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The mealtime experience of adults with mental health conditions: an integrative review.

Abstract

Background: Dysphagia and choking are highly prevalent in adults with mental health conditions. However, there is scant research considering the personal experience of dysphagia for this population.

Aims: to understand the evidence-base for strategies to involve the patient in recognition, assessment and treatment of mealtime difficulties

Methods: this integrative review synthesised the literature on the experience of dysphagia in patients with mental health conditions. Patient consultation led to co-designed search terms and eligibility criteria for a systematic search of five scientific databases following Prisma guidance. Quality assessment of the eligible studies and reflexive thematic analysis were completed.

Results: 31 studies were included for review. These included case reports, literature reviews and cross-sectional studies. Quality of evidence was weak and no intervention studies were identified. There was scant detail regarding the personal experience of dysphagia or choking. Themes identified related to biomedical perspectives, influencing factors presented without context, and decision-making led by clinicians.

Conclusions: guidance on mental healthcare calls attention to under-diagnosis of physical co-morbidities and advocates patient inclusion. However, the patient voice in this population is rarely described regarding dysphagia. Further inclusive research is indicated to explore the impact of dysphagia and choking, and implications for interventions and outcome measures

Keywords

Dysphagia, asphyxiation, choking, mental disorder, mealtime experience, quality of life, first person perspective.

Introduction

There is growing recognition of the importance of understanding the nature and impact of dysphagia in people with mental health conditions, related to a relatively high estimated prevalence. Estimates suggest that 19% to 46% of adults living with a mental health condition have experience of dysphagia (Aldridge and Taylor, 2012, Bazemore et al., 1991, Ruschena et al., 2003) potentially facing recognised health consequences, including poor nutrition, dehydration, aspiration pneumonia, choking on food, drink or medication, and premature death (Cicala et al., 2019, Corcoran and Walsh, 2003, Regan et al., 2006, Ruschena et al., 2003). Indeed, fatal and near miss choking incidents related to dysphagia are more common in people with mental health conditions compared to the general population (Aldridge and Taylor, 2012, Corcoran and Walsh, 2003, Regan et al., 2006, Ruschena et al., 2003, Yim and Chong, 2009). However, there is little attention to this in either mental health or dysphagia research (Cicala et al., 2019). Studies suggest that dysphagia and choking on food are underdiagnosed and underreported across mental health settings in the UK and that there is lack of attention in both national guidance documents and local clinical systems for adults with non-organic conditions (Guthrie et al., 2015, Regan et al., 2006). Current UK national policy directives mentioning physical health and non-organic mental health conditions do not include the topics of choking or dysphagia

(NHS England, 2019, NHS England, 2017) and the NHS clinical data systems do not acknowledge these co-morbidities (NHS Digital, 2020).

Influencing factors

Reports on medication used in the treatment of mental health conditions describe sequelae including dysphagia, odynophagia and choking (Cicala et al., 2019, Kulkarni et al., 2017). Case reports and cross-sectional studies present a wide range of dysphagia symptoms associated with the side effects of first and second generation antipsychotics, sedative, anxiolytic and other commonly prescribed medications. A high proportion of deaths from choking on food in adults taking psychotropic medication is also reported (Cicala et al., 2019, Kulkarni et al., 2017, Ruschena et al., 2003). Given that many older adults with mental health conditions have history of taking first generation antipsychotics, this group may have enduring symptoms of dysphagia despite the current trend to second generation (atypical) antipsychotics (Adityanjee et al., 1999). Incidence of patients declining medication due to anxiety about swallowing and choking on tablets is not well understood (Cicala et al., 2019). To date, research attention has not been given to how the side effects of medication might impact on a person with mental illness's psychological or social experience of mealtimes.

Considering the relation between medication side effects and dysphagia in adults with mental health conditions, and the variation in response to antipsychotics, it follows that dysphagia in adults with mental health conditions is variable and fluctuating in nature (Bazemore et al., 1991). Based on a sample of only 28 participants at the time, Bazemore et al.'s study (Bazemore et al., 1991) classified five categories of dysphagia in psychiatric inpatients. Each category includes a range of clinical signs and symptoms of dysphagia, giving a structure for clinicians' observations of swallowing in adults with mental health conditions. This descriptive classification informed subsequent studies investigating the prevalence of dysphagia in mental illness (Aldridge and Taylor, 2012, Fioritti et al., 1997, Regan et al., 2006). With no part of the classification relating to lived experience, Bazemore et al.'s (1991) work has not yet stimulated research on the nature of dysphagia from the perspective of adults with mental health conditions, their family members or other people in their support networks.

In addition to side-effects of medications, other factors reported to be associated with dysphagia and choking on food include co-existing neurological conditions, physical co-morbidities and behavioural aspects associated with the mental health condition (Aldridge and Taylor, 2012, Bazemore et al., 1991, Fioritti et al., 1997, Miarons Font and Rofes Salsench, 2017). Descriptions including rapid pace of eating or cramming food recognise the impact of mealtime behaviours on efficacy and safety of swallowing (Bazemore et al., 1991, Fioritti et al., 1997, McManus, 2001). These can be exacerbated by institutional settings or may be consequent upon a deterioration in mental health (Bazemore et al., 1991, Hemsley et al., 2019, McManus, 2001, Yim and Chong, 2009). However, support needs and intervention approaches for such coping behaviours are not well described in the literature.

Psychosocial influences

The factors described above indicate the varied nature of influences which impact on dysphagia and which may increase risk of choking. Details of the physiological features of dysphagia have been reported for people with mental health conditions (Dziewas et al., 2007) but psychosocial aspects have received less attention. Studies on the wider population exploring associations between brain and gastric motor function (brain-gut axis) have generally focussed on reflux and the impact of stress on the lower gastric tract (Bhatia et al., 2005, Lorena et al., 2004). However, studies also suggest that stress and anxiety can influence the functioning and coordination of the swallowing physiology (Jenkins et al., 2016, Taft et al., 2021). The rate of swallowing is known to increase with emotional arousal (Fonagy and Calloway, 1986) and increased stress is also reported to reduce saliva and contribute to dyspepsia (Lee et al., 2017, Leopold and Kagel, 1997, Lorena et al., 2004). In the field of psychiatric research, there have been few studies exploring the links between environmental stressors and choking (Guthrie and Stansfield, 2017, Guthrie et al., 2012, Fioritti et al., 1997). Mealtimes have been identified as a volatile time of day impacting on social wellbeing, escalating levels of anxiety and triggering aggressive incidents (Ferguson et al., 2005). The evening meal may be particularly stressful (Guthrie and Stansfield, 2017).

Anxiety and stress may also influence behaviours (such as fast pace of eating and drinking) which exacerbate risk of choking (Guthrie et al., 2015, Guthrie and Stansfield, 2017). Fast paced eating (Fioritti et al., 1997) and cramming food (Samuels and Chadwick, 2006) are described as risk factors in many studies exploring the nature of choking in adults with mental health conditions (Bazemore et al., 1991, Chen et al., 2015, Hwang et al., 2010). The factors influencing these behaviours have only recently been attributed to psychosocial aspects and include stressors such as intolerance of peers, dislike of close contact with others, and seeking other activities including time alone (Guthrie and Stansfield, 2017).

Patient perspective

Accounts of the lived experience of dysphagia or choking in people with mental health conditions are seldom heard (Guthrie and Stansfield, 2017, Guthrie and Stansfield, 2020). In the last decade, systematic reviews describing other populations have explored the impact of dysphagia on quality of life for both patient and caregiver (Jones et al., 2018, Watkins et al., 2017). The importance of the personal perspective in any dysphagia is acknowledged as essential for person-centred assessment and inclusive decision making (Belafsky et al., 2008, Guthrie and Stansfield, 2020, Hemsley et al., 2019, McHorney et al., 2000, Speyer et al., 2014). In adults with mental health conditions, the personal perspectives are complex and multifaceted. The clinician needs to seek to understand the range of influences affecting mealtime comfort and safety, to elicit any anxieties and distractions, and to support any difficulties around insight and communication (Guthrie and Stansfield, 2017, Guthrie and Stansfield, 2020, Leslie and Crawford, 2017). The term 'Mealtime difficulties' thus relates to more than purely physiological aspects of dysphagia and includes potential influences such as behaviours, psychosocial aspects and patient choices or preferences (Leslie and Crawford, 2017).

Inclusive approaches in mental health and dysphagia

Guidance such as ''No decision about me without me" (UK Department of Health, 2012) recognised patient choice and co-production as an important component of recovery in mental health practice and this has been reiterated more recently (NHS England, 2017, Subodh and Boardman, 2018). Efforts to understand the lived experience, and its impact on recovery care pathways, should be key drivers for clinicians supporting people with mental health conditions (Farr et al., 2019, Hughes et al., 2020, Simpson et al., 2016). However Friedman et al. (2018) reported that people with psychiatric conditions are still unlikely to have an active role in their treatment and care decision making. Despite the intention for services to move to co-production, the patient voice in this population is rarely described in regard to dysphagia and mealtime experiences.

This review aims to explore the literature on dysphagia for people with non-organic mental health conditions seeking to understand patients' experiences of dysphagia and choking on food.

Method

This systematic review was registered on Prospero and conducted following PRISMA guidance (see Figure 1) (Moher et al., 2009, Moher et al., 2015). In order to select relevant search terms, the authors first discussed concepts relating to mental health conditions and dysphagia with two patient representative groups. Patients and caregivers in these groups identified their concerns and priorities for search terms. Further search terms were selected based on prior literature and discussion among the co-authors. These included MeSH terms and keywords relating to mental health disorders, dysphagia, and mealtime experiences or related quality of life studies (see Appendix 1 concepts and search terms). Eligibility criteria included studies of adults with non-organic mental disorders (for example people with psychotic disorders including schizophrenia; depression, bipolar and other mood disorders; anxiety disorders) published in peer reviewed journals in English (Table 1). The focus of this review was limited to adults aged 18-65 years. The term 'eating disorder' was retained initially in searching as this can be used as a lay term for dysphagia; following abstract and full text screening anorexia and bulimia nervosa were excluded. Organic mental disorders such as dementia were also excluded.

Insert Table 1 about here: Table 1 inclusion and exclusion criteria

Insert Figure 1 about here: Figure 1 PRISMA flowchart

The search was conducted in July 2019 and followed the recommended stages for a systematic review (Cooper et al., 2018) across five scientific databases (MEDLINE, Embase, CINAHL , PsycINFO, and Cochrane Review). Searches included all dates from July 2019 back to inception for each database. The first author conducted the initial search with the other authors confirming eligibility. (See Appendix 2 example search strategy). Screening of titles and abstracts was followed by screening of full texts by two authors independently to agree inclusion. Manual searching of the full texts suggested further studies. Searching Cochrane, Prospero, Researchgate, Google Scholar and personal communication with key authors failed to retrieve any further relevant work in progress. An update search in April 2021 found no further eligible texts.

The majority of papers were excluded due to the primary focus being on eating disorders (*n*=1033), cancer (*n*=424), surgery (*n*=197), paediatric (*n*= 1163), degenerative conditions (*n*=310), dementia (*n*=84), and other acquired conditions including stroke (*n*=133). Authors reached consensus for inclusion of 31 full texts for review.

Quality appraisal of included studies

The authors appraised eligible full papers using the QAT-SDD (Sirriyeh et al., 2012) which provides a grading for each in terms of study design, justification of approach, and inclusivity. The appraisal scores were reviewed independently and agreed by the authors.

Data extraction

The characteristics of the studies were extracted for analysis into a database (Table 2). In addition to bibliographic information, relevant data included information on the study design, QAT-SDD quality scores, country and clinical setting of the study. A further column was added coding for any presence or absence of patient voice or perspective.

Insert Table 2 about here: Table 2 Characteristics of studies

Data analysis

The heterogeneity of the patient diagnoses, settings and study designs precluded meta-analysis. Rather, an integrative review method (Whittemore and Knafl, 2005) was used to analyse and integrate qualitative and quantitative data across included studies (see supplementary information Table 4). The first author, an experienced Speech and Language Therapist, used reflexive thematic analysis (Braun et al., 2019, Braun and Clarke, 2020) to code the data according to its content and develop a draft network of themes including categories and sub-categories of meaning. Qualitative data regarding patient perspectives were sought across studies. Themes were constructed in an iterative process (Braun et al., 2019). The authors discussed the resulting themes and subthemes which the first author also presented to the patient representative groups for comment. This supported trustworthiness and authenticity in the findings of the review (Lincoln and Guba, 1986).

Results

Characteristics of included studies

Information on the characteristics of the studies is presented in Table 2. Dates of publication ranged across three decades with the earliest paper dated 1991. In total, 17 studies were case reports of inpatients. In addition, there was one systematic review and three non-systematic literature reviews. The remaining ten papers were cross-sectional or cohort studies, of which seven were retrospective reviews of choking incident reports amongst varied inpatient populations.

The countries of origin were wide ranging representing a wide diversity of cultures. Most lead authors *(n=20*) appeared to have affiliation to psychiatry, but other disciplines were also represented: other lead and co-author affiliations included Speech and Language Therapy (SLT) (five papers), nursing (two papers), pharmacy (one paper) and other medical disciplines (four papers including two neurology). The settings of the studies were not always clearly indicated but 23 included inpatients on psychiatric wards, of these four were described as acute settings and five included long or short stay. Only three papers also included people with mental health conditions living in the wider community. Studies described a broad range of people with varying degrees of psychotic and affective conditions. The most common diagnoses identified were schizophrenia (18 studies); affective disorders (8 studies); bipolar (4 studies). In the literature reviews, cohort and cross-sectional studies, people with different psychiatric diagnoses were grouped together without differentiation regarding dysphagia. Our focus was people with primary diagnosis non-organic mental disorders, but the case reports also described a variety of organic neurological and physical health co-morbidities. Dysphagia was the main topic for 18 papers, with choking highlighted in 13 studies and aspiration in 21.

Quality appraisal

The majority of studies followed qualitative methods (*n*= 27) with the remainder being mixed methods studies. The QAT-SDD quality scores (see Table 2) ranged from 7% to 88% with the case studies all scoring at the lower end (below 40%) (Sirriyeh et al., 2012). There were six higher scoring papers (>60%) including cross-sectional retrospective studies and two literature reviews. All were retained to give a wide range of data across different patient settings and psychiatric diagnoses. Only one paper quoted a patient’s comments directly (Osman and Devadas, 2016) with four others quoting caregiver spoken or written comments (Guthrie et al., 2012, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Hemsley et al., 2019).

Thematic analysis

Reflexive thematic analysis highlighted a predominantly medical perspective covering three main themes (Table 3). Describing processes of initial assessment to intervention and management, the studies focussed on biomedical aspects of dysphagia and choking with minimal reference to patient views and experience. The studies included did not offer detailed description of how specific mental disorders related to a particular presentation of dysphagia. Patient experience was the focus of this review - thematic analysis did not identify any differences of experience in people that could be associated with specific mental disorders.

Insert Table 3 about here: Table 3 Themes and subthemes

Theme 1 Medical perspectives on experiencing dysphagia.

There was minimal detail regarding the personal perspective or direct experience (for dysphagia or choking). The cross-sectional studies and case reports described clinical symptoms at oral and pharyngeal stages of swallowing as observed by clinicians with additional detail from instrumental assessment. There was a paucity of information regarding the wider consequences of dysphagia in terms of psychosocial aspects for the individual. Most studies did not describe the potential impact of mealtime difficulties on mental wellbeing or on relationships with friends, family and direct support staff. Only two studies described the impact of the dysphagia on mealtime experience in detail (Guthrie et al., 2012, Guthrie and Stansfield, 2017).

Self report not elaborated

There was a general lack of description of how the dysphagia was first identified. In the case reports, some acknowledged ‘’self-report’’ (Bhat et al., 2010, Chen et al., 2015, Crouse et al., 2017) but without further detail of the patient perspective. There was variation in the brief reporting of patient concerns, with the majority of descriptions reflecting patient complaints of swallowing difficulty (Bhat et al., 2010, Crouse et al., 2017, Duggal and Mendhekar, 2008, Dziewas et al., 2007, Lin et al., 2012, Nieves et al., 2007, Osman and Devadas, 2016, Varghese et al., 2006), or feeling unable to eat (Cicala et al., 2019, Lin et al., 2012). Other accounts suggested patient complaints of sialorrhea (Osman and Devadas, 2016, Sagar et al., 2005), and concerns regarding tremor (Leopold, 1996). Coughing was identified in several self-reports (Chen et al., 2015, Dziewas et al., 2007, Nieves et al., 2007, Tang and Hsieh, 2010). One study captured a self-report of “difficulty chewing” (Leopold, 1996)p151. Other wider concerns raised by patients related to dysphagia included weight loss (Gregory et al., 1992, Osman and Devadas, 2016, Sico and Patwa, 2011), significant distress (Crouse et al., 2017, Mendhekar and Agarwal, 2010), regurgitation (Gregory et al., 1992), or difficulties swallowing medication (Cicala et al., 2019, Gregory et al., 1992, Guthrie et al., 2015, Hemsley et al., 2019).

Studies described the impact of mental health deterioration influencing or inhibiting the person’s reporting of swallowing difficulties (Crouse et al., 2017, Guthrie et al., 2012, Guthrie and Stansfield, 2017). Studies suggested that specific delusions, fears, or fixed ideas may have reduced self-awareness and reporting of difficulty (Chen et al., 2015, Guthrie et al., 2012, Hwang et al., 2010, Osman and Devadas, 2016). However, authors also acknowledged the contribution of self-reporting from patients with poor mental health presentation, including reports from people with deteriorating agitation, increased psychotic symptoms, or mania (Crouse et al., 2017, Dziewas et al., 2007, Lin et al., 2012, McManus, 2001, Nieves et al., 2007, Osman and Devadas, 2016, Sagar et al., 2005). Chen et al.'s (2015) study included patient self-report of choking incidents: patients able to give written informed consent were asked to report any coughing or swallowing difficulties. The authors acknowledged that there were no checks to confirm reliability of reporting by patients and no elaboration of patient concerns reported. A further three studies described staff reflections on mealtime experience and considered patient support needs (Guthrie et al., 2012, Guthrie and Stansfield, 2017, Hemsley et al., 2019). For the remaining studies, a clinician's perspective was presented with no acknowledgement of the mealtime experience from the patient's perspective.

Emotional impact reported by people other than the patient

Descriptions of emotional distress associated with dysphagia and choking were presented in just five of the 17 case reports and in two further studies (Crouse et al., 2017, Gregory et al., 1992, Guthrie et al., 2015, Hemsley et al., 2019, McManus, 2001, Mendhekar and Agarwal, 2010, Varghese et al., 2006). Two studies also considered embarrassment or concerns for personal dignity (Guthrie and Stansfield, 2017, Hemsley et al., 2019). Generally, the interpretation of the patient's dysphagia did not include consideration of the wider consequences on mealtime experience, but three studies did acknowledge the potential impact of loss of access to favourite or common foods (Guthrie et al., 2012, Hwang et al., 2010, Yim and Chong, 2009). Two studies described staffs' perception of how the patient was feeling (Guthrie et al., 2012, Guthrie and Stansfield, 2017) but only one presented the patient's voice "I did not mind the difficulty swallowing as the medication was helping me. I didn’t feel it was particularly bad”(Osman and Devadas, 2016)p3. However, this casual verbatim account appeared inconsistent with reported levels of distress in this service-user.

There was occasional mention of anxieties around choking (Gregory et al., 1992, Guthrie et al., 2015, Hemsley et al., 2019, Hsieh et al., 1986, McManus, 2001, Mendhekar and Agarwal, 2010), with patients using lay terms such as ‘’stuck in throat’’(Dziewas et al., 2007)p.161.; (Duggal and Mendhekar, 2008) or ‘’tightness’’ (Nieves et al., 2007). One study commented that ‘’minor incidents’’ which involve coughing but not severe choking are less likely to be reported (Yim and Chong, 2009)p.149. Another observed that only the most obvious difficulties are likely to be identified (Lin et al., 2012). Anxiety may fluctuate for some individuals depending on their mental well-being, presence of distractions and other contextual aspects even for those who have experienced severe choking incidents (Guthrie and Stansfield, 2017). Self-reporting of choking incidents for inpatients was thus presented as inconsistent. Awareness levels of patients may be limited; the significance and risk of a choking incident may not be fully understood by some (Guthrie and Stansfield, 2017). For some of the patients in this study there was a clear report of the incident triggering persisting distress and anxiety, but other patients were described as lacking insight. Patients may not retain the details of the choking incident, or retention may fluctuate with deterioration in mental health.

Family or support worker perspectives are limited

The input of family or partner was seldom described in the case reports. Only one included information from family members (Crouse et al., 2017). Case reports typically implied the dysphagia assessment had been supported or organised entirely by staff, including direct care staff, nursing, or other clinical staff. As a result, generally the dysphagia was described in technical, biomedical language and the reader gained little sense of the personal perspective of the dysphagia or its wider impact.

Information from direct support workers can also support the patient if insight and communication skills are impaired but such support staff reports were notably absent, apart from the descriptions in four studies (Guthrie et al., 2015, Guthrie et al., 2012, Guthrie and Stansfield, 2017, Hemsley et al., 2019). The reflections described in these studies suggested a readiness in staff to consider patient needs in principle but a lack of opportunity and attention to this during the normal routines. From some support staff narratives there was a clear sense of anxiety and concern in the observer in contrast to the reported lack of engagement from the person choking him or herself (Guthrie et al., 2015, Guthrie and Stansfield, 2017, Hemsley et al., 2019).

Two studies concluded with recommending future inclusion of patients and support staff for information gathering (McManus, 2001, Yim and Chong, 2009), others also considered the involvement of these others in further screening or ongoing monitoring (Corcoran and Walsh, 2003, Fioritti et al., 1997, Guthrie et al., 2015, Hemsley et al., 2019, Yim and Chong, 2009).

Theme 2 Influencing factors presented without context.

Medication side effects.

All studies highlighted how medication may be associated with a deterioration in swallowing with authors presenting clinical features without reference to impact on mealtime experience. Potential iatrogenic side effects (including extra-pyramidal symptoms, tardive dyskinesia or dystonia) were acknowledged in all 31 studies reviewed.

Deterioration in mental health.

Perceived deterioration in mental health was associated with choking incidents. Examples of presenting symptoms included mania (Bazemore et al., 1991), anxiety (Duggal and Mendhekar, 2008, Hemsley et al., 2019, McManus, 2001, Mendhekar and Agarwal, 2010), agitation (Guthrie and Stansfield, 2017), and distraction (Kulkarni et al., 2017). Poor self-care was also used to indicate level of mental health (Hwang et al., 2010) but it was not clear how this related to mealtime experience and there was no description of how the patient or family perceived this aspect.

Behavioural observations describing fast eating.

Behavioural aspects as observed by clinical staff (described by some as ''poor eating''(Cicala et al., 2019)p224 were also considered to contribute to mealtime difficulty (Aldridge and Taylor, 2012, Cicala et al., 2019, Fioritti et al., 1997). Specific behaviours identified as factors in choking incidents included fast paced eating (Bazemore et al., 1991, Chen et al., 2015, Cicala et al., 2019, Corcoran and Walsh, 2003, Fioritti et al., 1997, Funayama et al., 2018, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Hemsley et al., 2019, Kulkarni et al., 2017, McManus, 2001, Regan et al., 2006, Tang and Hsieh, 2010) and cramming a large bolus (Funayama et al., 2018, Guthrie et al., 2015, Kulkarni et al., 2017, Regan et al., 2006). Higher risk food choices were highlighted in reference to items influencing choking (Funayama et al., 2018, Guthrie et al., 2015, Hwang et al., 2010). Bazemore et al. (1991)p3 related ''fast eating syndrome'' to psychosis and institutionalisation. It was clear that there are multiple perspectives needed to understand fast eating including factors such as staffing pressures, staff and patient fatigue and psychosocial aspects between patients and their peers (Guthrie and Stansfield, 2017, Hemsley et al., 2019). No studies reported patient insights into behavioural influences.

Psychosocial and environmental influences

There was limited mention of psychosocial and environmental influences in the case reports. The studies reviewing choking incidents presented information on context including reference to institutionalisation and timing (Aldridge and Taylor, 2012, Fioritti et al., 1997, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Hemsley et al., 2019, Hwang et al., 2010, Yim and Chong, 2009). Patient distress or anxiety and wider social concerns were interpreted and described through staff perspectives (Guthrie et al., 2012, Guthrie and Stansfield, 2017, Guthrie et al., 2015).

Theme 3 Decision making led by clinicians

Clinician's perspective on assessment and intervention

Patient involvement in assessing the nature and severity of dysphagia or choking incident was described in few studies. Three studies described how swallowing concerns expressed by patients informed dysphagia assessment (Aldridge and Taylor, 2012, Chen et al., 2015, Regan et al., 2006). Options for further clinician led investigations were advocated including instrumental assessment (Bazemore et al., 1991, Cicala et al., 2019, Dziewas et al., 2007, Sico and Patwa, 2011) and reviews of medication (Armstrong et al., 2008, Bhat et al., 2010, Cicala et al., 2019, Corcoran and Walsh, 2003, Crouse et al., 2017, Duggal and Mendhekar, 2008, Dziewas et al., 2007, Fioritti et al., 1997, Gregory et al., 1992, Hemsley et al., 2019, Hwang et al., 2010, Kulkarni et al., 2017, Leopold, 1996, McManus, 2001, Mendhekar and Agarwal, 2010, Osman and Devadas, 2016, Sagar et al., 2005, Sico and Patwa, 2011, Tang and Hsieh, 2010, Varghese et al., 2006). Duggal and Mendhekar (2008)p161 advised however that clinicians should “curtail extensive diagnostic testing and unfruitful medication trials”’ and that review of medication should be prioritised. One study alone discussed supporting patient decision-making around changes to medication suggesting that it may be complex due to differing potential medication side-effects (Nieves et al., 2007).

Further assessment methods suggested for the person experiencing dysphagia were based on clinical perspectives. These included psychiatric assessment (Chen et al., 2015), and physical health assessment (Corcoran and Walsh, 2003, Leopold, 1996). Ten papers advised on the importance of considering dystonia or dyskinesia (Armstrong et al., 2008, Bazemore et al., 1991, Duggal and Mendhekar, 2008, Gregory et al., 1992, Kulkarni et al., 2017, Mendhekar and Agarwal, 2010, Osman and Devadas, 2016, Regan et al., 2006, Sico and Patwa, 2011, Tang and Hsieh, 2010). SLT assessment was acknowledged in 13 papers (Aldridge and Taylor, 2012, Bazemore et al., 1991, Cicala et al., 2019, Crouse et al., 2017, Guthrie et al., 2012, Guthrie et al., 2015, Hemsley et al., 2019, Kulkarni et al., 2017, Leopold, 1996, McManus, 2001, Regan et al., 2006, Tang and Hsieh, 2010, Yim and Chong, 2009) and nursing observation or assessment was highlighted in ten (Chen et al., 2015, Fioritti et al., 1997, Funayama et al., 2018, Guthrie et al., 2012, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Hemsley et al., 2019, McManus, 2001, Osman and Devadas, 2016, Regan et al., 2006, Yim and Chong, 2009).

Familiar staff develop insight into service-user needs and choices.

One study described in detail how familiar staff gained insight into patient preferences and difficulties intervening proactively to modify environmental and social aspects of a mealtimes to reduce distress and risk (Guthrie and Stansfield, 2017). Four studies described opportunities for including staff in treatment approaches (Crouse et al., 2017, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Tang and Hsieh, 2010). Some studies recommended inclusion of the patient, support staff and family members in training approaches for raising awareness of risk (Fioritti et al., 1997b, Hemsley et al., 2019, Kulkarni et al., 2017, Nieves et al., 2007, Tang and Hsieh, 2010, Yim and Chong, 2009) and for awareness around modifying behaviour when eating (Guthrie and Stansfield, 2017, Hemsley et al., 2019, Kulkarni et al., 2017, Osman and Devadas, 2016).

Inclusion, consent and capacity seldom described

Patient perspectives or involvement in the decisions around further assessment, treatment and outcome measures for dysphagia or choking were seldom described in the papers. One case study described obtaining consent from the patient (Osman and Devadas, 2016) and one other explored the use of a 'best interests' approach (Guthrie et al., 2012). Difficulties with engaging the patient in discussion were mentioned by seven (Corcoran and Walsh, 2003, Guthrie et al., 2012, Guthrie and Stansfield, 2017, Hemsley et al., 2019, Kulkarni et al., 2017, McManus, 2001, Tang and Hsieh, 2010). Three papers reflected on the difficulties of engaging the patient with decisions about mealtime adaptations (Aldridge and Taylor, 2012, Guthrie et al., 2012, Hemsley et al., 2019). Hemsley et al. (2019) described how patient accounts contributed to evaluation of choking but other studies highlighted the fact that reporting of choking remains a staff led process (Guthrie et al., 2015, Guthrie and Stansfield, 2017).

A dysphagia programme approach was described by three authors (Bazemore et al., 1991, Guthrie and Stansfield, 2017, McManus, 2001). The primary focus of these appeared to be staff training and reporting to raise awareness across multidisciplinary teams. Monitoring, screening and supervision were described but the inclusion of the patient was not mentioned, nor the impact of these approaches on patient choice, mealtime experience and well-being.

Patient perspective in decision-making not elaborated

Only three studies advocated approaches to enable patient awareness of swallowing difficulties (Fioritti et al., 1997, Hemsley et al., 2019, Kulkarni et al., 2017). Five described direct interventions, for example teaching compensatory swallow techniques to the patient (Dziewas et al., 2007, Kulkarni et al., 2017, Leopold, 1996, Osman and Devadas, 2016, Tang and Hsieh, 2010). There were no studies evaluating the effectiveness of interventions for this population as found by earlier reviews (Aldridge and Taylor, 2012, Bazemore et al., 1991, Kulkarni et al., 2017). Four recommended considering non-oral feeding options or surgery but with no discussion of the wider impact of this from the patient's perspective (Corcoran and Walsh, 2003, Gregory et al., 1992, McManus, 2001, Sagar et al., 2005). One case report reflected on a patient who declined direct SLT input, resisted nursing advice and necessitated a best interests approach following deterioration in mental health and capacity (Guthrie et al., 2012).

Discussion

The papers reviewed included a diversity of clinical settings and diagnoses. The reviews, cross sectional studies and case reports described clinical symptoms at oral and pharyngeal stages of swallowing as observed by clinicians with additional detail from instrumental assessment. There was a lack of information on the wider consequences of dysphagia and psychosocial aspects for the individual. The perspectives of patients or support staff were briefly acknowledged by few. The majority of the patients in the studies reviewed were in inpatient accommodation which may account for the lack of information regarding perspectives of family, partners and wider social relationships. Lack of personal perspectives and the focus on assessment of clinical symptoms and instrumental investigations are of concern. Instrumental assessments have been criticised for offering information which has little relevance to mealtime functioning (Keage et al., 2015) and the implementation of extended instrumental procedures may exacerbate anxiety (Sico and Patwa, 2011). Items which did prompt self-report or patient concern included coughing, sialorrhea, swallowing difficulty, weight loss and choking. There was an absence of consideration of the impact of emotional arousal, stress and anxiety on the physiology and safety of the swallow for the patients described despite these being commonly occurring features of mental health conditions.

Medication side effects were the most commonly described factors influencing dysphagia and choking, but the majority of authors presented these as clinical features without reference to impact on mealtime experience. Mealtime behaviours were also described as risk factors however these were generally presented from a clinical perspective without service-user insights or others' interpretation. Risks associated with fast eating were acknowledged but the underlying stimuli triggering this were not discussed. Two studies did suggest that personal choice and wider psychosocial influences have the potential to influence behaviours, physiological difficulties and compliance with clinicians' advice (Guthrie et al., 2012, Guthrie and Stansfield, 2017).

It is of concern that there were no studies describing inclusive approaches, shared decision-making or interventions for dysphagia in this population. The clinician-centric focus of interventions described in case reports offered a weak level of evidence and opinion. Patient perspectives in the decisions around further assessment, treatment, risk management and outcome measures for dysphagia or choking had scant attention. This is at odds with national aspirations for co-produced recovery and inclusivity in mental healthcare approaches and contrasts the growing attention to person centred care in other dysphagia patient populations (Faraday et al., 2019, Hansjee, 2018, McHorney et al., 2000, Vieira and Antunes, 2017). Shared decision making acknowledges the patient perspective, and ensures approaches are relevant, feasible and sustainable. Some papers acknowledged the potential for inconsistency, fluctuating capacity and difficulties with insight experienced by people with mental health conditions. Understanding and supporting the patient's perspective allows clinicians to perceive more than the pathophysiological measures and attends to the psychosocial sequelae of dysphagia recommended in other patient populations (Leslie and Crawford, 2017, McHorney et al., 2000).

Reports are beginning to emerge describing the experience and impact of choking and dysphagia in adults with non-organic mental health conditions (Guthrie et al., 2012, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Guthrie and Stansfield, 2020, Hemsley et al., 2019). These researchers have highlighted under-reporting of choking incidents and a need to raise awareness in patients, support staff and the wider staff team regarding underlying dysphagia. Further studies have explored shared approaches to mitigating risk of choking and suggested a wide range of potential factors influencing the frequency and severity of choking (Hemsley et al., 2015, Hemsley et al., 2019, Yim and Chong, 2009). The free text descriptions in choking incident reports were found to have more accounts of psychosocial factors and deterioration in mental wellbeing than of physical symptoms and concerns (Guthrie et al., 2015, Guthrie and Stansfield, 2017). Discussions with patients and support staff suggested psychosocial aspects were relevant and important considerations offering a wealth of information on risk mitigation for this population as previously described for other settings (McHorney et al., 2000). Patients who choked appeared to be responding to environmental and social pressures which fluctuated more than their medical and physiological characteristics. The impact of stress and anxiety on the person's swallowing and general wellbeing at mealtimes has not been described for adults with mainstream non-organic mental health conditions. This contrasts the growing volume of research into the mealtime experiences of people with other mental health conditions such as dementia (Liu et al., 2015, Murphy et al., 2017) and eating disorders (Flint et al., 2020, Petry et al., 2017). There was little description of communication difficulty in people with dysphagia despite the known high prevalence of communication difficulty (Walsh et al., 2007). More subtle features may be overlooked or unvoiced by patient and caregivers until more severe choking or other consequences occur. SLTs are well placed to support patients' communication and raise awareness of how dysphagia and choking risk present in people with mental health conditions but this discipline is a scarce resource in mental health units across the UK. Increased patient, caregiver and multidisciplinary understanding and communication of the variation in features and impact of each person's dysphagia is needed to inform and prompt more preventative approaches.

Limitations

Publication bias is acknowledged and may have influenced the findings (Dickersin, 2005, Hopewell et al., 2005). Unpublished studies may have been missed and any publications not in English, but further search time was limited due to funding constraints. Quality appraisal evaluated the evidence across the diverse studies. The case reports scored low due to the lack of patient inclusion and absence of methodological detail. However the value of a total quality score is negligible as totals may conceal relevant detail and also mask omissions (Crowe and Sheppard, 2011, Pollock and Berge, 2018). All 31 papers were retained to allow synthesis of the widely different perspectives and approaches.

It is possible that the predominance of medical perspectives related to a publication bias towards medical over social impacts of mental health conditions in health journals. Systematic bias in analysis was addressed using a team approach to check method and findings, and service-user discussion to evaluate relevance (Pollock and Berge, 2018, Whittemore and Knafl, 2005).

Conclusion

Research to date describes the physical aspects of dysphagia or choking for people with mental health conditions but offers little information about the nature of the experience or its impact on participation and quality of life. Further person-centred research is needed regarding the service-user perspective in recognition, assessment and treatment of dysphagia, and in implementing mitigation strategies for risk of choking. The wider psychosocial impact of dysphagia is generally not considered but can be far reaching. Improving understanding and awareness of triggers for choking incidents is vitally important to reduce fatal and near miss incidents. Lack of acknowledgement and understanding of this aspect is likely to impact on quality of mealtime experience and hinder recovery generally. It is also a matter of concern that the physiological impact of emotional arousal at mealtimes on oral and pharyngeal aspects of swallowing function is not reported nor understood for people with mental health conditions. Consensus from the studies reviewed here suggests that only the most obvious symptoms of dysphagia are recognised and reported by staff or patients. Further research is indicated to understand how dysphagia assessment and treatment can be made accessible and inclusive for patients with non-organic mental health conditions.

The wide range of psychosocial influences which may exacerbate dysphagia and choking for adults with mental health conditions are not clearly understood. As services strive towards more holistic inclusive approaches and for genuine patient involvement to be sustained, clinicians need to understand the patient's quality of life issues and to be able to support each person to evaluate and decide on options for assessment, interventions, and outcome measures.

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