Living with Urinary Diversions: Patient insights to improve the perioperative experience

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Digital AUA May 2020
Few studies exist to evaluate effectiveness of current perioperative counseling for patients undergoing urinary diversion. Here we utilized a patient centered approach to delve deeply into the perioperative experience surrounding urinary diversion.
Methods

• Patients 6-12 m s/p radical cystectomy
  Diversions: Indiana pouch, neobaldder and ileal conduit
• Semi –structured interviews by 2 urologists
• 9 open ended questions
• Unscripted follow up questions
Open Ended Questions

“Tell me about your experience reaching a decision on what type of urinary diversion to choose.”

“What do you know now, that you wish you knew before your urinary diversion?”

“What lessons do you have for other patients?”

“What might we do to better prepare patients to make this decision?”

“When should patients' receive information about urinary diversion types?”
Analysis

Common themes were identified

We worked with the department of Health Services Research and Population Science to determine the best method for qualitative analysis

>20 recurrent topics were identified

Each interview was reviewed and the presence or absence of themes or emotions were noted; taking into consideration the patients’ diversion type
Results

• 13 interviews were conducted
• No patient expressed decision regret
• Those with continent diversions- high levels of motivation and all used online communities
• BCAN website was most quoted as an information source
• Patients found it very difficult become comfortable with ancillary equipment such as catheters and ostomy appliance
Did they feel well counseled?

- 77% expressed **specifically** that they had adequate information

- 46% of patients expressed surprise about post op complications

- 0/13 felt the diversion had a significant impact on their body image

- 85% (1 patient with an ileal conduit and 1 patient with a neobladder) felt that their urinary diversion did not impact everyday function

- 4/7 of patients with a continent diversion expressed concern about the functional longevity of their diversion
Peer to Peer Support

• Recurrent theme was the desire for a type of buddy system
• 62% of patients reported this would have been the single biggest area for improvement
• Most important post OP
• All patients asked were open to talking to others
• 100% of patients were receptive about talking to others

"It would have been nice to be buddied up with someone because, you guys (doctors) can only do so much"
Limitations

• Limited sample size
• Single institutional study
• Qualitative study
Conclusion

• Highlights the need to focus on post surgical maintenance care counseling
  - urostomy appliances
  - catheters
  - irrigation technique and equipment

• Peer to peer support seems to be most valuable in the post OP period
  - Provides both technical insight and emotional support
Further Research

• Similar studies at other institutions

• Evaluate current peer-peer networks

• Our role in facilitating access to peer-peer resources

• Lack of control/oversight

Grant from NIH/NCI under award number P30CA016672 and the Shared Decision Making Core.
"The doctor told me about the surgical aspects but left the maintenance instruction to the nurses."

"I used a Facebook group about women with bladder cancer. It's like second nature now, but the day the catheter came out was the worst day."

"I would follow instructions more if I had to do it again."

"People like us should be talking to others, separate from the role of the doctors."

"The care and maintenance is very time-consuming."

"Discuss the process with your family."

"Be patient, it's going to get better."

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