# "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 is this instance consisted of first person accounts written by family of people with oropharyngeal dysphagia secondary to that 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 Thirteen progressive diagnosis. 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 retranscribed 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

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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.

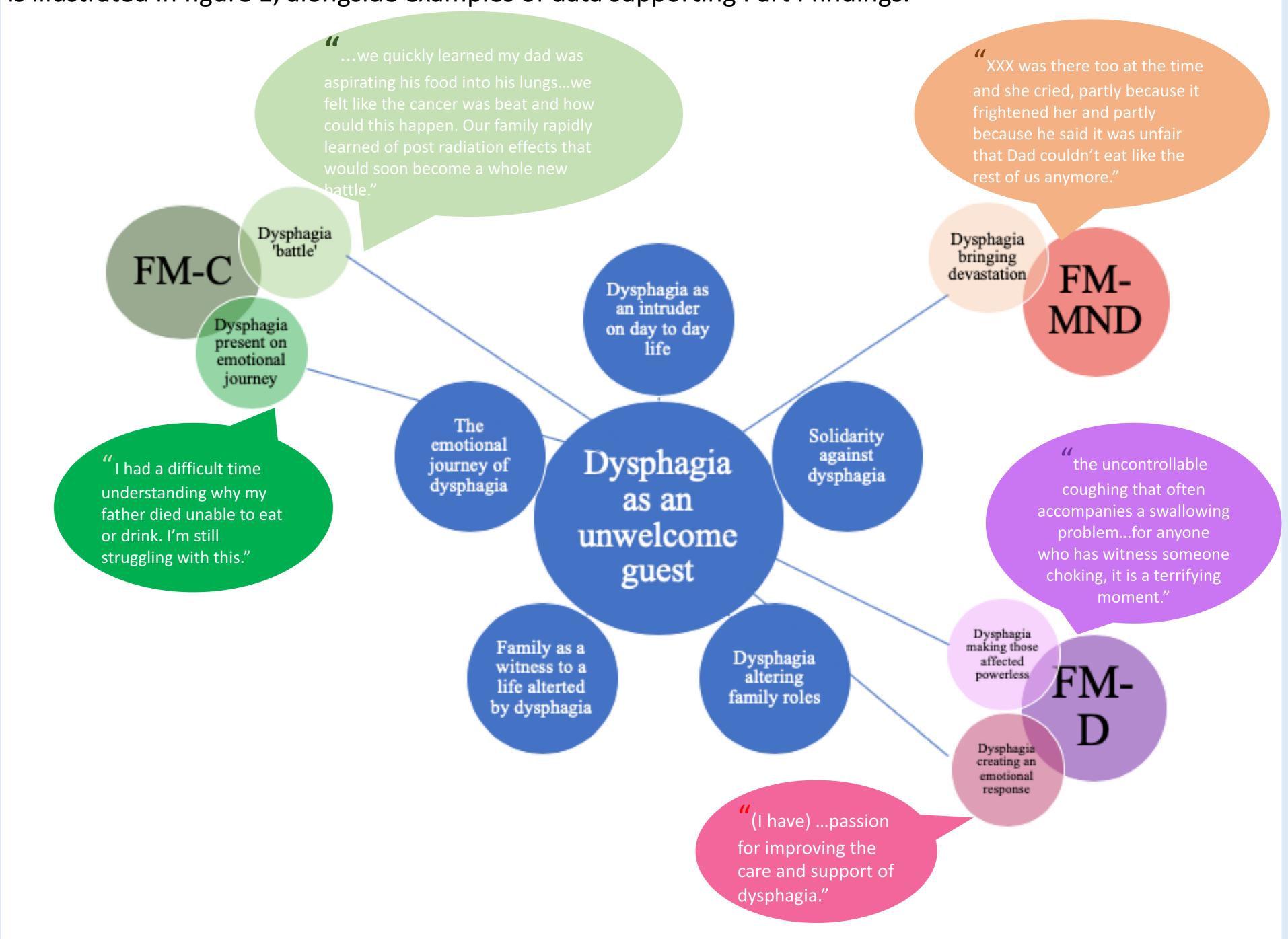


Figure 1: Global theme of 'dysphagia as an unwelcome guest' displayed with sub- themes common to all transcripts, as well as sub-themes associated with individual accounts specific to co-occurring diagnosis.

#### FINDINGS- PART II: "I am holding onto the hope "I have learned that we are that someday I can have a not the only family going cup of coffee with my Dad "Our entire family through this...the member again, maybe even our learned how to stories always seems to traditional dish of pasta on modify our dining appear at just the right Sunday" schedule..." Solidarity "He was eating orally again, but not like "I was angry at food. I was angry my against before. His saliva was a thing of the past; father died unable to eat or drink dysphagia he carried a water bottle around orally. I was angry my father died constantly, and was always choking. Family as a without his last meal." Slowly, he began to recover, but some The emotiona witness to a foods, like steak, were a thing of the past" journey caused life altered by "...I slowly began to recover my by dysphagia dysphagia "As his life was nearing its end, he appetite. I began to feel that by enjoying my meals I was became incapable of swallowing memorializing my father" anything..." Dysphagia as Dysphagia Dysphagia an intruder on as an altering family "My father's birthday. His day-to-day life "One of the reasons I am so open about unwelcome pump was humming away what is happening to my husband is to guest while we snapped this get the facts of what this disease does photo...it symbolized what out there, to educate others as we go was taken from us." through this..." as educators and being educated actively involve as advocates "It has been four years since I had the pleasure of sitting in "every day is a test of "...Friday was a visit to "XXXX will need extra nutrition a restaurant with my our imagination to think the neurologist...the during the day now as he is father...four years since he of tasty food that is easy speech therapist also only have 1350 calories via the could come to my house, sit for him to swallow." called to make an PEG at the moment..." at the table and eat with the appointment..."

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:**



[5]Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative Phenomenological Analysis: Theory, Method and Research. London: SAGE Publication:



Consideration of the pyschosocial impact of dysphagia on family members by clinicians when goal setting.



RESEARCH exploring the psychosocial impact of dysphagia on the family unit.

SELECTED REFERENCES

1]Royal College of Speech & Language Therapists (RCSLT). (2014), Resource manual for commissioning and planning services for SLCN, Dysphagia. London: RCSLT [3]Nund, R. L., Scarinci, N. A., Cartmill, B., Ward, E. C., Kuipers, P., & Porceddu, S. V. (2016). 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 [4] Larkin, M., Shaw, R., & Flowers, P. (2019). Multiperspectival designs and processes in interpretative phenomenological analysis research. Qualitative Research in Psychology, 16(2), 182-198. doi:10.1080/14780887.2018.1540655