



Surveying the International Prevalence and Nature of Eating, Drinking and Swallowing Difficulties in Adults Presenting with Fibromyalgia

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Abstract

Fibromyalgia is a centralized pain syndrome characterized by widespread pain, fatigue, sleep and sensory issues. Fibromyalgia is present in up to 8% of the global population, disproportionately affecting females. Research acknowledges that patients with similar rheumatic/neurological disorders experience eating, drinking and swallowing difficulties. There are also anecdotal reports regarding dysphagia among the fibromyalgia community. However, there is limited research exploring these issues, with potential impact on care delivery and patient outcomes. This study investigated the nature and prevalence of dysphagia in an international sample of adults with fibromyalgia. An online cross-sectional survey design was used to gather data. Questions were adapted from a criterion-based assessment and available evidence. The survey focused on demographics, dysphagia symptoms, and symptom experiences. Results were analyzed using descriptives and correlational analysis. 1983 individuals participated (age range: 18–94), located: Australia (n = 18), Ireland (n = 63), Canada (n = 174), New Zealand (n = 253), the UK (n = 434) and the USA (n = 1024). Many eating, drinking and swallowing symptoms were reported, including food sticking in the throat during swallowing (89%), and pills taking extra effort to swallow (88%), and dry mouth (85%). This study identified previously under-explored eating, drinking and swallowing difficulties among adults with fibromyalgia. These difficulties were self-reported across age, gender, and location, highlighting the potential prevalence of these concerns among a wide range of people, despite having not been explored in depth in previous studies. Timely and accurate dysphagia identification is vital given the its' potential impact on nutrition, prognosis and quality of life. This study highlighted the importance of honoring patient experiences in fibromyalgia management while also recommending input from allied health professionals such as SLTs and dietitians to improve therapeutic relationships and clinical outcomes. As such, continued research into the cause, implications, and management of these issues beyond is required to inform and optimise future patient-centred service delivery and care provision.

Keywords Dysphagia · Fibromyalgia · Swallowing · Pain · Management

Introduction

Fibromyalgia is a globally prevalent centralised pain syndrome [1] characterised by symptoms such as chronic widespread pain, decreased tolerance to pain, heightened sensitivity and tenderness to pain, and significant psychosocial implications, among a myriad of other highly variable symptoms [2] [3]. Definitive causation is currently

uncertain, although centralised sensitization is hypothesised to be a primary contributing factor [1]. Fibromyalgia disproportionately affects women, with a female: male ratio of 9:1, and the average onset of the illness between 45 and 60 years [4]. The trajectory of fibromyalgia is chronic and symptoms vary between individuals, making it challenging to assess and manage [3].

The invisible nature of fibromyalgia, coupled with its' complex poly-symptomatology, lack of as-of-yet established biomarkers, and ever-evolving diagnostic criteria contribute to a lack of clarity and general awareness regarding the nature and impact of this illness [5]. This can make it difficult for patients to advocate effectively for care that they require and can also create clinical uncertainty among medical practitioners regarding the most appropriate diagnostic

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tools and clinically effective management options available for patients with fibromyalgia [6], potentially leading to delayed diagnosis or management of the cardinal pain- and fatigue-based symptoms. ([3] [6] [5]). Considering that patients face such difficulties in seeking care for established and well-known symptoms of fibromyalgia (e.g.: pain, fatigue, sleep disturbances), it is logical that there would be even less awareness of and management options available for some of the lesser-known patient reported symptoms (e.g.: dysphagia).

Dysphagia is the inability to swallow or feeling that solids or liquids do not pass effortlessly from the mouth to the stomach [7]. The prevalence of dysphagia can vary but generally ranges between 2 and 20% of the general population among available research studies [8]. In non-fibromyalgia-specific populations, dysphagia often results from illnesses such as cerebrovascular diseases, progressive disorders, trauma, infection or surgery to the oral cavity, pharynx or oesophagus, among others [9]. Dysphagia can lead to serious health consequences when unmanaged, including airway obstructions, malnutrition, pneumonia, increased and prolonged hospitalisations, resulting in a reduction in quality of life and increased financial burdens [8]. Dysphagia also can lead to social and emotional changes, depression and social isolation and have a significant impact on oral medication administration ([7] [10]).

Research into illnesses similar to fibromyalgia have documented a range of dysphagia-like symptoms including dry mouth (xerostomia), an abnormal or altered taste (dysgeusia) and painful swallowing (odynophagia) [11]. Furthermore, early-stage research has recently suggested that people living with fibromyalgia may also often experience dysphagia and odynophagia [12], with suggestions that eating, drinking, and swallowing problems may occur in 37.3% of those with fibromyalgia in comparison to 0.4% of controls [13]. Research regarding causation of dysphagia in those living with fibromyalgia remains sparse, with tentative suggestions that centrally mediated alterations in sensory functioning may play a role in the development of swallowing difficulties, in addition to the potential role of poly-pharmacy, and heightened orofacial pain impacting masticatory functioning [14]. However, available studies have been completed on small sample sizes, with heterogenous study designs, which

limit our current scientific understanding of fibromyalgia-associated dysphagia.

As discussed, numerous studies among non-fibromyalgia-specific cohorts suggest associations between poor oral health and dysphagia and reductions in health outcomes and quality of life [15]. Individuals living with dysphagia which is not related to fibromyalgia regularly report reduced social interactions, impaired access to activities of daily living, and poorer health-related quality of life [15]. As those living with fibromyalgia already report poorer health outcomes, reduced levels of quality life, and impaired access to activities of daily living, without the consideration of the potential extra burden of dysphagia, it is imperative that we investigate if fibromyalgia-associated dysphagia is contributing to this complex clinical picture in order to begin to optimise care delivery to this cohort and to address potentially unmet medical needs. Therefore, this study investigated the experience of dysphagia or eating, drinking, and swallowing problems among people living with fibromyalgia, via the use on an online cross-sectional survey, with the aim of better understanding the symptom profile of fibromyalgia-associated dysphagia and it's associated level of care needs, leading to design of patient-centred care for this vulnerable patient group.

Methods

This cross-sectional survey used the CROSS reporting guidelines to provide evidence-based direction [16]. Institutional ethical approval was received in advance of starting the study. Participants were eligible for inclusion if they had a clinical diagnosis of fibromyalgia and were adults over 18 years of age. No other restrictions to inclusion were applied.

Selected international organisations and social media groups which provide support for people living with fibromyalgia were contacted to ask them to disseminate the online Qualtrics survey to their members via snowball sampling (Table 1).

The survey was available between 21st September and 31st October 2021, subsequent to piloting with 4 speech and language therapists and 1 person with fibromyalgia, with minimal changes to formatting suggested. The final survey

Table 1 Organisations which disseminated the survey

Fibromyalgia organisations who accepted the invitation to participate in this research study	
FibroIreland	ME/CFS/Fibromyalgia support association queensland incorporated
Fibromyalgia Research UK	National fibromyalgia association
Arthritis New Zealand	Fibromyalgia association Canada
ME/CFS Support Auckland incorporated	Fibromyalgia London Group Canada

Table 2 Symptoms surveyed

Symptoms surveyed	
Unpleasant/abnormal/altered taste sensation	Burning/prickling sensations on the tongue or other areas of the mouth
Decrease in taste sensitivity	Absence of taste
Dry mouth	Infections on the tongue or other areas in the mouth
Painful swallowing	Reflux

Table 3 Clinical scenarios adapted from the EAT-10

Clinical scenarios from EAT-10	
My swallowing problem has caused me to lose weight	Swallowing is painful
My swallowing problem interferes with my ability to go out for meals	The pleasure of eating is affected by my swallowing
Swallowing liquids takes extra effort	When I swallow food sticks in my throat
Swallowing solids takes extra effort	I cough when I eat
Swallowing pills takes extra effort	Swallowing is stressful

comprised 3 sections which contained 12 questions in total. The first section investigated participant demographics using multiple-choice questions. The second section investigated symptom experience, frequency and severity via matrix questions, with suggested symptoms reflecting findings from the evidence base ([13], [4], [17]) (Table 2). The final section included clinical scenarios and symptom experiences sourced from the Eating Assessment Tool (EAT-10) (Table 3) [18].

Data Synthesis and Analysis

Descriptive analysis was carried out and then a series of Chi Square tests, correlations and analysis of variance tests (ANOVAs) were carried out to identify key links and differences between variables, using SPSS [19].

Results

In total, 2,072 people completed the survey, and after the elimination of partially completed surveys, 1,983 participants, whose ages ranged between 18 and 94 years, were included in the sample. The sample was divided into four age groups as follows: group 1, ages 18–34 ($n = 186$), group 2, ages 35–54 ($n = 770$), group 3, ages 55–74 ($n = 937$), group 4, ages 75–94 ($n = 82$). Most of the participants were aged between 35 and 54 ($n = 770$) and 55–74 ($n = 937$) and most of the sample identified as female (95.4%) ($n = 1892$) and 3.4% ($n = 67$) identified as male (Table 4).

Most of the participants resided in the USA (52.16%, $n = 1024$) or the UK (22.11%, $n = 434$), and the remaining participants resided in New Zealand (12.88%, $n = 251$),

Table 4 Description of sample

Demographics	N	%
Participant age bracket	1975	–
18–34	186	9.41
35–54	770	38.98
55–74	937	47.44
75–94	82	4.15
Gender	1959	–
Female	1892	95.4
Male	67	3.4
Non-Binary	16	.8
Prefer Not to Say	5	.3
Country	1963	–
Australia	18	.9
Canada	174	8.9
Ireland	63	3.2
New Zealand	251	12.8
United Kingdom	433	21.9
United States of America	1024	51.6

Canada (8.86%, $n = 174$), Ireland (3.2%, $n = 63$) and Australia (0.91%, $n = 18$).

Oral Stage Sensory Swallowing Problems

Participants from the total sample ($n = 1983$) were asked to indicate if they experienced the following oral stage sensory issues: dry mouth, intra-oral prickling/burning, intra-oral infections, unpleasant/abnormal/altered taste (i.e.: previously/typically pleasant tasting food/fluid now tasting unpleasant/abnormal/altered), decreased taste

sensitivity (i.e.: a perceived reduction in typical acuity of taste), or absence of taste (i.e.: perceived total inability to taste foods or fluids) (Fig. 1).

The oral stage sensory issue, dry mouth, was experienced most frequently by participants (85%, $n = 1673$), while abnormal taste was experienced by over half of the participants (51%, $n = 999$) and prickling/burning sensations was experienced by 40% ($n = 786$) of participants. Decrease in taste was experienced by 34% ($n = 680$), oral infections was reported by 30% ($n = 585$) of the participants, while absence of taste was the issue that was experienced the least (16%, $n = 317$).

Pharyngeal and Oesophageal Stage Swallowing Issues

Participants indicated within the general survey questions if they experienced the pharyngeal stage swallowing issue of painful swallowing and oesophageal stage swallowing issue of reflux (Fig. 2).

Painful swallowing was experienced by 53% ($n = 933$), and reflux was experienced by 77% ($n = 1513$) of the participants in the study.

Frequency of Experience of Pharyngeal and Psychosocial Symptoms

Pharyngeal and psychosocial issues were subsequently measured in more detail using the EAT-10 tool. Figure 3

Fig. 1 Oral stage sensory swallowing problems reported by total sample

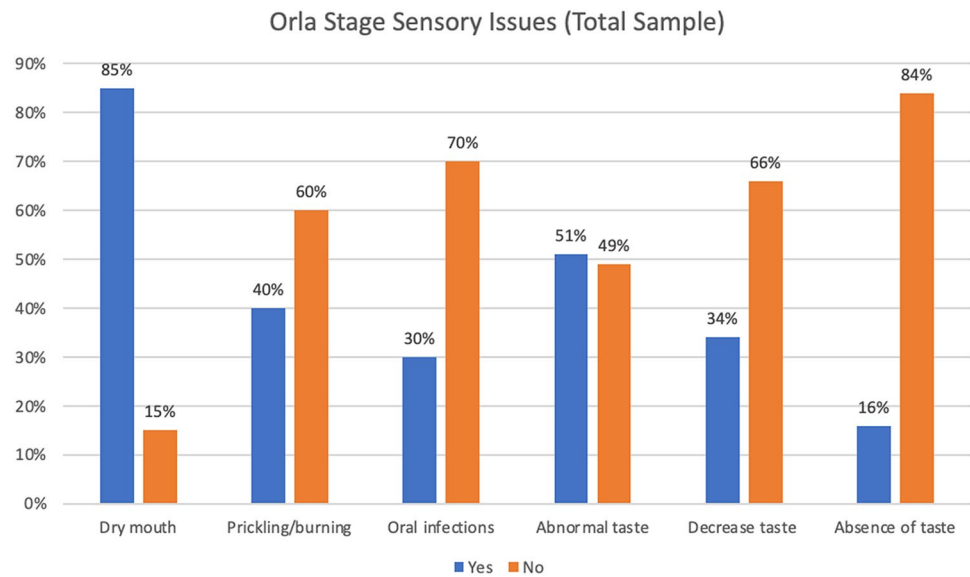
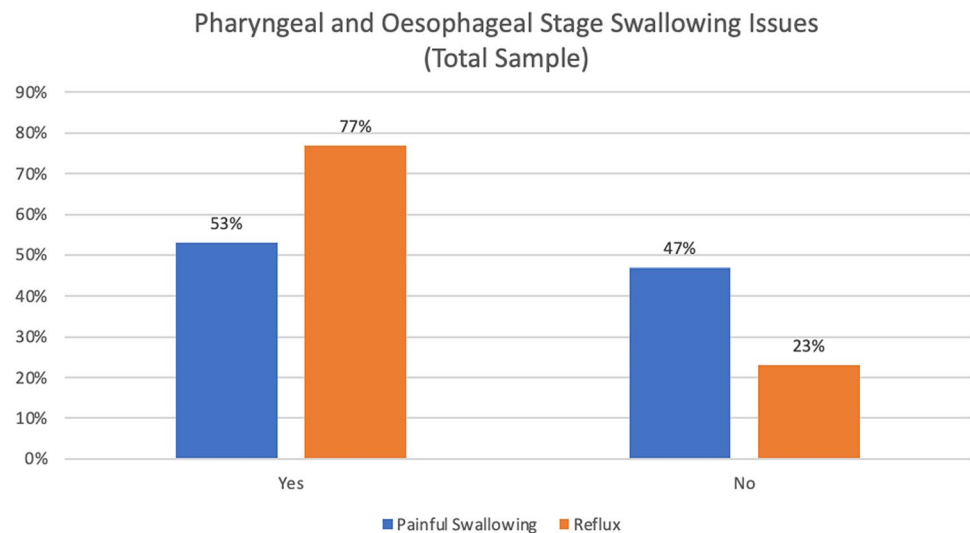


Fig. 2 Pharyngeal and oesophageal stage swallowing problems reported by total sample



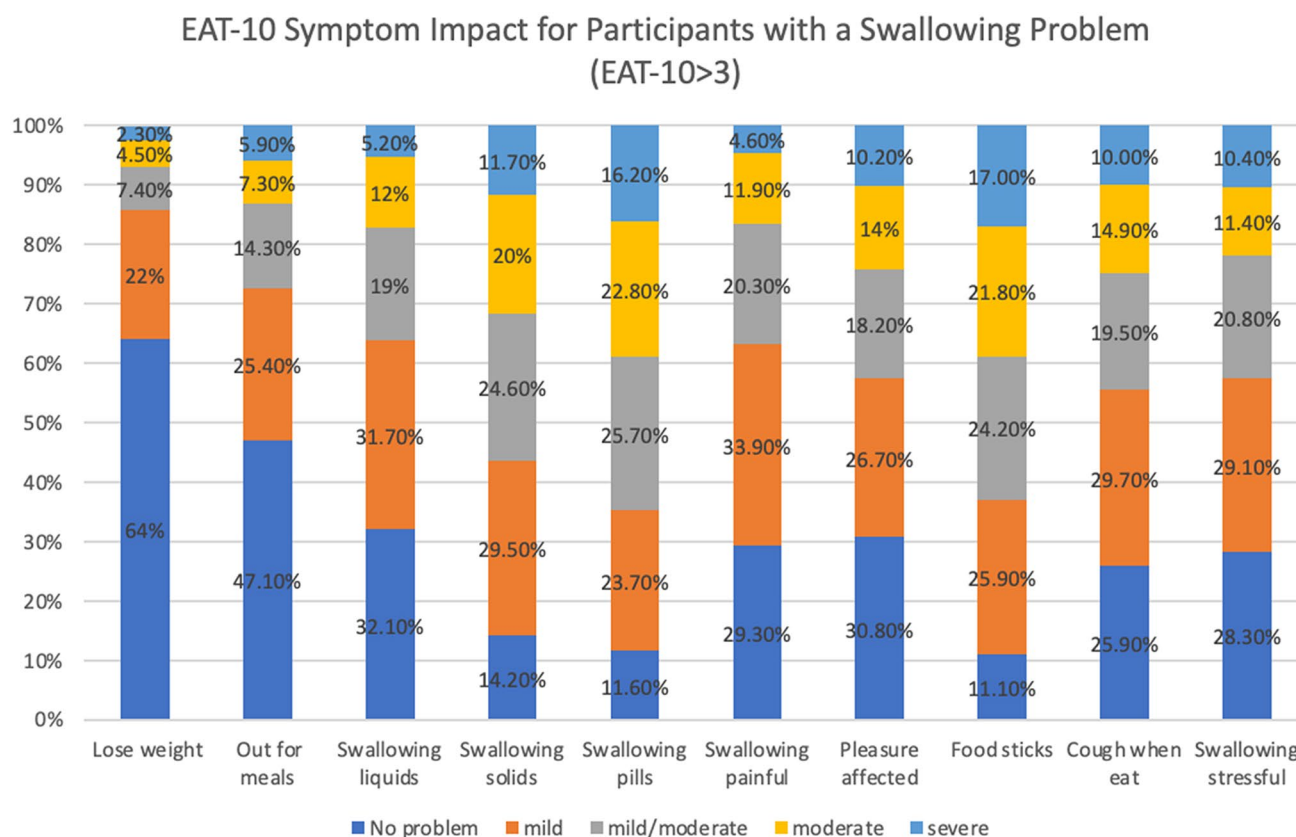


Fig. 3 EAT-10 scores

displays the degrees of impact of pharyngeal and psychosocial symptoms for participants who scored 3 or more on the EAT-10.

The reported symptoms that impacted the participants most were food sticking in the throat when eating and swallowing pills and swallowing solids taking extra effort. Food sticking in the throat was an issue for 89% ($n = 1040$) of participants, with 17% ($n = 200$) reporting that this was a severe symptom. Most of the participants (88%, $n = 1035$) reported that swallowing pills takes extra effort with 24% ($n = 277$) of those who indicated that this was an issue for them reporting that it was a mild problem, and 495 ($n = 568$) reporting that it was a mild or mild to moderate problem. Swallowing solids takes extra effort for 76% ($n = 1005$) of participants with most reporting that it was a mild (30%, $n = 371$) or a mild to moderate (19%, $n = 222$) issue.

Coughing when eating and swallowing experienced as painful were also experienced by a high proportion of participants whose EAT-10 total score was greater than 3. Coughing when eating was experienced to some degree by 74% ($n = 868$) of participants, however it was most reported as a mild to moderate symptom with only 10% ($n = 118$) reporting that this was a severe symptom for them. Swallowing liquids was reported as an issue for 68% ($n = 795$)

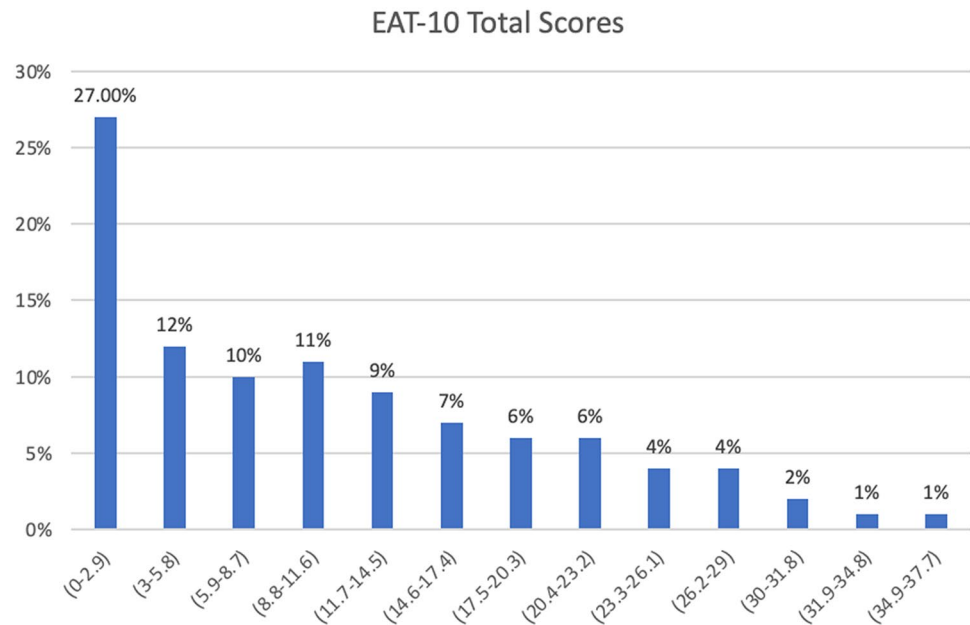
of participants with 32% ($n = 371$) of those who indicated that it was a mild problem and only 5% ($n = 61$) reporting that it was a severe problem. The least impactful swallowing issue reported by participants was weight loss with only 2% ($n = 27$) of participants with swallowing problems reporting that this was an issue for them.

Extent of Swallowing Problems Measured by the EAT-10

Participants were asked to rate the extent of their swallowing problem from “no problem” to “severe problem” for each scenario clinical scenario from the EAT-10. For each item on the EAT-10, a score of 0 indicates no problem, a score of 1 indicates a mild problem, a score of 2 indicates mild to moderate problem, a score of 3.00 indicates a moderate problem and a score of 4 indicates a severe problem. Total scores of three or higher on the EAT-10 are indicative of a swallowing problem. Out of the whole sample, 73% ($n = 1171$) of participants had total scores EAT-10 that were equal to or greater than 3 (Fig. 4).

While 27% ($n = 426$) of participants scored less than 3 on the EAT-10, an overwhelming majority (73%, $n = 1171$) met

Fig. 4 Extent of swallowing problems measured by the EAT-10



the criteria on the EAT-10 to be deemed to have a significant swallowing problem.

Mean Likert Scale Items Scores (1–4) for Participants with EAT-10 Total Scores Equal to or Higher than 3 or Higher

The mean scores for the 10 clinical scenarios in the EAT-10 were highest for the following pharyngeal stage swallowing issues [swallowing pills ($M=2.08$, $SD=1.25$), food sticking in throat ($M=2.07$, $SD=1.26$), swallow effort ($M=1.85$, $SD=1.22$), swallowing solids ($M=1.85$, $SD=1.22$) and coughing when eating ($M=1.53$, $SD=1.29$)]. Participants were less impacted by the pharyngeal stage issues swallowing pain ($M=1.28$, $SD=1.42$) and swallowing liquids ($M=1.26$, $SD=1.17$). Of the psychosocial issues related to swallowing problems for participants with EAT-10 scores greater than 3, the experience of swallowing as stressful ($M=1.46$, $SD=1.29$) and having the pleasure of eating affected ($M=1.46$, $SD=1.32$) were the most impactful symptoms, while eating meals out ($M=0.994$, $SD=1.19$) was not as impacted by having a swallowing problem. The nutritional impact, measured by whether the swallowing problem caused participants to lose weight, was the least impactful swallowing issue ($M=0.592$, $SD=0.969$).

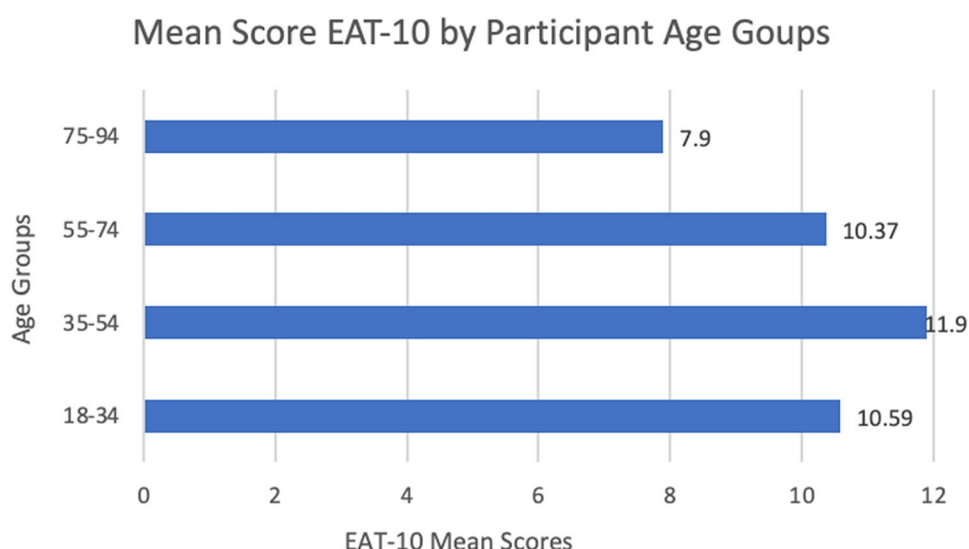
EAT-10 Total Mean Scores by Age Groups for Whole Sample

The reported impact of having a swallowing problem varied by age groups (Fig. 5).

Participants aged 35–54 reported more severe dysphagia related symptoms ($M=11.90$, $SD=10.38$) than any other age group. Participants aged 18–34 ($M=10.59$, $SD=9.79$) and 55–74 ($M=10.37$, $SD=9.25$) reported similar experiences of the impact of dysphagia in their lives, while participants aged 75–94 ($M=7.90$, $SD=8.05$) reported that based on the clinical scenarios presented, dysphagia had a lower level of impact on their lives.

Psychosocial Impact for Participants with EAT-10 Total Scores Equal to or Higher than 3

The psychosocial impact of having a swallowing problem for participants who had total scores greater than 3 on the EAT-10 were measured by the extent to which participants reported that pleasure when eating, swallowing experienced as stressful and going out for meals were impacted by their swallowing problem. Swallowing was reported as stressful for 72% ($n=840$) of the participants in the study, with most of these participants indicating that this issue was a mild (29%, $n=342$) or mild to moderate problem (21%, $n=243$) and considerably fewer participants reporting that the experience of swallowing as stressful was an issue for them (10%, $n=122$). Pleasure when eating was affected to some degree for 69% ($n=810$) of participants, with 10% ($n=120$) of participants reporting that the pleasure of eating was severely affected. Going out for meals was the psychosocial impact that was least affected by having a swallowing problem with just over half of the participants (53%, $n=620$) with total scores of greater than 3 on the EAT-10 reporting that this was an issue for them. Of those who reported eating out as

Fig. 5 Mean scores by age groups on EAT-10

an issue, 25% ($n = 298$) indicated that it was a mild problem and only 6% ($n = 68$) indicated that it was a severe problem.

Discussion

This cross-sectional international study generated new information on the nature and prevalence of eating, drinking and swallowing problems in adults with fibromyalgia. Findings suggest that eating and drinking problems across all stages of swallowing are common amongst this group, with adults primarily reporting food sticking in the throat during swallowing (89%), pills taking more effort to swallow (88%), and dry mouth (85%). Expanding beyond purely physiological difficulties, the swallowing problems reported here also had psychosocial implications. For example, swallowing difficulties here were reported to cause reduced pleasure in eating and drinking (69%) and stress (73%). This suggests that eating, drinking, and swallowing problems are prevalent among adults living with fibromyalgia and can have debilitating physiological, nutritional, and social implications, despite limited research in this field. This evidently signals the need for greater research into the presentation and management of these difficulties to ensure that people living with fibromyalgia can eat and drink safely and fully engage with personally relevant activities of daily living.

Oral Stage Sensory Swallowing Issues

Oral stage sensory difficulties were common in this group, with dry mouth and unpleasant/abnormal/altered taste being a primary area of concern for participants. Despite the prevalence of these oral stage sensory issues, causation remains unknown. Recent research has emphasised the role of central sensitization in the overall illness experiences of people

living with fibromyalgia. People with fibromyalgia have demonstrated dysfunctional evaluation during sensory processing, resulting in hyperalgesia for noxious stimuli combined with hypoalgesia for non-noxious stimuli [20]. This can lead to tactile anhedonia, unpleasant sensory experiences [21] and reduced sensation seeking [22]. Additionally, another contributing factor may also be the impact of polypharmacy on the intra-oral biome. It is long established that certain pain medications prescribed to people with fibromyalgia are xerogenic in nature and can cause dry mouth [13]. Dry mouth can contribute to altered taste, mouth ulcers, candidiasis, periodontal disease, and oral stage dysphagia [11] [23]. Changes in taste and dry mouth may contribute to reduced pleasure in eating and lead to reduced or altered oral intake. It is essential that the oral health of those taking xerogenic medications is reviewed regularly to ensure that these undesirable outcomes don't occur. Finally, burning mouth syndrome often occurs comorbidly with fibromyalgia. This complex condition is thought to be neuropathic in origin, with peripheral and central sensitisation components, sometimes resulting in dry mouth, altered taste, and swallowing difficulties. It is possible that the above factors may be contribute to the intra-oral sensory experiences reported here, warranting greater research attention in the future to improve management options and patient outcomes.

Pharyngeal Stage Swallowing Problems

Pharyngeal swallowing issues were highly prevalent amongst this group, with both sensory and motility concerns reported here. As above, it is currently unclear about the exact causation of these pharyngeal issues in people living with fibromyalgia. However, the role of central sensitization combined with peripheral and autonomic nervous system dysregulations has been hypothesised to contribute

to changes in the normal swallow among people living with conditions such as fibromyalgia and GERD, although further research is required ([24] [25] [26])

The majority of participants (89%) reported experiencing food sticking in their throat, with 76% and 68% reporting that they needed extra effort to swallow liquids and solids, respectively. This was in addition to 74% who experience coughing while eating. This suggests the possibility of pharyngeal residue post-swallow which may irritate laryngeal and pharyngeal sensitivity, and the potential for choking or penetration/aspiration if boluses are not moving through the area promptly. This sensation may be linked with the reported levels of stress associated with swallowing amongst this group. Given the multitude of health concerns that people living with fibromyalgia already contend with, and the potential for increased morbidity and mortality if choking, penetration, or aspiration occur, it is imperative that the nature and severity of this risk is established in order to guide management.

Of note, 88% of participants reported that swallowing tablets takes extra effort also. Research suggests that swallowing problems can result in a range of difficulties for oral medication management especially for solid, oral and extended-release formulations which are typically recommended for use in the management of chronic pain [7]. It has been reported that to reduce the distress and pain associated with the difficulty of swallowing pills, patients with chronic pain sometimes elect to crush, chew or open extended-release capsules [7]. However, by altering the formulations, patients may risk serious adverse effects, especially regarding opioids where modified formulations can result in respiratory decline, overdose and death [7]. As such, it is essential that the management of dysphagia for medications among people with fibromyalgia is investigated urgently, to ensure that patients can take their required medications to help manage their primary symptoms, while also reducing the risk of them incurring serious side effects from self-modifying their pills.

Oesophageal Stage Swallowing Problems

Reflux was experienced by three quarters of all participants (77%). While causation is yet unclear, it is hypothesised that medications commonly prescribed for fibromyalgia (e.g.: antidepressants and anti-inflammatory agents) could be contributing to the development and maintenance of GERD [27]. In addition, research has also suggested that people living with fibromyalgia may be hypersensitive to small amounts of acid in their oesophagus, or perhaps, the stress of managing chronic pain and other symptoms of fibromyalgia may also contribute to chronic GERD [28]. Therefore, management of reflux should be prioritised among people living with fibromyalgia and managed effectively to avoid additional

discomfort, worsening of dysphagia, respiratory difficulties, potential for oesophageal damage, and food avoidance, amongst other concerns often associated with uncontrolled reflux [27] [29].

Evidently, a range of eating, drinking, and swallowing problems are reported by this group, with wide ranging psychosocial and physical implications. As available research is currently limited on this topic, management options are similarly restricted. Patients would benefit from multi-disciplinary support to help them to live well with these concerns. It is suggested here that patients may be best supported by a varied team of clinicians with expertise in dysphagia (e.g.: speech and language therapists), nutrition (e.g.: dietitians), neurology and pain management (e.g.: neurologists and anaesthesiologists), and psychology (e.g.: clinical psychologists), among others. Future research is recommended into the most impactful configuration of this multi-disciplinary team (MDT) and the most effective way to empower patients to work collaboratively with clinicians to facilitate them to live well with their concerns.

Limitations

Data for this study was collected from self-selecting survey responses only. While this allowed for large amounts of international data to be gathered, this data only provided an overview of the condition, and could not establish whether fibromyalgia specifically was the primary cause of the dysphagia, or whether other factors could be contributing to the clinical presentation (e.g.: presbyphagia in the older cohort potentially resulting in motoric and sensory deglutition changes). In future studies, completing objective assessments (e.g.: videofluoroscopy) would allow for the gathering of standardised data regarding the presence and nature of dysphagia in this group, while completion of in-depth interviews would allow for greater understanding of the lived experience of people who report these issues.

Conclusion

This study described the eating, drinking, and swallowing difficulties which a large cohort of international adults living with fibromyalgia experience. A myriad of symptoms across all stages of swallowing were reported by people living with fibromyalgia, with the most common issues being food sticking in the throat during swallowing, requiring more effort to swallow tablets, and dry mouth. Findings suggest that dysphagia is common among adults living with fibromyalgia, underlining the need for future MDT management of these issues to adequately support the patient living with the physiological and psychosocial implications of these issues. Authors also advocate for continued research in this field

into the cause, implications, and management of these issues beyond this initial study to ultimately inform and optimise future patient-centred service delivery and care provision.

References

1. Clauw DJ. Fibromyalgia: a clinical review. *JAMA*. 2014;311:1547–55. <https://doi.org/10.1001/jama.2014.3266>.
2. Cabo-Meseguer A, Cerdá-Olmedo G, Trillo-Mata JL. Fibromyalgia: prevalence, epidemiologic profiles and economic costs. *Med Clin (Barc)*. 2017;149:441–8. <https://doi.org/10.1016/j.medcli.2017.06.008>.
3. Arout CA, Sofuoglu M, Bastian LA, Rosenheck RA. Gender differences in the prevalence of fibromyalgia and in concomitant medical and psychiatric disorders: A national veterans health administration study. *J Womens Health (Larchmt)*. 2018;27:1035–44. <https://doi.org/10.1089/jwh.2017.6622>.
4. Balasubramaniam R, Lauenbach JM, Stoopler ET. Fibromyalgia: an update for oral health care providers. *Oral Surg Oral Med Oral Pathol Oral Radiol Endod*. 2007;104:589–602. <https://doi.org/10.1016/j.tripleo.2007.05.010>.
5. Aloush V, Niv D, Ablin JN, Yaish I, Elkayam O, Elkana O. Good pain, bad pain: illness perception and physician attitudes towards rheumatoid arthritis and fibromyalgia patients. *Clin Exp Rheumatol*. 2021;39(Suppl 130):54–60.
6. Plaza C. Miss Diagnosis: Gendered Injustice in Medical Malpractice Law. *Columbia Journal of Gender and Law*. 2020;39:91–139. <https://doi.org/10.7916/cjgl.v39i2.5701>.
7. Argoff CE, Kopecky EA. Patients with chronic pain and dysphagia (CPD): unmet medical needs and pharmacologic treatment options. *Curr Med Res Opin*. 2014;30:2543–59. <https://doi.org/10.1185/03007995.2014.967388>.
8. Ninfa A, Crispiatico V, Pizzorni N, Bassi M, Casazza G, Schindler A, Delle Fave A. The care needs of persons with oropharyngeal dysphagia and their informal caregivers: A scoping review. *PLoS One*. 2021;16.
9. Leslie P, Carding PN, Wilson JA. Investigation and management of chronic dysphagia. *Bmj*. 2003;326:433–6. <https://doi.org/10.1136/bmj.326.7386.433>.
10. Ekberg O, Hamdy S, Woisard V, Wuttge-Hannig A, Ortega P. Social and psychological burden of dysphagia: its impact on diagnosis and treatment. *Dysphagia*. 2002;17:139–46. <https://doi.org/10.1007/s00455-001-0113-5>.
11. Jeon Y. Fibromyalgia: practical considerations for oral health care providers. *J Dent Anesth Pain Med*. 2020;20:263–9. <https://doi.org/10.17245/jdpm.2020.20.5.263>.
12. Seccia TM, Rossitto G, Calò LA, Rossi GP. Oral burning with dysphagia and weight loss. *Medicine (Baltimore)*. 2015.
13. Rhodus NL, Friction J, Carlson P, Messner R. Oral symptoms associated with fibromyalgia syndrome. *J Rheumatol*. 2003;30:1841–5.
14. Sasagbon A, Hamdy S. The anatomy and physiology of normal and abnormal swallowing in oropharyngeal dysphagia. *Neurogastroenterol Motil*. 2017. <https://doi.org/10.1111/nmo.13100>.
15. M Furuta, Y Yamashita. Oral Health and Swallowing Problems. *Curr Phys Med Rehabil Rep*. 2013;1:216–22. <https://doi.org/10.1007/s40141-013-0026-x>.
16. Rofes L, Arreola V, Almirall J, Cabré M, Campins L, García-Peris P, Speyer R, Clavé P. Diagnosis and management of oropharyngeal dysphagia and its nutritional and respiratory complications in the elderly. *Gastroenterology Research and Practice*. 2011;2011:818979.
17. Vivino FB, Bunya VY, Massaro-Giordano G, Johr CR, Giattino SL, Schorpion A, Shafer B, Peck A, Sivils K, Rasmussen A, Chiorini JA. Sjogren's syndrome: An update on disease pathogenesis, clinical manifestations and treatment. *Clin Immunol*. 2019;203:81–121. <https://doi.org/10.1016/j.clim.2019.04.009>.
18. Fitzgerald RC, Triadafilopoulos G. Esophageal manifestations of rheumatic disorders. *Semin Arthritis Rheum*. 1997;26:641–66.
19. Kravitz HM, Katz RS. Fibrofog and fibromyalgia: a narrative review and implications for clinical practice. *Rheumatol Int*. 2015;35:1115–25. <https://doi.org/10.1007/s00296-014-3208-7>.
20. Rehm S, Sachau J, Hellriegel J, Forstenpointner J, Børsting Jacobsen H, Harten P, Gierthmühlen J, Baron R. Pain matters for central sensitization: sensory and psychological parameters in patients with fibromyalgia syndrome. *PAIN Reports*. 2021;6:e901.
21. Boehme R, van Ettinger-Veenstra H, Olausson H, Gerdle B, Nagi SS. Anhedonia to gentle touch in fibromyalgia: Normal sensory processing but abnormal evaluation. *Brain Sciences*. 2020;10:306.
22. İnal Ö, Aras B, Salar S. Investigation of the relationship between kinesiophobia and sensory processing in fibromyalgia patients. *Somatosensory and Motor Research*. 2020;37:92–6. <https://doi.org/10.1080/08990220.2020.1742104>.
23. McGoon MD, Ferrari P, Armstrong I, Denis M, Howard Luke S, Lowe G, Mehta S, Murakami N, Wong Brad A. The importance of patient perspectives in pulmonary hypertension. *European Respiratory Journal*. 2019;53:1801919. <https://doi.org/10.1183/13993003.01919-2018>.
24. Cohen H, Neumann L, Kotler M, Buskila D. Autonomic nervous system derangement in fibromyalgia syndrome and related disorders. *Isr Med Assoc J*. 2001;3:755–60.
25. Raj SR, Brouillard D, Simpson CS, Hopman WM, Abdollah H. Dysautonomia among patients with fibromyalgia: a noninvasive assessment. *J Rheumatol*. 2000;27:2660–5.
26. Gomes LMS, Silva RG, Melo M, Silva NN, Vanderlei FM, Garner DM, de Abreu LC, Valenti VE. Effects of effortful swallow on cardiac autonomic regulation. *Dysphagia*. 2016;31:188–94. <https://doi.org/10.1007/s00455-015-9676-4>.
27. Corp I. IBM SPSS Statistics for Mac. 2019.
28. Popham K, Calo WA, Carpentier MY, Chen NE, Kamrudin SA, Le YC, Skala KA, Thornton LR, Mullen PD. Reporting guidelines: optimal use in preventive medicine and public health. *Am J Prev Med*. 2012;43:e31–42. <https://doi.org/10.1016/j.amepre.2012.06.031>.
29. Mokhlesi B. Clinical implications of gastroesophageal reflux disease and swallowing dysfunction in COPD. *American Journal of Respiratory Medicine*. 2003;2:117–21. <https://doi.org/10.1007/BF03256643>.

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