

The Patient's Voice at Scale: Understanding Why Patients are Not Sexually Active Post Radical Prostatectomy Through Qualitative Coding of Responses on a Patient Reported Outcome Instrument

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INTRODUCTION AND OBJECTIVE: While Patient reported outcome measures (PROMs) can capture the patient perspective at scale, that perspective is often constrained by available survey items. To amplify the patient's voice as communicated through a PROM, free text, or open response, items may provide a more nuanced rendering of what a patient is experiencing. The objective of this paper is to understand in qualitative terms, why patients are not sexually active pre- and post-radical prostatectomy.

METHODS: Survey responses from the Michigan Urological Surgery Improvement Collaborative prostate cancer disease registry were collected pre-treatment and at 3-, 6-, 12-, and 24-months post-surgery. Written responses to the question "Why are you not sexually active?" beyond were independently analyzed and iteratively refined into higher-level codes. For the same question, patients could select 8 other options ("Lack of a willing partner", "Lack of interest," "Lack of confidence," "No ejaculate," "No erection," "Urine leak during intercourse", "Pain/discomfort during intercourse", and "Not applicable"); a free-response option was provided next to the "Other" option. Prevalence of codes was examined after two independent raters reached agreement on code definitions.

RESULTS: Between 1/2018 and 12/2021, 24,568 PROMs were collected, and 20,268 patients responded to the sexual activity question. Approximately 7% of patients provided a text response: 1,448 unique patients submitted 1,875 written responses. Table 1 summarizes the identified codes and the percent of overall responses with each code. The three most common codes were complications (e.g., treatment-specific change in anatomy of function), partner (e.g., own health and interest), and structural issues (e.g., lack of time). Other factors that patients identified included comorbidities and explicit choices not to be sexually active.

CONCLUSIONS: Written responses provide a glimpse into a more nuanced view of post-treatment sexual activity that can be used to not only develop a more robust understanding of patients but also develop survey items that better capture patient concerns and hesitations.

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Table: Codes and short definitions

| Code | Count | % | Short definition |
|-----------------------|--------------|-------------|--|
| Complications | 570 | 30% | Complications secondary to management of prostate cancer |
| Partner | 385 | 21% | Partner's health or energy; stress of relationship |
| Structural | 253 | 14% | Lack of time; lack of energy due to responsibilities |
| Comorbidity | 169 | 9% | Additional medical conditions |
| Inactive by choice | 118 | 6% | Not sexually active for some time; focus on other things |
| Psychosocial | 80 | 4% | Anxiety; unsatisfying sex |
| Sexual aid | 46 | 2% | Discomfort with or access to sexual aid |
| Active-nonpenetrative | 43 | 2% | Sexually active but not having penetrative sex |
| Medical advice | 19 | 1% | Advised against activity |
| Religion/Moral | 8 | 0% | Religious or moral beliefs |
| Sexuality | 3 | 0% | Non-heterosexual activities |
| Not coded/Active | 181 | 10% | Missing, error, or patient was active |
| Totals | 1,875 | 100% | |