"It’s really very disturbing to me" : The Social Reality and Real-life Challenges of Living with Oro-pharyngeal Dysphagia

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Background

A paucity of literature exists documenting the lived experiences of adults with oro-pharyngeal dysphagia, which can impede a focus on psychosocial aspects of management.

Despite reports in the literature justifying the capacity of holistic models of care to improve and enhance management and individualised outcomes, there has been an almost exclusive focus on impairment-based management for this clinical population (Threats, 2007; Robbins, Kays & McCallum 2007).

Yet, impairment-based management will fail to fully meet the support needs of this clinical population, as difficulties extend far beyond its presenting signs and symptoms (Vessy, 2013).

Research Aims & Rationale

Aims of this research were to:

- Explore the real-life challenges and psychosocial experiences of oro-pharyngeal dysphagia, through analysing online first person, personal accounts
- Gain insight and improve general knowledge and understanding of the disorder by accessing a range of ‘voices’ and perspectives from those living with the condition
- Enhance clinical practice.

Methodology

- A qualitative, inductive approach to research was carried out using an interpretative phenomenological approach (IPA) to analyse the data.
- Eight first person, oral and written accounts documenting adults’ experience of living with oro-pharyngeal dysphagia, were selected from online sources, according to inclusion criteria and transcribed verbatim.
- An example of an oral account can be found at: https://www.youtube.com/watch?v=3uARo456G0k&spfreload=10 (‘Thoughts of Water’, by Julia Tuchman)
- An example of a written account can be found at: http://swallowingdisorderfoundation.com/looking-barrel-feeding-tube/ (‘Looking Down the Barrel of a Feeding Tube’, by Barbara Blades)
- A case-by-case analysis of each account was carried out, followed by a comparison and/or contradiction of themes within and across accounts, to explore the different domains of experience and to gain an ‘insider’s perspective” (Smith & Osborn, 2007).
- Textual and interpretive analyses was undertaken to reveal descriptive, linguistic and conceptual features of accounts.

Findings

Eleven emergent themes informed four main superordinate themes, as follows:

- ‘Life Changes’ suggested that an altered lifestyle was synonymous with the diagnosis of dysphagia.
- ‘Emotional Upheaval’ emerged from ample descriptions of grief and devastation, as the individuals discussed negative emotions and consequences associated with dysphagia.
- ‘Professional & Familial Involvement’ suggests that relationships between individuals and their family and/or associated professionals (both supportive and unsupportive) either positively/negatively influenced the individual’s psychosocial well-being and outlook on their disorder.
- ‘Hope and Healing’ mechanisms were supported by faith and acceptance, and despite feelings of injustice, life’s positives were appreciated by many of the individuals, providing them with strength to move forward and to bear hope for the future.

Life Changes

Life Changes

Emotional Upheaval

Professional & Familial Involvement

Hope and Healing

Summary

- What emerged as an over-arching theme, was a Life Altered, resulting from both the disorder itself, and their own and other people’s responses to it.

Conclusions

- Findings from this study emphasise:
  (i) the importance of understanding the real-life challenges of dysphagia
  (ii) the requisite skills SLTs must exhibit to ensure sufficiently holistic management, in guiding clinical practice and management
  (iii) the invaluable information that can be utilised for an expanded focus on comprehensive patient-centred care.

Finally, the study has provided information to guide and enhance clinical practice regarding the ‘well-being’ component of the ICF, while concurrently bringing knowledge and information concerning the psychosocial experiences of oro-pharyngeal dysphagia to the forefront for both clinicians and patients.

Selected References