"Patient Voice"  
Uncovering The Voices of Radiology Patients

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Study Domain  
The project focuses on the radiology care pathway, and the patient journey through the end-to-end experience, from the initial entry in which radiology services were recommended, to the final discussion of findings, and billing for radiology services.

Dimensions  
The construct of Patient Journey in Radiology was broken down into four dimensions:
- What surprised them  
- What confused them  
- What frustrated them  
- What worked well for them  
- What worked poorly for them.

Each dimension was explored along three facets:
- The description of the experience  
- The part of the radiological or overall care process  
- The effect on the patient and their families

CONCLUSIONS  
Participants’ insights were valuable in identifying quality and process challenges that would not be readily identified by clinical staff, nor captured within the standard clinical quality dimensions of the facilities or by leading healthcare quality and safety organizations.

To improve care quality and safety, it is imperative to engage the patient in identifying quality dimensions and to secure their feedback on established healthcare policies, technologies, and workflows.

Participants highlighted several quality and safety issues related to navigating to and within the clinical setting.

Participants offered a broader perspective, than those of the clinician, on the importance of logistical issues pertaining to care coordination outside of exam and procedure room.

Expansion in the use of the patient’s voice presents opportunities to develop or modify the quality and safety metrics to be used by facilities to assess, monitor, and enhance their delivery of care in a way that significantly improves the patient experience and healthcare outcomes.

ACKNOWLEDGEMENTS  
- We give heartfelt thanks to the patients and caregivers who participated in these interviews, and whose stories and insights are woven through our research.  
- We especially acknowledge the gift of time that was broken, initial impression of the repeating themes in the participant transcripts and interviewer notes, and to develop temporary coding.  
- Manual coding was carried out during textual analysis to identify segments related to apparent risks, issues, or opportunities for improvement.  
- Free codes were developed by reading the texts in a Grounded Theory approach and considering what facets of patient experience were being identified. We used a mixed-methods approach, including:
  - Ethnographic
  - Phenomenological
  - Participative
  - Significant event or occurrence

Ours was a good day.

The team asked participants to reflect on their experience with radiology were invited for interviews.

Data collection methodology:
- Data collection was conducted through semi-structured interviews in 60-90 minute Skype for Business audio sessions that could be accessed either through Voice over IP (VOIP). Participants were informed of their rights to anonymity and the voluntary nature of sharing their experiences.
- The team asked participants to reflect on their experience with radiology were invited for interviews.

We used a mixed methods analysis to identify segments related to apparent risks, issues, or opportunities for improvement. We especially acknowledge the gift of time that was broken, initial impression of the repeating themes in the participant transcripts and interviewer notes, and to develop temporary coding. The team used MAXDictio Word Combinations and Word Juxtaposition to mark segments related to the temporary codes, as well as code for Participant and Question items.

As a result, participants were all adults, and included patients with chronic illnesses with multiple comorbidities, patients with terminal stage IV cancer, patients in remission from cancer, and parents of a child with a chronic condition.

Project Initiative & Execution

1. Formally declare research project
2. Create research plan
3. Create MAXQDA project
4. Select from publication options
5. Select from funding alternatives
6. Initiate project
   - 1. Recruit participants via social media
   - 2. Schedule interviews
   - 3. Set up funding page
   - 4. Contact donors
   - 7. Conduct interviews
   - 8. Distribute gift cards
   - 9. Conduct Analysis
   - 10. Develop report
   - 11. Publish report
   - 12. Distribute participant copies
   - 13. Close out project
     - 1. Destroy patient identifying information
     - 2. Close MAXQDA project
     - 3. Archive project artifacts
     - 4. Declare project close
   - 14. Conduct “Lessons Learned” session
   - 15. Update processes, forms, methods accordingly

METHOD

Selection
Participants were recruited through social media using several popular hashtags related to healthcare, and through convenience and snowball recruiting.

Of those who responded, patients or care-givers with experience with radiology were invited for interviews.

Data collection methodology:
- Data collection was conducted through semi-structured interviews in 60-90 minute Skype for Business audio sessions that could be accessed either through Voice over IP (VOIP). Participants were informed of their rights to anonymity and the voluntary nature of sharing their experiences.
- The team asked what they felt worked well for them during their journey, and what didn’t work well.
- Interview recordings were transcribed in MAXQDA.
- Follow-up emails were used to clarify any doubts or inconsistencies.

Analysis
The team used MAXDictio Word Combinations and Word Juxtaposition to mark segments related to the temporary codes, as well as code for Participant and Question items.

Manual coding was carried out during textual analysis to identify segments related to apparent risks, issues, or opportunities for improvement. Free codes were developed by reading the texts in a Grounded Theory approach and considering what facets of patient experience were being identified. We used a mixed-methods approach, including:

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Project Objective

Discover and construct an ontology of the “kinds of things” that patients or care-givers experience in the end-to-end careflow, and that can be used to develop PRO measurements of quality that amplify the patient voice.

Method Overview

Interview patients and care-givers using a semi-structured interview format, and performing mixed methods analysis to construct an ontology that describes the key events and milestones of the careflow from the patient’s perspective.

Participant Profile

Participants were patients and care-givers who have experienced radiological services in hospital or outpatient settings. Participants were all adults, and included patients with chronic illnesses with multiple comorbidities, patients with terminal stage IV cancer, patients in remission from cancer, and parents of a child with a chronic condition.

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Methodology

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MAXQDA forms the integrating core of the study from start to finish

RESULTS

Participant reported experiences
Participants shared their experiences from the point of being referred for radiology to the point of receiving the outcomes of the treatment(s). The most notable feedback was related to communication, patient specific needs, and administrative processes.

Communication challenges were pervasive amongst the study participants. They include:

- Being ill or under-informed about how to prepare and what to anticipate prior to treatment which translated to increased anxiety and confusion.
- Failure to properly communicate next steps in treatment and care thereafter which resulted in confusion and frustration.
- Delay in or failure to fully disclose and or interpret results caused the participants significant anxiety and regarding the quality of care received.
- Inadequate explanation of what to expect with regards to symptom, including those that are rare but possible, caused stress and fearfulness.
- Having none of the “typically expected” symptoms induced fear regarding the effectiveness of the treatment.
- Having a symptom not described at the time of consult caused stress, surprise, and concern as it was not anticipated.

Patient specific needs were mentioned several times. Notably, patients indicated the following:

- Approach to care should take into account the needs of each patient, with special considerations and sensitivity for those with rare conditions.
- Appropriate accommodations (waiting room configuration and quick physical access to the radiology department) for the patient population including:
  - Waiting areas that allow for wheelchair bound patients to sit with their families and or caregiver.
  - Ease of access to the department without having to navigate through a large facility in light of the patient’s frequent visits.

Administrative processes such as referrals, scheduling appointments, and extensive wait times on the day of appointment were the three most pervasive examples of frustrating aspects in coordinating radiology care. Patients felt they had to do considerable due diligence to ensure referrals progressed and appointments were successfully scheduled. Extensive wait times were inconvenient and impacted the flow of the rest of the patient’s day.

Future Steps

The potential Metric Groups identified during this study will be further analyzed to determine the various facets that can theoretically be measured. These metrics will be outcomes, process, or balancing measures used for quantification of patient quality and safety.