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Engaging Emergency Department Patients in the Creation of a Shared Decision-Making Tool Regarding CT Scanning in Kidney Stones: Challenges to Traditional Stakeholder Engagement

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Background

Each year, approximately 2 million patients are seen in US EDs for suspected renal colic and the majority receive CT scans. The objective of our study was to develop a stakeholder-informed conversation aid to help clinicians use Shared Decision-Making regarding the use of CT for patients with suspected renal colic.

Traditional Decision Aid Development involves iterative stakeholder engagement. However, ED patients represent a challenging population for many reasons.

- No shared identity (no identity as “ED patients”)
- No clear way to recruit/retain
- No longitudinal relationships

We sought to use multiple methods to engage stakeholders in the development of this decision aid. Traditional benefits of Focus Groups and Interviews are below.

Focus Groups	Interviews
More people in less time	Able to explore sensitive topics
More ideas, collaboration	Flexible scheduling
Lower cost (transcription)	All voices heard (no dominant voice)
Consensus/disagreement apparent	

Methods

A. Direct from ED recruitment for Focus Groups

- Research assistants approached patients age 18-50 and asked if they would be willing to return for focus groups. If yes, they collected contact information.
- Texts/emails/phone calls used to gather participants
- Participants offered \$20 to return to ED for focus groups
- Participants invited to bring friend, who would also be reimbursed \$20
- Focus groups set for 4 or 5 pm after 9am focus groups failed to attract participants
- Pizza provided at focus groups

B. In-ED interviews

- PI directly approached appropriate patients
- Interviews occurred at the same time, recorded

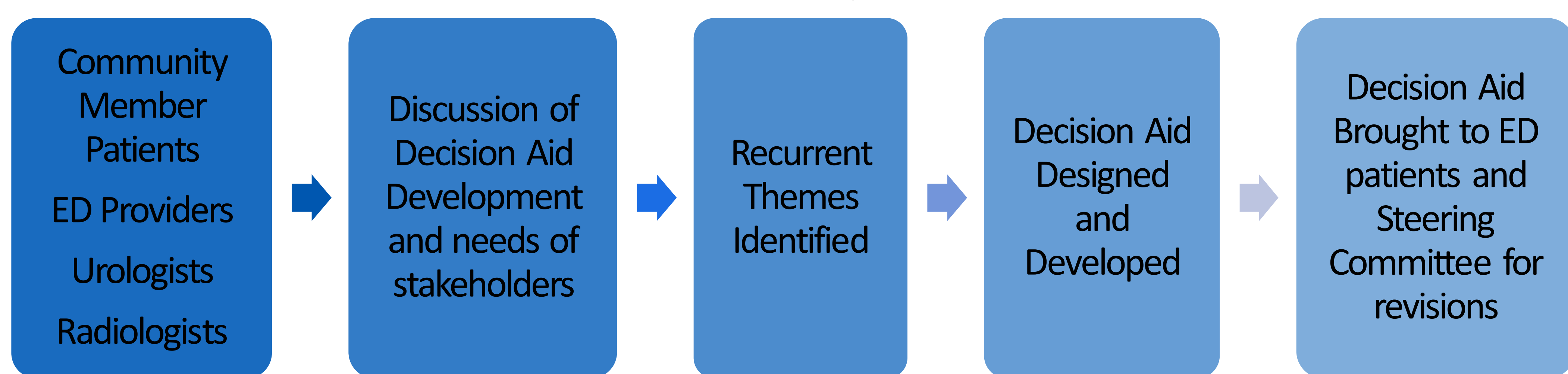


Figure 1. Overview of Decision Aid development and testing.

Results

Our Experience with Focus Groups

108 patients agreed to share contact information (phone numbers, email addresses) to be invited to future focus groups.

- Research assistants sent invitations via text, email, and some phone calls at least three time prior to each focus group, asking for participants
- Most didn't respond, ~25 responded that they would attend
- 17 showed up (between 5 scheduled focus groups)
- Several were under the influence of substances and had difficulty participating in focus groups. Several focused on their own ED care and used focus groups to vent about perceived injustices relating to their ED experiences

Total = 17 participants in 4 focus groups

~ 4 hours of transcription

Effort: >120 hours, over 3-4 months for research staff

Our experience with Interviews

Eight ED patients approached for decision-aid review and commentary, during the course of their ED care (as of March 15)

- In-ED patients generally happy to participate and be of help, surprised to be reimbursed for their time.
- Nearly always consented to involvement.
- Despite medications, able to focus on issues.

Total = 8 participants in interviews (not including family members)

~ 4 hours of transcription

Effort: ~ 8-16 hours, for PI (requires flexibility)

Conclusions

1. Engaging ED patients IN the ED is much easier than recruiting them for a later event.
2. Asking patients to return to the ED may not be worth your time.
3. Consider training research staff to do semi-structured interviews with patients in the ED.
4. The traditional benefits of focus groups are not likely worth the costs, for this population.

What Are Kidney Stones?

It looks like you have a kidney stone.

A kidney stone is a tiny stone that forms in your urine, right in your kidneys. Stones can be as small as sand or bigger than a pea. Your body tries to pee it out, and this causes pain that can be anywhere from your kidneys (back) down to your bladder. Some people feel the pain in their testicles or labia.

Signs of a kidney stone:

- The pain is severe, and started suddenly
- The pain comes and goes, and it's hard to sit still. The pain is in your mid- or lower-back, on one side, and might radiate around to the front
- The pain comes with nausea or vomiting
- The pain started recently, such as earlier today (not weeks or months ago)
- Your urine test shows red blood cells*
- Your ultrasound shows some swelling in your kidneys*

*If you're not sure about these results, ask your doctor to tell you.

If you have 4 or more checked, there is a VERY GOOD chance you have a kidney stone.

How do doctors diagnose kidney stones?

- Most kidney stones come with many of the signs and symptoms listed above.
- Sometimes people have microscopic blood in their urine.
- Blood tests are usually normal and don't always need to be checked.
- An ultrasound might show swelling of the kidney, from pressure from the stone. Sometimes the ultrasound will show the stone itself.
 - An ultrasound does not expose you to radiation.
 - An ultrasound can also show gallstones, ovarian cysts, and other causes of pain.
- A CT scan will usually show the size and location of the stone. Most stones are small, but the CT will show if a stone is one of the less common, larger stones.
 - A CT scan exposes you to radiation. The radiation is similar to about 200 x-rays.
 - This amount of radiation may increase your future risk of cancer by a very small amount.
 - A CT is pretty accurate for other things, like appendicitis.

Emergency Department Care for Patients with Kidney Stones

Why me? Why did I get a kidney stone?

We all have minerals in our urine. Sometimes these minerals clump together and make stones. Some people get stones because they have been dehydrated or they have too much calcium in their urine. Often it's just luck and we don't know why one person gets kidney stones.

When will I feel better?

Kidney stones are very painful. The pain medications will help you start to feel better. Some people pee out the stone in a day or two, but for other people it can take up to 3-4 weeks. During that time, some people need pain medication, and some people need to see a kidney stone specialist. If you are feeling better in the ER, that is great, but the pain often comes and goes for a few days before it is totally gone.

Nausea medication and hydration

If you are dehydrated or vomiting, your team might give you IV fluids or medications for nausea.

Admission or Discharge?

About 9 out of 10 of people with kidney stones feel well enough to go home after they get pain medication in the ER. 1 out of 10 will get admitted.

Will I pee the stone out?

Usually, 8 out of 10 people like you will pee the stone out without any procedure, but some people will need to see a kidney stone doctor (urologist).

Do I need a CT right now?

Probably not. We can talk about your options: getting a CT now or getting CT later only if you need it. The next page gives you more information about kidney stones, and the last page talks about the CT question.

Common Questions about Kidney Stones

What is a kidney stone?

- Kidney stones form when minerals like calcium form crystals in the urine.
- Stones become a problem when they get larger and move down into the ureter (the tube that connects the kidney to the bladder).
- Stones moving through the ureter can cause pain in the back, side, or groin.
- The good news is that the pain can be treated with medications and most kidney stones will pass through on their own.

Will my stone pass on its own?

- Most stones pass in the urine without treatment.
- Experts agree that most patients with a kidney stone should have a period of observation to see if the stone will pass on its own. During this period, the doctor will prescribe medications to relieve pain and to make it easier for the stone to pass.
- ***Stones can take days or weeks to pass, and people can expect episodes of pain during that time, and can take medications as needed for pain.**

What are the treatments for kidney stones?

- There is a medication that might help your stone pass (Tamsulosin).
- If the stone doesn't pass in 3 weeks, or if the pain becomes too severe or you develop a fever, you should see a doctor to see if other tests or treatments are needed.
- Possible treatments include surgery to remove the stone, or lithotripsy (where sound waves break the stone into smaller pieces that are easier to pass).
- These treatments can have side effects like pain, infection or complications of surgery, so they are not used if the stone will pass by itself.

What medications should I take?

1. Ibuprofen (like Advil or Motrin) 600 mg, 3 or 4 times in 24 hours as needed for pain
2. Acetaminophen (Tylenol) 500 mg, 3 or 4 times in 24 hours as needed for pain
3. Tamsulosin (Flomax) 0.4 mg, once a day until pain is gone

Other medications for nausea (Ondansetron/Zofran) are taken up to 3 times a day. Narcotic pain medications are sometimes prescribed and should be used carefully.

What else should I do?

- 1. Drink plenty of fluids (water is best).
- 2. Use a strainer to check your urine for the stone. The stone can be sent for analysis, which might help you learn how to avoid more stones in the future.
- 3. Make a recheck appointment with your primary doctor 7-14 days after your hospital visit.

What should I watch out for?

1. If you have a fever (temperature 100 or higher) or your pain or nausea is not controlled by the medications, you should return to the ER.
2. If your symptoms continue for more than 2 weeks, you may need to see a urologist (kidney stone doctor) for treatment of the stone. If you have not had a CT scan, you should have a CT scan (ordered by your primary doctor or the ER) before seeing the urologist.
3. If you are feeling better, you should talk to your doctor about having an outpatient ultrasound 6 weeks after your ER visit to make sure there are no signs of the stone.

Other patients with kidney stones want you to know:

1. Narcotic pain medications can be addictive, Ibuprofen (Motrin) and Toradol work well.
2. Stay hydrated! Now that you have had one stone, you are at risk another stone. The best way to avoid kidney stones is to stay hydrated and eat a healthy diet.

Let's talk about the options, one of these approaches is probably best for you

	Plan 1: <input type="checkbox"/> Wait and See	Plan 2: <input type="checkbox"/> CT scan before going home
If your doctor checks one of the boxes, it is still important for you to think about what makes the most sense for YOU. Let your doctor know your thoughts.	<input type="checkbox"/> Likely kidney stone: try to pass stone at home, CT later* if needed <i>*CT scans expose you to radiation, which increases your risk of cancer in the future by a small amount</i>	<input type="checkbox"/> Stay in the ED for a CT scan* now, then go home <i>*CT scans expose you to radiation, which increases your risk of cancer in the future by a small amount</i>
This plan is good for you if:	<input type="checkbox"/> You are starting to feel better <input type="checkbox"/> Your doctor thinks there is a low chance that your pain is caused by something other than a kidney stone <input type="checkbox"/> You would prefer to minimize radiation to your body AND/OR you have had CT scans before	<input type="checkbox"/> You have a fever <input type="checkbox"/> Your pain has been going on for more than a week or two <input type="checkbox"/> Your doctor thinks you need to see a urologist (kidney stone doctor) today
Plan	If you are feeling better, you could go home with medications and a clear plan from your doctor. Most people will pee out their stone, but a few will need to get a CT scan in a week or two and see a kidney doctor (urologist).	You could stay in the ER for a CT scan. This would show all the details of the stone, but it does not usually change what happens next. Most people will go home and pee out the stone, and a few will have to see a kidney doctor. Some people will need a repeat CT in 1-2 weeks.
What are the benefits of this plan?	<ol style="list-style-type: none"> 1. Less radiation to your body 2. Shorter ED visit 3. Lower cost (to you or your insurance) 	<ol style="list-style-type: none"> 1. Your doctor would see size of stone 2. We could see stone "mimics" (things that act like stones but aren't)
What are the risks (or disadvantages) of this plan?	<ol style="list-style-type: none"> 1. The doctors could miss a diagnosis that acts like a kidney stone but isn't. 2. You may still need a CT in the future if you don't feel better in 1-2 weeks. 	<ol style="list-style-type: none"> 1. You will be exposed to radiation from the CT scan one or more times. One CT is not a lot of radiation, but people with kidney stones often get multiple CT scans. 2. CT scans usually keep you in the ER longer, and will cost you or your insurance more. 3. You may need another CT in the future.
Questions you might ask your doctor:	<input type="checkbox"/> If I get a CT, will the results of the CT change the plan? <input type="checkbox"/> What is the chance that I have a "kidney stone mimic" or something like appendicitis?	
Please tell your doctor:	<input type="checkbox"/> Do you have a doctor you can follow up with? <input type="checkbox"/> Can you come back to the ED if your pain is not controlled, or if you start having a fever? <input type="checkbox"/> Have you had a CT scan before?	
Put notes and questions here:		

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