

# “My father died asking me for a glass of water”: The lived experience of supporting a family member with dysphagia secondary to a progressive diagnosis.

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## BACKGROUND:

- The nature and presentation of oropharyngeal dysphagia exists as a multifaceted entity. However, the effects of the disorder are often cited as the physical manifestation with which it is associated.
- Current guidelines highlight the importance of holistic, person-centred care, and consideration of not only the physical effects, but also the psychosocial impact of dysphagia on the individual [1].
- Research in the area has confirmed that the effects of dysphagia cannot be confined to physiological elements of the condition, in that it affects day-to-day life, and overall quality of life [2].
- With the effects of dysphagia being apparent in a person's everyday routine and indeed, social situations, the family unit are also affected by the psychosocial impact of dysphagia [3].
- As such, the current study explored the lived experience of oropharyngeal dysphagia on family members who support those living with the diagnosis.

## METHODOLOGY:

- Study design:** The study took the form of a qualitative multiperspectival design utilizing an Interpretative phenomenological analysis (IPA) methodology [4][5]
- Sampling method:** Governed by the IPA methodology of the study, a purposeful sample was gathered which in this instance consisted of first person accounts written by family members of people with oropharyngeal dysphagia secondary to that had been published online on 'blogging' or medical websites.
- Data collection:** First person accounts publicly available on the internet, written by family members who support an individual with oropharyngeal dysphagia secondary to a progressive diagnosis. Thirteen accounts met inclusion/exclusion criteria set out in the study.
- Transcription:** In order to elicit content meaning from the data, the format proposed by Smith, Flowers, and Larkin, (2009) was utilized. Data from written accounts were re-transcribed in their original forms as they appeared on the medical website/blog post. Transcribed text was then line numbered with wide margins and spacing between turns as required in IPA research. This resulted in 56 pages of data for analysis.
- Data analysis:** Data was analyzed using the analysis protocol suggested by the founders of IPA research to identify descriptive, linguistic, and conceptual elements of the text which then informed subthemes, superordinate themes, and the global theme [5].

## PARTICIPANTS:

Participants in the study were family members supporting an individual with oropharyngeal dysphagia secondary to a progressive diagnosis, as illustrated in table 1.

Table 1: Participant details

| Participant code | Relationship to person with dysphagia | Co-occurring diagnosis | Original data type    |
|------------------|---------------------------------------|------------------------|-----------------------|
| FM-C             | Daughter                              | Cancer                 | Blog/ medical website |
| FM-D             | Daughter                              | Vascular Dementia      | Blog                  |
| FM-MND           | Wife                                  | Motor Neurons disease  | Blog                  |

## FINDINGS- PART I:

Acknowledging the multiperspectival design of the study, findings are presented in two parts. Part I acknowledges and provides insight into participants' life experiences of oropharyngeal dysphagia across the diagnoses with pertinent superordinate and sub-themes unique to each participant illustrated. Part II presents the shared themes amongst all accounts. The global theme of “dysphagia as an unwelcome guest” is illustrated in figure 1, alongside examples of data supporting Part I findings.

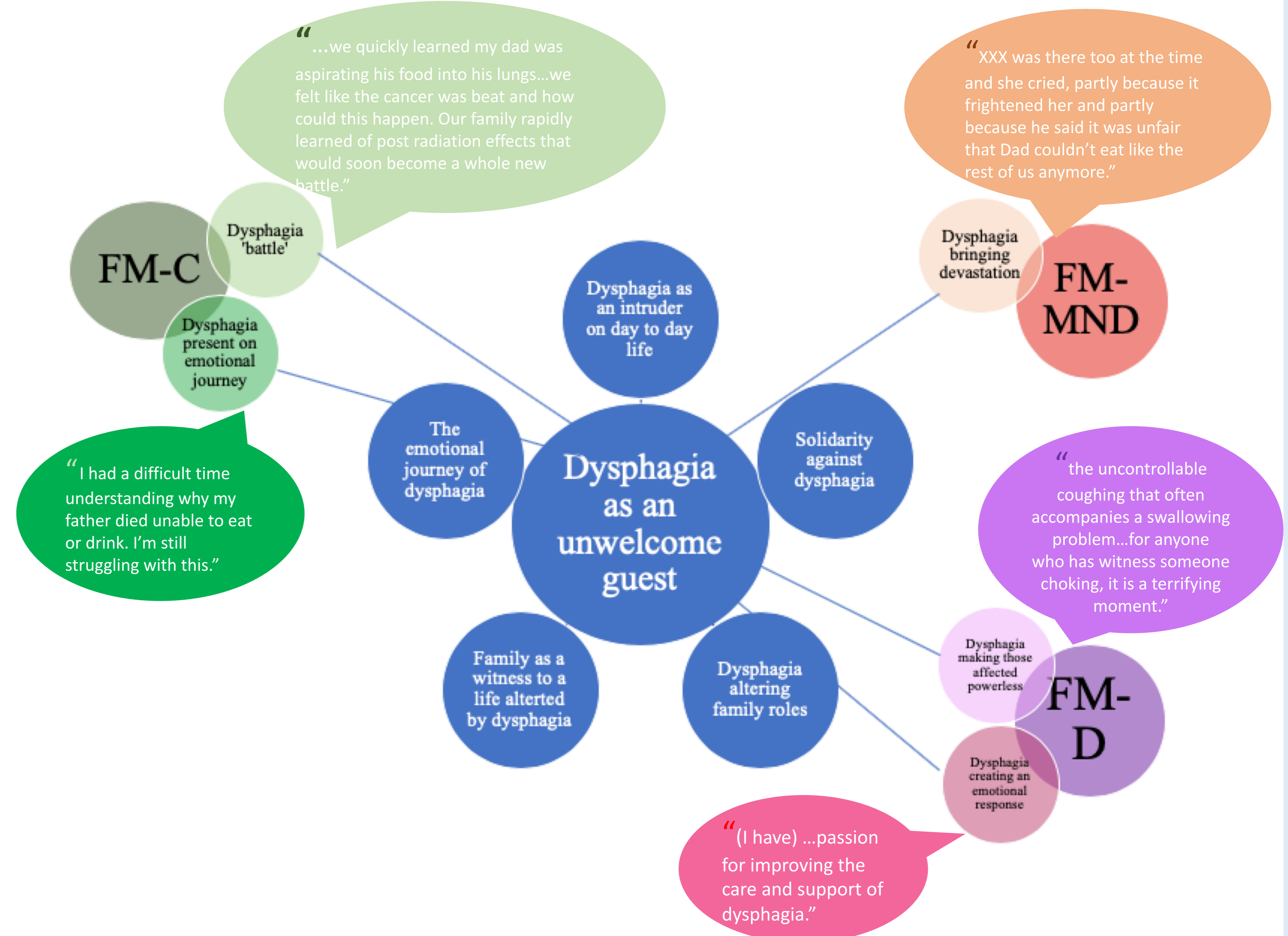


Figure 1: Global theme of 'dysphagia as an unwelcome guest' displayed with sub- themes common to all transcripts, as well as sub-themes associated with individual accounts specific to co-occurring diagnosis.

## FINDINGS- PART II:

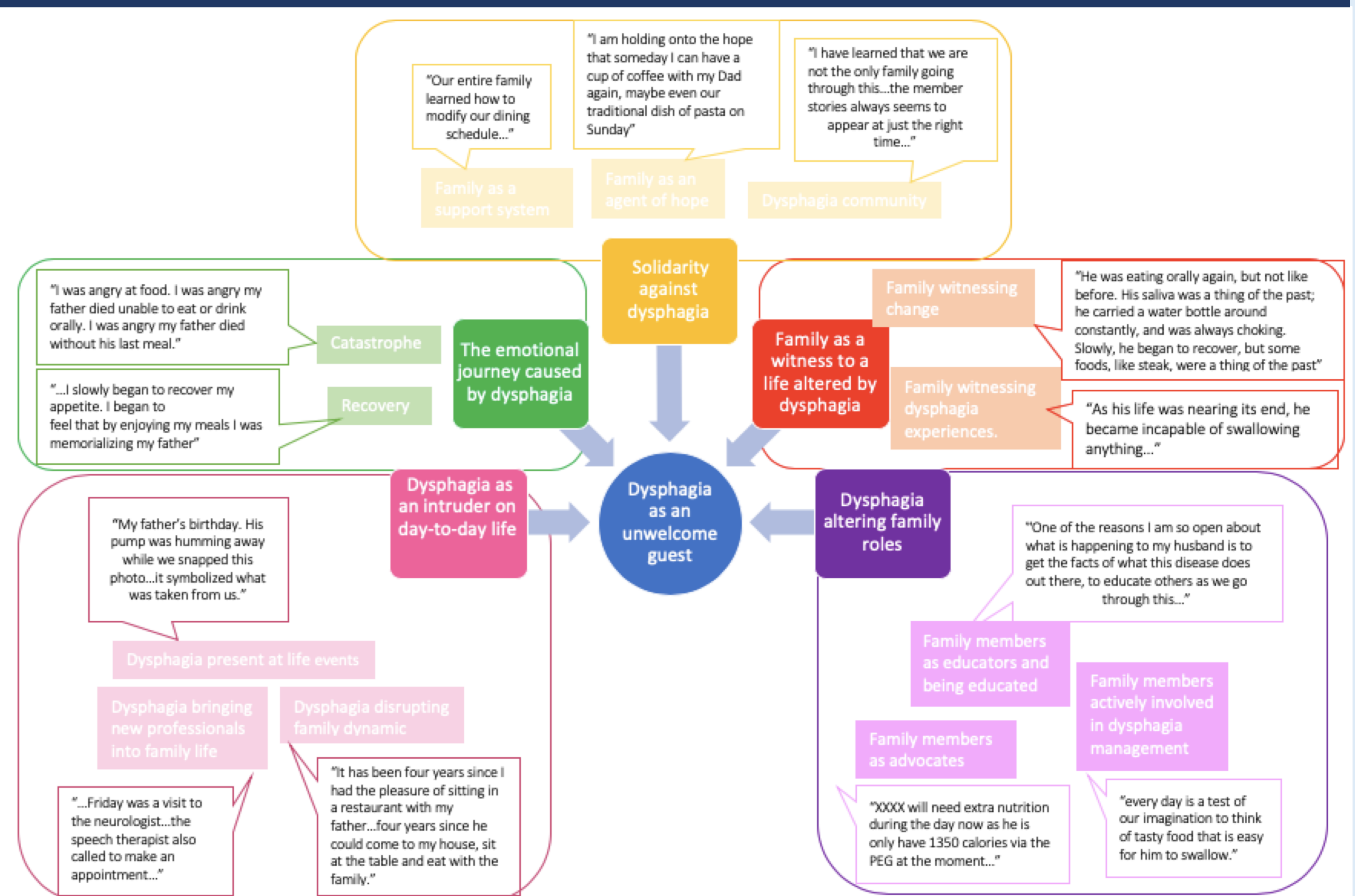
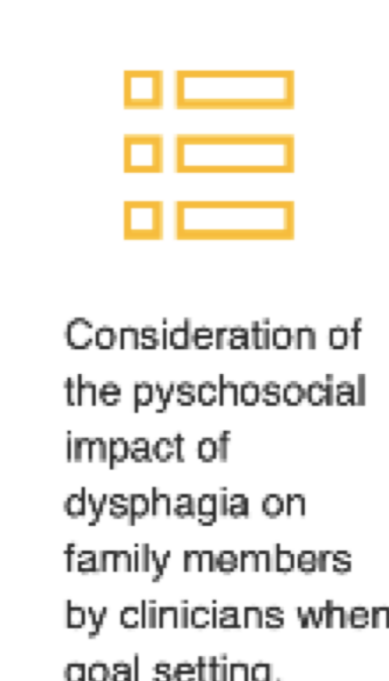


Figure 2: Global theme of 'dysphagia as an unwelcome guest', with informing sub-themes common to all the transcripts with illustrative quotes.

## ACTIONS FOR THE FUTURE:



## SELECTED REFERENCES

- [1] Royal College of Speech & Language Therapists (RCST). (2014). Resource manual for commissioning and planning services for SLDN. Dysphagia. London: RCST.  
 [2] Davis, I. A. (2007). Quality of life issues related to dysphagia. Topics in Geriatric Rehabilitation, 23(4), 352-365.  
 [3] Hund, R. L., Scarinci, N. A., Carim, B., Ward, E. C., Kujpers, P., & Porceddu, S. V. (2015). Third-party disability in carers of people with dysphagia following nonsurgical management for head and neck cancer. Disability and Rehabilitation, 38(5), 462-471. doi:10.3109/09638288.2015.1046563  
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