



KEY POINT SUMMARY

OBJECTIVES

To investigate how patients with a disability perceive the effectiveness of PGTs for understanding their experiences while receiving primary healthcare.

Patient-guided tours: A patient-centered methodology to understand patient experiences of health care

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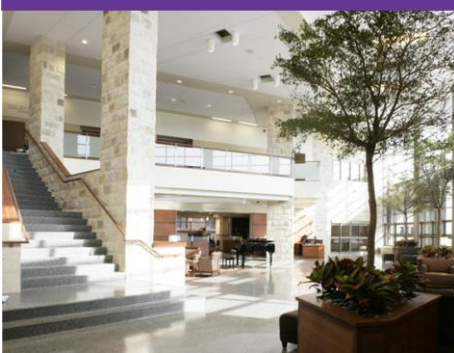
Key Concepts/Context

Traditionally, assessments of patient-centered models of care would focus on patient attitudes rather than their overall experiences. Previous studies have found that patient-guided tours (PGT), which allow patients to identify aspects of the healthcare environment that align with or deviate from patient-centered care, have been an effective way to understand patient experiences. The results of this study indicate that PGTs may also help patients with disabilities share their experiences more effectively.

Methods

This study took place in an academic hospital and utilized convenience sampling, or the involvement of participants who were conveniently recruited with no predetermined pattern for selection outside of the inclusion criteria. The inclusion criteria for the study included: 1) being a patient of the clinic, 2) being 18 years of age or older, 3) identifying as having a disability, 4) being fluent in English, 5) being cognitively intact or with a power of attorney who was cognitively intact and could provide consent, 6) being willing to participate and be audio recorded. Prospective participants were excluded if they did not wish to participate, if they knew the researchers prior to the study, if they felt physically unable to complete the PGT, or if there were language barriers, learning disabilities, or any form of cognitive impairment that would require the use of aids or support personnel.

Data were collected over an 11-month period. A total of 18 participants were recruited. During each 30- to 45-minute PGT, a participant would lead one of the researchers through various parts of the healthcare environment, including triage and check-in areas and ending with the clinic room. Participants were advised to express their thoughts, experiences, and feelings throughout the tour. They were also encouraged to reflect on their thoughts regarding the PGT process overall.



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Field notes were gathered by the researcher, as well as audio recordings of the tour which were transcribed verbatim. Transcripts and field notes were analyzed for recurring themes and were cross-checked with previous research.

Findings

Analysis of the data revealed four major participant-generated themes regarding the PGT process itself:

1. Physical cues and “touchpoints” within the built environment were helpful for reminding the participants of experiences they might otherwise have forgotten.
2. Participants noted that communication was simplified and a sense of empowerment was developed through the ability to physically show caregivers aspects of the healthcare environment that impacted their experience (i.e., “seeing things through their eyes”).
3. The PGT format encouraged active participation and attention, resulting in collaboration and comfort.
4. The PGT format may exclude those who live with severe disabilities or other certain medical conditions.

Overall, participants described the PGT process as being a valuable experience that provided new degrees of objectivity and relief. Relief came from the sense of being “seen” or “heard” by caregivers through the ability to reference aspects of the physical environment in real-time. These results underscore the impact that physical space has on patient perceptions overall.

Some participants noted that at certain points they felt uncomfortable vocalizing their feelings and experiences during the PGT due to the usual staff and patient traffic flowing through the building during the tour. Researchers noted that some of these participants used more hushed tones of voice when speaking near staff or patients.

Limitations

The authors note several limitations within the study, as well as drawbacks of the PGT method. The PGT method is time consuming. There were various instances where participants were hesitant to express their perceptions due to a lack of privacy during the tours. The exclusion of patients with mobility issues, who are unable to speak English, or who otherwise are in greater need of care leaves noticeable gaps in the data. Lastly, the authors note that the data were not triangulated, and that future studies could benefit from feeding the results back to clinical staff and participants.



Design Implications

PGTs can be an effective way to understand which aspects of the built environment directly affect patient experiences the most. Perceptions shared through PGTs may influence design decisions in a way that benefits both patients and staff.

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