

## Abstract

Limited patient understanding due to challenges in physician-patient communication and inadequate patient education materials (PEMs) can result in poor outcomes after pelvic organ prolapse (POP) repair. Qualitative analysis of interviews of 13 participants averaging 58 years old yielded several preliminary themes including: insufficient information to guide treatment decisions, preference for multimodal, dynamic, and comprehensive materials, and lack of support leading to avoidance of care, misinformation, and self-advocacy mechanisms. Developing a reproducible methodology to create evidence-based PEMs will significantly decrease patient misinformation, apprehension, and use of inaccurate sources of information.

## Introduction

Multiple studies have evaluated the etiology of poor patient satisfaction and outcomes after urogynecologic and reconstructive pelvic surgery. Factors such as lack of patient understanding due to challenges in physician-patient communication and inadequate patient education materials (PEMs) were identified as key drivers behind unsatisfactory outcomes(1-3). Our objective was to identify the process by which patients learned about POP and review their perception of available educational tools.

Preliminary Themes	Illustrative Quotes
Insufficient education received to guide patient treatment decision	"I wish they would explain that there are other options we could try first before surgery"
Patients preferred multimodal, dynamic, comprehensive education materials	"I would love something interactive talking about what the repercussions of cystocele at each stage."  "I love the diagrams. There have been so many times when I wished I had something to show people so I could explain what was going on."
Lack of support lead to avoidance of care, misinformation, and self-advocacy mechanisms	"Sometimes just hearing 'you're not alone, this happens to people, and sometimes we don't even know why' makes you feel a whole lot better than hearing nothing."

**Table 1.** Preliminary Themes and Illustrative Quotes

## Methods

Patients with history of POP were recruited using ResearchMatch and invited to participate in a virtual semi-structured interview where they were shown a website (womenshealth.gov), brochure (IUGA pamphlet), and a highly rated YouTube video. The interviews were transcribed, coded, and qualitative data analysis was performed using grounded theory methodology in an iterative process to determine themes and emerging concepts (4).



**Figure 1.** Word cloud of codes used in Ground Theory Methodology Analysis

## Results

- Qualitative analysis of interviews of 13 participants averaging 54 years old yielded several preliminary themes (Table 1) including:
  - insufficient information to guide treatment decisions
  - patients preferred multimodal, dynamic, and comprehensive materials
  - lack of support lead to avoidance of care, misinformation, and self-advocacy mechanisms.
- Emerging concepts can be found in Table 2. Participants developed self-reliant strategies for making treatment decisions, including the use of online resources, advice from friends, and independent search for more specialized physicians.

Emerging Concepts	Illustrative Quotes
Participants felt uninformed about disease process and treatment options which led to self-advocacy mechanisms and at times increased misinformation, stress, and use of treatments that were out of standard of care	"I still felt in a position where I had to do most of the research. I wish that I had something that was succinct and laid out."  "I stopped going to the doctor. I bought this naturopath's book and tape." "I remember at the time being curious about pelvic floor therapy that was never mentioned. I'd only seen it online ventures and was never mentioned by my doctor"
Participants felt distrustful during physician visits which led them feelings of isolation, desire of support groups, and loss of follow up	"My doctor never brought it up. I wasn't comfortable, either. I remember asking on a message board, hey, how do people deal with POP and sex? Do I basically need to use an enema anytime I'm planning to have intercourse?"  "My uterus is completely prolapsing. I've been avoiding the doctor because I don't see any good solution"
Participants desired well-organized, detailed, multi-modal, and destigmatizing materials as a guide to their disease process, prevention and risk factors, its natural progression, and treatment decisions	"I love how much information is here about the different treatment options including the different types of surgeries. I didn't know any of this."

**Table 2.** Emerging Concepts and Illustrative Quotes

## Discussion

Women with POP reported lack of information and support which resulted in the generation of self-coping mechanisms, leading to significant anxiety surrounding their diagnosis and treatment.

## Conclusions

Developing a reproducible methodology to create evidence-based PEMs will significantly decrease patient misinformation, apprehension, and use of inaccurate sources of information.

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