PATIENT ENGAGEMENT, EDUCATION, AND LITERACY FOR PELVIC FLOOR DISORDERS (J ANGER, SECTION EDITOR)



The Patient Perspective on Adverse Surgical Events After Pelvic Floor Surgery

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Abstract

Purpose of Review To review the present literature describing the patient experience of adverse events (AEs) following pelvic reconstructive surgery (PRS).

Recent Findings Patients' perceived importance of AEs changes over the short-, medium-, and long-term postoperative period, with functional outcomes gaining dominance over time. Surgical failure is consistently the principal severe AE perceived by patients both pre- and postoperatively. New or worsening adverse bowel or urinary symptoms are also consistently rated as a severe complication. Long-term AEs can be broadly categorized into psychological, functional, and relational AEs that impact patients' emotions surrounding treatment, physical, and physiological function, as well as social network and intimate relationships. Long-term AEs that diminish function or quality of life are perceived by patients as being just as severe as AEs that surgeons typically view as "very severe."

Summary As patients' surgical expectations and goals may not always be in agreement with what a given PRS can consistently resolve, especially as it relates to associated urinary or bowel symptoms, surgeons should elicit and address patients' expectations and goals of treatment preoperatively.

Patients tend to view surgical failure and recurrence as personal failures, and thus, surgeons should have honest preoperative discussions of recurrence risk following PRS and the reasons for recurrence, proactively shifting blame away from the patient herself. Finally, by emphasizing PFDs as being chronic conditions rather than episodic problems that can be surgically "fixed," the surgeon can reframe the relationship with the patient to being one of optimizing pelvic floor health throughout her lifetime.

Keywords Surgical adverse events · Pelvic floor disorders · Functional outcomes · Pelvic reconstructive surgery

Introduction

Eleven percent of all women will undergo pelvic reconstructive surgery (PRS) to improve bothersome symptoms associated with pelvic floor disorders by age 80 [1]. While the

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¹ Department of Obstetrics and Gynecology, Division of Female Pelvic Medicine and Reconstructive Surgery, Duke University Health System, 5324 McFarland Drive Ste 310, Durham, NC 27707, USA principal reason to perform PRS is to address bothersome symptoms, short- and long-term complications can occur which may impact the patient so negatively that they compromise the index surgery's attempt to improve quality of life. Various scales to measure the occurrence and severity of surgical adverse events exist, such as the Clavien-Dindo classification of surgical complications, which rates the severity of complications on a 4-point ordinal scale, and the condition-specific Pelvic Floor Complication Scale (PFCS) developed by the Pelvic Floor Disorders Network and Urinary Incontinence Treatment Network [2, 3]. As expected, worse PFCS and Clavien-Dindo scores in PRS populations have been associated with longer length of hospitalization, lower satisfaction, lower Health Utilities Index, and worse general and condition-specific quality of life measures [3].

The principal limitation of these existing measures is the exclusion of the patient perspective in their definitions of

what constitutes a "complication" and the severity of each complication. Patient satisfaction has been found to be directly related to expectations and attainment of preoperative goals [4•, 5]. Therefore, it is essential that the patient's perspective be central to the measurement of complications of a surgery specifically designed to improve a patient's own perceived quality of life. We present a summary of the present literature describing the patient experience of adverse events following PRS and provide recommendations on the counseling process based on existing data, while highlighting areas meriting further study.

Patient Expectations for Surgery for Pelvic Organ Prolapse (POP)/Stress Urinary Incontinence (SUI)

Before embarking on a discussion of how patients perceive adverse surgical events, it is necessary to delineate what patients' expectations are for the surgery. In a survey of women undergoing PRS, achievement of surgical goals-the most common being symptom relief related to prolapse or urinary incontinence-was associated with greater satisfaction and less regret than women who did not achieve their stated surgical goals [4•]. Understandably, surgical expectations are primarily linked to the resolution of the offending pelvic floor symptoms-such as bulge and pressure related to prolapse, urinary or bowel symptoms, pain, or sexual dysfunction. Goals of surgery mirror expectations regarding surgery in achieving relief of bothersome pelvic floor symptoms and resumption of general health. When women undergoing pelvic reconstructive surgery were asked to state goals regarding surgery, the most commonly reported goals were related to the resolution of urinary incontinence (UI) and POP symptoms, as well as achieving "general health and lifestyle goals" [6]. Aside from treating the index pelvic floor symptoms, patients also prioritize the avoidance of future retreatment of their index condition [7]. In a study of patients undergoing surgery for pelvic organ prolapse (POP), the third most commonly prioritized goal of treatment, after resolution of prolapse and UI symptoms, was avoidance of a worsening condition or need for further treatment [5].

Given the myriad of potential etiologies of individual pelvic floor symptoms, not all patients' functional health expectations and goals may be guaranteed to be improved by the surgery. In a randomized controlled trial comparing Burch colposuspension to autologous fascia sling for the treatment of SUI, 92% of women who reported urgency and 83% of those who had frequency preoperatively expected significant improvement of these symptoms after surgery as well [8]. A recurring example is a desire for resolution of all urinary symptoms which are inconsistently associated with prolapse—and similarly inconsistently treated by prolapse surgery [9, 10]. In a Dutch study of patients undergoing prolapse surgery, the most common goal reported was to resolve symptoms-and most commonly the urinary symptoms associated with prolapse (i.e., urinary incontinence) [7]. Similarly, patients undergoing prolapse surgery who reported goal non-achievement were more likely to report new or worsened irritative lower urinary tract symptoms. Symptom goals that were not achieved included decreasing UI, pain relief, and relief of fecal urgency or fecal incontinence [4•]. In another study of women undergoing pessary or surgical treatment for prolapse, top symptom goals for women undergoing surgery were relief of urinary symptoms in 39% and relief of bowel symptoms in 7.5%. While 96% of women with prolapse symptom goals reported goal attainment, only 69% and 62.5% of urinary and bowel-related goals were attained, respectively [11].

The potential discrepancy between patients' surgical expectations and goals and what a given PRS can consistently resolve, especially as it relates to the relief of associated urinary or bowel symptoms, underscores the importance of explicitly discussing patients' expectations and goals of treatment preoperatively.

Patients' Perceived Severity of Shortand Long-Term AEs Changes with Time

The relative perceived importance of AEs changes over the short-, medium-, and long-term postoperative period, with functional outcomes gaining dominance over time. In a longitudinal study of patients' perceptions of AEs prior to PRS, patients preoperatively tended to be most concerned regarding complications immediately related to the surgery. However, as the time from surgery progressed to 6 to 8 weeks postoperatively, patients tended to focus more on functional outcomes, such as reduction of symptoms and ability to perform activities of daily living. By the late postoperative period, the primary adverse events were having an unsuccessful surgery, urinary incontinence, and sexual dysfunction [12••]. Postoperative patients who were more remote from surgery focused on long-term functional issues such as sexual function, needing a repeat surgery or surgical failure, chronic pain, continued UI, mesh complication, anal incontinence (AI), constipation, or stitches being too tight [13••]. Interestingly, while poor functional outcomes seem to gain relevance as "severe AEs" over time, this was not necessarily the perception preoperatively, as women tended to rate sexual function, urinary urgency/frequency, and anorectal problems less frequently as their most important goals before surgery [6].

When compared with surgeons' general perceptions of PRS complications, patients also tended to equate adverse

functional outcomes as being consistently highly relevant. In a study of patients and providers, the most relevant complications noted by patients were de novo urinary urgency incontinence (UUI), the need for clean intermittent catheterization (CIC) postoperatively, and dyspareunia. While providers similarly viewed CIC and de novo UUI as being severe, they also highly prioritized intraoperative complications-as evidenced by the emphasis often placed on organ-specific surgical complications at the time of the preoperative consent process [14]. In another qualitative study of separate groups of preoperative and postoperative patients undergoing PRS, patients who were in the immediate postoperative period were rated as "very severe AEs" perioperative complications, with the highest concern being surgical failure. Interestingly, preoperative patients did not see mesh complications as "severe." The authors postulated this to be related to the large attention recently given to mesh and related complications and the resultant emphasis on such complications by surgeons in surgical discussions [13••].

The timing of the complication in relation to the surgery and the extent of interventions required can result in patients experiencing the same type of complication in disparate ways. In a study of patient perceptions of complications following PRS in which patients were asked to rank the severity of postoperative complications, intraoperative injuries such as vascular or bladder injury which were repaired intraoperatively (and did not require transfusion or prolonged drainage, respectively) were considered minor complications. However, the same injuries requiring more interventions such as transfusion or prolonged drainage were rated as severe. Similarly, while a reoperation within the same admission or emergency department visit was deemed "severe," a reoperation as an outpatient after discharge was deemed a "moderate" complication, and additional office visits were regarded as "minor" [15•].

As time passes from the surgery, functional health goals seem to gain more importance. Experiencing de novo or worsening of preexisting adverse bowel or urinary symptoms, such as de novo or worsening constipation or new recurrent urinary tract infection, is consistently rated as a severe complication [15•]. In a Dutch study of preoperative patients with POP, the most common "fear" regarding surgery was experiencing de novo symptoms, specifically UI, whereas less common were deterioration of sexual life or physical function [7]. Recognizing the evolving nature of patient-important adverse events, it is imperative that the surgeon broaden the surgical risk discussion to include the anticipated long-term pelvic floor functional outcomes of each surgery. This includes reviewing the risks of de novo symptoms, as well as the realistic setting of expectations regarding whether surgery will improve or cure associated urinary, bowel, and sexual function.

Patient Experiences of Specific Adverse Events in the Short and Long Term

Short-Term (Perioperative) AEs

Short-term adverse events are situations in which the immediate postoperative recovery process deviates from a normal course, or if the surgery was unsuccessful, where the patients felt unprepared for that outcome. Patients preoperatively tended to be concerned mostly regarding complications related immediately to the surgery—such as anesthesia complications, pain, injury, catheter issues, and having an unsuccessful surgery $[12^{\bullet\bullet}]$.

Long-Term AEs

Long-term AEs that diminish function or QOL were rated by patients as being just as severe as AEs that surgeons typically rank as "very severe" [13••]. Long-term AEs can be broadly categorized into psychological, functional, and relational AEs.

Psychological AEs

Negative emotions surrounding treatment are primarily related to the psychological devastation of a prolapse recurrence or anxiety regarding the possibility of experiencing a recurrence at some point. In a qualitative study of women with symptomatic prolapse, some patients continued to note negative emotions even after treatment due to feeling their treatment-related hopes were not realized. These negative emotions are broken down into 3 subgroups: emotions related to persistent symptoms postoperatively, fear of recurrence, and the challenges of postoperative recovery. Such negative emotions persisted for some even when symptoms were resolved by the surgery, as some women continued to live in fear of recurrence of her prolapse. However, despite experiencing significant negative emotions and anxieties related to the postoperative state, not all patients reported talking to their surgeon about these emotions [16]. During focus group discussions of women who had previously undergone PRS, women commonly reported experiencing a sense of personal failure and shame when faced with recurrent prolapse or lack of reduction in symptoms [13••].

Functional AEs

Functional outcomes are critical for a women's assessment of whether she had experienced an adverse surgical outcome. Women want to easily engage in activities such as leisure, work, and childcare—especially after having had the prolapse prevent her from participating to her fullest ability $[13 \bullet , 17]$. Postoperative patients tended to prioritize AEs that impacted pelvic floor and physical function—including constipation, fatigue, pain, the need for a catheter, and infection-related issues $[13 \cdot \bullet]$. Thus, the surgeon should address the realistic probabilities of achieving functional outcome goals and those of experiencing a functional adverse event (such as de novo constipation), as it is primarily when these outcomes do not align with preoperative expectations that they risk becoming a serious adverse AE for the patient.

Relational AEs

While women experienced personal shame when faced with surgical failure, such shame was compounded by the fact that, once she made the decision to proceed with surgery, the problem was no longer perceived as being hers alone, but was shouldered by the social network of family members and friends who supported her while recovering from surgery [13••]. Because the ability to maintain an active role in work and/or daily supportive activities is paramount to the patient's sense of reciprocating the support she had received during her surgical recovery, a suboptimal surgical outcome further amplified a sense of shame and loss of self-esteem. Furthermore, adverse impacts on sexual function can further negatively impact the patient's experience of partner and family dynamics [13••].

Implications for Counseling

While patient perceptions of the relative importance of AEs change with time, surgical failure was consistently the principal severe AE perceived by patients both pre- and postoperatively. This reflects the profound psychological impact of a surgical failure, given patients' tendency to perceive this as reflective of personal failure.

To close the gap between patients' preoperative expectations and postoperative experiences, patients desire transparent, honest communication with surgeons in terms of realistic expectations of surgery [13••, 15•]. After providing patients the opportunity to articulate their goals of surgery preoperatively, the surgeon should give realistic estimates as to the probability of achieving that goal given a patient's unique history and risk factors. Furthermore, preoperative counseling and expectation-setting should include a discussion of the anticipated functional outcomes associated with surgery, as well as the risk of de novo adverse functional outcomes. This should include a frank discussion regarding the anticipated resolution of each bowel, urinary, or sexual functionrelated symptom, which will become more important to the patient with the passage of time after the surgery. Such discussions must occur well in advance of the day of surgery, as dissatisfaction is highly associated with feeling unprepared for surgery [6].

Patients have a tendency to perceive surgical failure and recurrence as personal failures. Therefore, the surgeon should proactively address the anticipated risk and likely causes of such an event by initiating an honest discussion behind recurrence risk following PRS and the reasons for recurrence. The surgeon should also emphasize the independence of recurrence from the patient's own behaviors. Such discussions should emphasize that there is always a chance the prolapse or urinary incontinence could recur with time, and one should provide the patient with realistic estimates of recurrence risks based on the available literature surrounding the surgical approach. Furthermore, we suggest avoiding emotionally charged words such as "failure" or "failure rates" when referring to symptomatic or surgical recurrence, and instead referring to such events as simply "recurrence of the symptom" or "need for another treatment." Finally, by emphasizing PFDs as being chronic conditions rather than episodic problems that can be "fixed" with surgery, the surgeon can reframe the relationship with the patient to being one of optimizing pelvic floor health throughout her lifetime, which, much like other chronic conditions, may involve future treatment adjustments.

Areas for Future Research

With increasing recognition of patients' expectations surrounding surgery—and the critical role that functional outcomes play in these expectations, there have been recent national efforts to emphasize patient-important outcomes in the measurement of overall quality of prolapse care. In 2016, the American Urogynecologic Society (AUGS) convened a consensus conference in which the development of a standardized group of patient-reported outcome measures for POP treatment was recognized as a critical area of need for prolapse research, which had been historically limited to process-driven measures [18]. This patient and provider-driven effort will aim to fill the existing need for an efficient tool to systematically track the quality of POP care in a way that focuses on the outcomes most relevant to patients.

While more data have recently emerged to describe the patient impact of each "severe" adverse functional outcome, the experience of adverse events continues to represent an understudied component of the overall patient surgical experience, and future studies should further elaborate on the impact of each of the psychological, functional, and relational AEs on the patient, as well as strategies to mitigate the impact of these AEs. Furthermore, future studies should also further explore how patient perspectives of complications after surgery may differ based on race, ethnicity, education level, and socioeconomic status. Finally, in order to fully empower patients with actionable information regarding surgical risk, continued efforts should be directed towards the development of prediction models to allow for individualized assessments of the risks of developing patient-important AEs. In the interim, to maximize the transparent preoperative counseling to which all patients are entitled, surgeons should proactively elicit and address patients' expectations, goals, and concerns regarding the surgery, while including a discussion of the anticipated longitudinal functional outcomes of each proposed procedure.

Conclusions

Patients' perception of AEs evolves with time, and functional outcomes become central in the long term. Therefore, in addition to the discussion of "standard" perioperative complications such as visceral injury and mesh-related complications, surgeons should discuss anticipated short- and long-term functional outcomes when counseling patients on surgical risk. Surgeons should also elicit a patient's specific expectations and goals of treatment preoperatively and provide her with honest expectations of the likelihood of the surgery meeting those expectations and achieving those goals. Finally, with the understanding that patients view surgical failure and symptom recurrence as personal failures, surgeons should review the probability and possible causes of symptom recurrence and retreatment following PRS, proactively shifting blame away from the patient herself if such an outcome occurs.

Declarations

Conflict of Interest The authors declare no competing interests.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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