Beyond the Diagnosis: Advocating for Patient Understanding and Partnership in Stage I Testicular Cancer Management

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BACKGROUND

- Surveillance is often the preferred management option in Stage I testicular cancer (TCa).
- Limited data exist on the role of patient counseling in shaping TCa decisions and what factors most influence patients' choice of surveillance versus intervention.
- This study aims to gain insight on the shared-decision making process for stage I TCa management from the patient perspective.

METHODS

Survey

- 17-question survey posted to the Testicular Cancer Awareness Foundation Facebook group (n ≈ 4,200) at three timepoints (July 2024–May 2025)
- Questions addressed decision-making influences, satisfaction, understanding of management, and survivorship concerns

Interviews

- Five patients with stage I TCa (diagnosed Mar 2024 – 2025) completed semi-structured phone interviews focusing on their experiences with counseling and management of stage I TCa

RESULTS

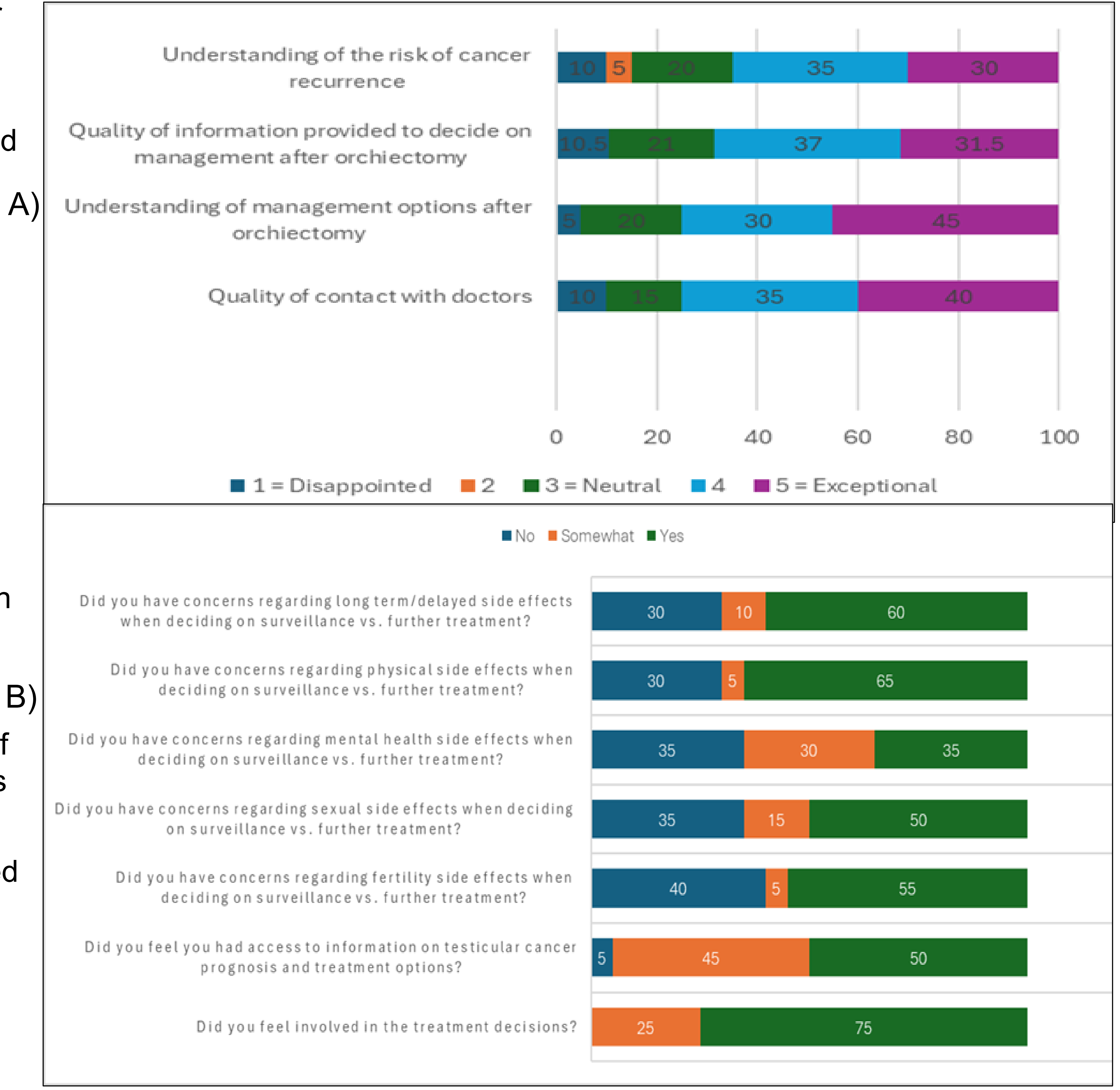

Figure 1: Twenty survey results of patients' perception of A) Satisfaction of care; B) Concerns regarding treatment decisions and survivorship outcomes

Table 1: Themes from Patient Interviews on Perception of Medical Process after Orchiectomy

Themes	Quotes
Significant Trust in Physician Recommendations	- "Honestly, whatever he [the doctor] said, I kind of did." - "I did do my own research, but I think I lean more so on what my doctor recommended doing."
Proactive Personal and Family Research	- "I'm a worry-wart… even though we were given all this information, I still wanted to research it." - "We still got a second opinion… but it wasn't because they didn't do a good job." - "We always assume that they [doctors] know what they're doing, and I like to believe they do... But I would say it was just either between what the doctor said and kind of my own research."
Gaps in Communication	- "We were told about surveillance but didn't have much discussion about chemo or preventative options." - "No one relayed the timeframe for surveillance. I had no idea when that was coming up." - "There's a disconnect… you're told to be on top of it, but not exactly how."
Coping	- "More than anything, just a lot of time and prayer." - "Although I am not a super community-based guy... it was nice that they [the Adolescent and Young Adult support team] reached out."

Take-Aways

- **Clarify management options and risks and benefits even if surveillance is the preferential option**
- **Encourage patients to research their diagnosis and provide education material if possible to improve long-term understanding**
- **Ensure patients have logistical understanding and resources to ensure appropriate follow-up**
- **Offer support group resources**

CONCLUSIONS

- Enhancing shared decision-making by encouraging patients' active participation in their care as well providing patients outlets for diagnosis information and support are essential to optimize care in stage I TCa.
- The survey and interview samples provide interesting, yet preliminary data on survivorship care necessitating further studies to continue improving patient counselling in stage I TCa.
- The study highlights the need for more testicular cancer patient-centered outcomes research and improved support for patients and their families in finding diagnosis resources and support groups