'What are patients’ post-operative experiences and quality of life managing their orbital prosthesis following orbital exenteration surgery?'

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What are patients’ post-operative experiences and quality of life managing their orbital prosthesis following orbital exenteration surgery.

Background

• Exenteration surgery mutilating and facially disfiguring\(^1\)

• Management of periocular malignancies\(^2\)

• 4 – 6 patients per year MREH

• Concurrent radiotherapy/chemotherapy

• 3 – 5 month healing period

• Considerable MDT team input
What are patients’ post-operative experiences and quality of life managing their orbital prosthesis following orbital exenteration surgery.

Psychological Impact & Stigma

- Major cause of distress³
- Wellbeing related to body image & self image⁴
- Likened to a grieving process⁵
- Anxiety & Depression⁶
- Lack of social interaction⁷
- ‘not quite human’⁸
- Type & Timing of support
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Patient Satisfaction & Service Impact

- Facial prostheses improve self-esteem\(^9\)
- Prostheses hand-made, silicone
- Expensive £5000
- 10 hours (and several visits) to fabricate
- ‘end goal’
- Many patients don’t wear prosthesis
- Time and cost efficiency
- Very few studies related to this area
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Aims:

1. Facilitate more appropriate & coordinated care/support with a better understanding of value of prosthesis
2. Gain better understanding of when/how to introduce prosthesis, and those who may not wear it

Objectives:

1. Explore process how/why patients access the facility and decide to wear prosthesis
2. Explore patient experiences and QOL
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Grounded Theory

- Glaser & Strauss (1967)
- Philosophy in its own right based on symbolic interactionism
- Structural process, little known about topic
- The lived experience, but also the impact external forces (not lived in isolation)
- Generation of theory & theoretical sensitivity
- Theoretical Sampling (Purposive initially)
- Constant Comparison
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Method

• Retrospective
• Semi-structured interviews
• Interview Guide – 5 Areas
• Theoretical analysis/content analysis
• Interviews (at home or hospital)

Sample

• PAS system
• Approximately 20 patients/saturation
• Purposive sample initially
• Theoretical Sampling
• Exenteration in the last 8 years
• Consent
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Data Collection

- Interviews recorded electronically
- Transcribed *verbatim*
- Anonymised
- Theoretical Sampling – coding/themes
- Constant Comparison
- Schedule possibly altered in light of findings
What are patients’ post-operative experiences and quality of life managing their orbital prosthesis following orbital exenteration surgery.

Data Analysis

- Theoretical Sensitivity
- Constant Comparison
- Coding, themes & contextual links – Categories
- Theory generation
- Steering Group - Rigour
- Manual analysis
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Clinical Output & Dissemination

- Local Oculoplastic team
- Clinical Action Plan – improvements in patient care & service provision
- Communication
- Conferences/Lectures
- Publications


