, gender, number of stone events or type of surgery did not reach statistical significance for any other questionnaire category suggesting that a variety of patients with different clinical histories and ages can benefit from the use of a PDMA. One limitation of this conclusion is the small sample size, which may have made it difficult to reach statistical significance despite the use of statistical analysis tests specifically designed for small sample sizes.

Few healthcare providers use SDM due to indifference of the provider, concern about disruption of workflow or lack of confidence in the utility of decision support intervetions.[19] A common reason cited against the use of PDMAs is the lack of resources required for implementation. While effective widespread use of PDMAs will require financial support, participation by healthcare providers, support staff, and training of those involved in the use of PDMAs for SDM, small-scale implementation can be accomplished with relative ease. While we chose to create new PDMAs, there are a variety of free PDMAs available for download from the Internet.[20]

Another concern of healthcare providers is that providing patients with several options to choose from may increase anxiety in the decision making process. While this was not specifically addressed in our study, several studies have demonstrated that the use of decision aids do not increase patient anxiety and even decrease patient anxiety in some cases.[21-27] These data are extremely important to consider as healthcare providers may erroneously feel as if they are overwhelming patients with information and causing undue burden with shared decision-making and the use decision aids, which the data does not support.

In the future, we would like to conduct a randomized prospective control trial assessing patient experiences using a validated questionnaire in patients provided with PDMAs versus those who are not given PDMAs. We would also like to compare the treatment choices of patients who used PDMAs with those who did not. This could help to determine whether or not the use of PDMAs results in less invasive surgical treatments as previously reported.[28-30] A multi-center study could address the potential for regional differences and provide a wider range of socioeconomic status and diversity. Finally, surveying patients after treatment could provide useful feedback about the information in the PDMA that was most helpful and what additional information should be added.

The limitations in our study include a small sample size at a single institution. The demographics of patients in our study included those with a higher education level than the national average; the majority completed college or graduate level education, which may have influenced our results.[14] Moreover, regional and socioeconomic variation is not accounted for in this study. We recognize that PDMAs for urolithiasis treatment may need to be

customized to take into account the clinical practice of a particular institution as well as the needs and preferences of the population in a given geographic region.

Conclusion

In conclusion, PDMAs developed at our institution resulted in patient self-reported understanding of the treatment options for stones and assisted patients in making an informed decision and feeling involved in the decision-making process. The use of PDMAs allow for a standardized and systematic way to educate patients, improving upon the standard informed consent process. As the usefulness of PDMAs in patient-centered care is further studied, and if PDMAs can continue to demonstrate decreases in healthcare costs[25,30] and/or improvements in patients' health-related quality of life, perhaps more internally driven motivation and financial incentives for investment of widespread implementation and use of PDMAs will emerge. □

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