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Family Members' Experiences of Dysphagia after a Stroke: A Qualitative Study of Family Members Living in London

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Abstract

Purpose: This study explored family members' (FM) experiences of living with a loved-one with post-stroke dysphagia. Dysphagic patients may require assistance from family to modify food/drink or administer tube-feeds. Previous survey studies have found dysphagia may increase FM burden. However, the experiences of FMs in this population have not been fully explored.

Methods: This qualitative study used one-to-one interviews to explore FMs' experiences. Ethical approval was gained from Harrow NHS Research Ethics Committee, and approvals gained from the Health Research Authority and the local NHS trust research and development department. FMs were asked open questions about their previous family eating routines, onset of dysphagia, their role, and future hopes. Interviews were audio-recorded, transcribed and analyzed thematically to determine key features of FMs' experiences.

Results: Five spouses (three women and two men) aged 60-95 participated. The patients had had their strokes between three months and three years ago. Six themes were identified: 'I do all of it'; making sense of dysphagia; emotional responses; reflecting on relationships; redefining lifestyle; and things that help.

Conclusions: FMs can struggle to understand their loved-one's dysphagia up to three-year post-stroke. Maintaining normality in relationships and lifestyle, based on pre-existing beliefs and eating routines, is important. Healthcare professionals should consider these when making recommendations. FMs have differing perspectives of the comparative impact of dysphagia. Inter-disciplinary professionals should consider patient/family priorities to provide the best-targeted support.

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