

Not Just Dyspnoea – Swallowing as a Concern for Adults with Laryngotracheal Stenosis Who Undergo Reconstructive Surgery?

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Abstract

Background and Purpose: Adults with laryngotracheal stenosis who undergo reconstructive surgery experience significant breathing, swallowing and voice symptoms. The lived experience of these patients has not been researched before. Our purpose was to understand the concerns of adults with laryngotracheal stenosis who live with the condition and have had reconstructive surgery.

Methods: We conducted a qualitative study using a Framework Analysis approach. Patients, carers and multidisciplinary team members helped guide research design and topic guide. Following ethical approval and informed consent, participants who had had reconstructive surgery for laryngotracheal stenosis were recruited to either focus groups or one to one interviews. Purposive sampling was used and analyzed using a post-positivist approach. Transcripts were coded by the first author. The second author verified the analysis.

Results: Participants frequently expressed concerns about their symptoms and the psychological challenges that did not match clinician expectation that dyspnoea is their main problem. Participants reported issues that related to identity, managing experts and information provision, symptom management and living with a lifelong/rare disease. Experience of dysphagia management and symptoms was interrelated to each of these themes and highlighted that the experience of the patient often conflicts with clinician pre-conceptions or expectations.

Conclusions: Our study demonstrates how patient experience is independent of clinical expectations and knowledge. Current practice for laryngotracheal stenosis focuses on breathlessness; however, symptoms are multifactorial and include dysphagia. Clinicians need to listen and learn from patient experience to individualize supportive care and education from first contact with patients throughout the care pathway.

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