

# Shared Decision Making in Urolithiasis: The Use of a Patient Decision Making Aid

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## Abstract

**Introduction:** Patients desire an active role in health care decisions. We evaluated whether a patient decision making aid is useful when considering surgical treatment for urolithiasis.

**Methods:** Patients with a history of urolithiasis were recruited for study. They were asked to consider a hypothetical case of an asymptomatic 10 mm proximal ureteral stone for which elective surgical intervention was recommended. Shock wave lithotripsy and ureteroscopy were presented as potential options. A patient decision making aid was developed to explain and compare the options. A urologist presented the information to the patients, once using the patient decision making aid and then without the aid. We assessed participant satisfaction with each format and invited comments about the aid and its content, design and clarity.

**Results:** Mean  $\pm$  SD age of the 4 male and 10 female participants was  $61 \pm 9$  years. Of the participants 86% found the patient decision making aid helpful but identified areas for improvement. Specifically, patients wanted more information on stent placement, stent discomfort, long-term effects and cost. Of the participants 79% reported that the aid improved their understanding of the treatment options compared to the session without the aid. While 8 of 14 participants preferred hearing surgeon recommendations, most still reported value in the patient decision making aid.

**Conclusions:** Patient decision making aids are increasingly used in the management of several diseases and they require patient input into development. In our study the aid improved patient self-reported understanding of surgical options for ureteral stone removal. Notably, most participants still preferred to make decisions based on the surgeon recommendation. Modification of the patient decision making aid based on patient suggestions will enhance its usefulness and applicability in the clinical setting.

**Key Words:** urolithiasis, patients, clinical decision-making, lithotripsy, ureteroscopy

## Abbreviations and Acronyms

PDMA = patient decision making aid

SWL = shock wave lithotripsy

URS = ureteroscopy

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The dynamics of the patient-physician relationship have evolved in recent years with increased emphasis on patient education and involvement in shared decision making. PDMA, which are tools intended to facilitate this process, are becoming increasingly popular. This type of aid is thought to help patients make a fully informed decision about therapy, especially in situations in which more than 1 suitable option exists. Currently PDMA are not routinely used for surgical management decision making in urolithiasis.

PDMA are formatted as written materials, videos or online platforms designed to educate patients and their families about care options, including outcomes, benefits, risks and cost.<sup>1,2</sup> PDMA are often used to compare equivalent or equally acceptable options. Key features of PDMA development include the involvement of patients and clinicians in the design and development of a prototype, alpha testing with patients and clinicians, field testing in the clinical setting, production of a final version, evaluation and validation.<sup>3</sup> In particular, patient input regarding content, design and clarity of the aid is considered crucial prior to utilization in the clinical setting.

We evaluated whether a PDMA would be useful to patients with a history of urolithiasis who make decisions regarding surgical treatment. The secondary purpose of this study was to gather patient input for further modification of the PDMA before clinical use.

## Materials and Methods

Adult patients (older than 18 years) with a history of urolithiasis were recruited from our urology clinics from September to October 2013. Participants attended 1 of 3 evening sessions, each lasting approximately 1 to 1.5 hours. The study format was designed so that each participant was presented with information about the treatment options by a urologist, once using the PDMA and once without the aid, with randomization of the format order. A questionnaire was administered after each format was presented to assess satisfaction with each presentation format and the degree of understanding of the advantages and disadvantages of each procedure. At the conclusion we had an informal discussion to gather patient input to improve the design and content of the PDMA.

During each session the participants were initially presented with a hypothetical scenario describing an asymptomatic left 10 mm proximal ureteral stone for which surgical treatment was recommended. An illustration was provided to participants to explain urinary system anatomy and stone location.

The PDMA prototype was developed according to IPDAS (International Patient Decision Aids Standards) principles and based on the design of aids for other medical conditions (fig. 1).<sup>3</sup> The PDMA was constructed with a goal of complementing the information provided by the surgeon about factors associated with treatment options. In the PDMA the surgical options were described in a balanced manner and in plain language written at an eighth-grade level. SWL and URS were described side by side on a handout with text headings of “surgery consists of,” “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 the surgical procedure.

Participants in each session were then presented with information on SWL and URS in 2 formats and were told that either treatment option was acceptable in this hypothetical scenario. In 1 format participants received verbal explanations from the urologist about the 2 procedures with their advantages and disadvantages, similar to what would be done in a clinical setting without a visual aid. In the second format the urologist reviewed the same type of information but used the visual aid of the PDMA to guide the explanation. Both formats included a script to ensure standardization among the 3 evening sessions. All participants were presented with information using both formats. Figure 2 shows details of the session sequence of events.

During both presentation formats SWL was described as a noninvasive, approximately 1-hour outpatient surgery using general anesthesia in which shock waves are generated outside the body and directed at the stone to break it into smaller fragments under x-ray guidance. Participants were told that they could return to work after 2 days and there is typically minimal pain postoperatively. Participants were told that there is typically no need to place a ureteral stent after SWL and the success rate is approximately 77%. Patients were advised that secondary procedures may be necessary.<sup>4</sup>

URS was described as a minimally invasive outpatient surgery in which a scope would be inserted through the urinary system to visualize the stone and a laser fiber would fragment the stone into smaller pieces. They were told that surgery would take approximately 1 hour using general anesthesia. Participants were told that they could return to work in approximately 2 days. We discussed that a ureteral stent is typically placed for 3 to 5 days as part of this surgery and bothersome symptoms from the stent are common. The success rate of this approach was discussed as greater than 92% for

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