

**The mealtime experiences of adults with mental illness living on inpatient wards.**

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## **IPR Statement**

The candidate confirms that the work submitted is her own and that appropriate credit has been given where reference has been made to the work of others.

Chapter 2 refers to a joint publication (the lead author and primary contributor was the PhD candidate): Guthrie, S., Baker, J., Cahill, J. and Hemsley, B., 2023. Mealtime difficulties in adults with mental health conditions: an integrative review. *Journal of Mental Health*, 32(2), pp.504-516.

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## **Abstract**

### **Background**

Dysphagia, its associated risk of choking, and the impacts on quality of life, are serious concerns for people with mental illness and their caregivers. Prior research has highlighted the prevalence of premature, preventable death from choking on food and the consequences of dysphagia on physical health. However, there is little known about the lived experience of dysphagia and choking for people with non-organic mental illness.

The aim of this study was to explore patients' perspectives of mealtime experiences on inpatient wards to improve understanding of dysphagia and risk of choking.

### **Method**

This thesis presents an integrative literature review which drew attention to the medicalised perspectives in existing research regarding dysphagia and risk of choking in working age adults with non-organic mental illness. Thematic analysis highlighted a lack of information on patient experiences, insight and inclusion in the literature confirming the need for further research.

Consultation with patients and caregivers involved discussing the literature review themes and then co-designing interviews to investigate patients' perspectives of mealtime difficulties. The interviews included patients, staff, and speech and language therapists. Reflexive thematic analysis constructed themes relating to the heightened emotions associated with inpatient mealtimes.

### **Findings**

Patient perspectives included themes of connections, autonomy, and the impact of stressful mealtimes on swallowing. Staff and speech and language therapists also presented insights on negative mealtime experiences and the impact on mental health recovery.

### **Conclusions**

Synthesis of the themes raised important questions for patients' recovery and clinical practice. The stressful nature of mealtimes appeared counter to patients' wellbeing and recovery and impacted negatively on staff's and speech and language therapists' practice. Inpatient mealtimes are a missed opportunity to promote mental health recovery, build patient skills, and raise staff morale. There is clear need for further research into adapting and improving mealtimes on mental health wards.

## List of contents

<b>IPR Statement.....</b>	<b>ii</b>
<b>Acknowledgements .....</b>	<b>iii</b>
<b>Abstract .....</b>	<b>iv</b>
<b>List of contents .....</b>	<b>v</b>
<b>List of tables.....</b>	<b>xiii</b>
<b>List of figures .....</b>	<b>xiv</b>
<b>List of abbreviations.....</b>	<b>xv</b>
<b>Chapter 1 Background: context, development, and rationale for the research .....</b>	<b>1</b>
1.1 Dysphagia in adults with mental illness .....	2
1.2 Dysphagia and medication .....	4
1.3 Choking definition and prevalence .....	6
1.4 Assessing dysphagia.....	7
1.5 Understanding the experience of mealtime difficulties.....	10
1.6 Mental illness.....	11
1.7 Recovery and mealtimes in inpatient settings .....	12
1.8 Person centred inclusive approaches.....	14
1.9 Rationale and aims for this PhD .....	15
1.10 Terminology.....	16
<b>Chapter 2 Integrative literature review.....</b>	<b>17</b>
2.1 Background .....	17
2.2 Methodology: literature reviews.....	17
2.3 Reflexivity: the researcher's perspective .....	18
2.4 Options for methods of review .....	19
2.4.1 Scoping reviews .....	19
2.4.2 Narrative reviews and synthesis.....	19
2.4.3 Integrative reviews .....	20
2.4.4 Systematic reviews .....	20
2.4.5 Options for methods of analysis .....	21

2.4.6	Quality assessment.....	22
2.5	Method for integrative review .....	22
	Determining the aims and purpose. ....	23
2.5.1	Search limits.....	24
2.6	Preliminary review .....	24
2.7	Consultation .....	25
2.8	Systematic search method .....	25
2.8.1	Aims and objectives .....	26
2.8.2	SPIDER framework .....	26
2.8.3	Method: search strategy.....	27
2.8.3.1	Search techniques.....	28
2.8.3.2	Manual searches .....	29
2.8.4	Results of database searches .....	29
2.8.5	Prisma flowchart (Moher et al., 2009) .....	30
2.8.6	Screening for eligibility .....	30
2.9	Literature search results .....	31
2.10	Quality assessment .....	32
2.11	Data extraction process.....	33
2.11.1	Case reports - characteristics.....	37
2.11.2	Cohort studies - characteristics. ....	39
2.11.3	Literature reviews - characteristics.....	42
2.12	Reflexive thematic analysis .....	43
2.12.1	Theme: medical perspectives predominate.....	44
2.12.1.1	Absence of patients' report of difficulties .....	44
2.12.1.2	Brief reporting of emotions associated with mealtime difficulties.....	45
2.12.2	Theme: lack of patient insights on influencing factors for mealtime difficulties. ....	46
2.12.2.1	Mental health and swallowing.....	46
2.12.2.2	Mealtime behaviours causing concern .....	47
2.12.2.3	Influence of mealtime environment and social aspects .....	47

2.12.3 Theme: levels of patient inclusion in decision making .....	48
2.12.3.1 Lack of patient involvement in dysphagia assessment ..	48
2.12.3.2 Lack of inclusion in decisions around intervention .....	48
2.13 Discussion .....	49
2.14 Strengths and limitations .....	51
2.15 Implications for further research .....	52
<b>Chapter 3 Methodology .....</b>	<b>54</b>
3.1 Introduction.....	54
3.2 Reflection on researcher's positionality .....	55
3.3 Definitions.....	55
3.3.1 Ontology.....	56
3.3.2 Epistemology.....	57
3.3.3 Methodology.....	57
3.4 Considering paradigms.....	58
3.4.1 Positivist vs non-positivist .....	59
3.4.2 Quantitative vs qualitative research processes .....	61
3.5 Theoretical perspectives.....	62
3.5.1 Interpretive approaches .....	62
3.5.2 Defining the research problem .....	64
3.6 Methodology.....	65
3.6.1 Inductive vs deductive.....	66
3.6.2 Trustworthiness.....	66
3.7 Ethical considerations.....	68
3.7.1 Risks, burdens, benefits.....	70
3.8 Method: rationale for choice of interview .....	71
3.8.1 Data collection processes .....	71
3.8.2 Online interviews.....	73
3.8.3 Sample size.....	74
3.8.4 Recruitment.....	75
3.8.5 Analysis.....	76

3.8.6	Synthesis of themes across 3 groups .....	76
3.8.7	Summary of chapter .....	79
<b>Chapter 4</b>	<b>Method.....</b>	<b>80</b>
4.1	Planning the study: consultation .....	80
4.1.1	Reflection on service user collaboration in research .....	82
4.2	Aims and objectives.....	82
4.2.1	Objectives for groups: patients and ward staff .....	82
4.2.2	Objectives for group: speech and language therapists .....	83
4.2.3	Objective: comparison across all groups.....	83
4.3	Study design.....	83
4.3.1	Sample for interview.....	84
4.4	Recruitment .....	85
4.4.1	Group: inpatients.....	86
4.4.2	Group: inpatient ward staff .....	86
4.4.3	Group: speech and language therapists .....	87
4.5	Data collection.....	87
4.5.1	Interview guide .....	87
4.5.2	Interview structure for speech and language therapists .....	88
4.6	Interview process - Developing interview skills.....	89
4.6.1	Reflection on developing research interview skills .....	90
4.7	Transcription and analysis of interviews .....	90
4.7.1	Audio recording and transcription.....	91
4.7.2	Transcription .....	91
4.8	Data Analysis .....	92
4.8.1	Phase 1 Familiarisation.....	92
4.8.2	Phase 2 Coding.....	93
4.8.3	Phase 3 Generating initial 'candidate' themes .....	93
4.8.4	Example of coding and theme development .....	94
4.8.5	Phase 4 Developing and reviewing themes .....	95
4.8.6	Phase 5 Refining, defining and naming themes .....	95



4.9	Synthesis.....	96
4.9.1	Synthesis process .....	96
4.10	Ethical considerations.....	97
4.10.1	Consent and capacity.....	97
4.10.2	Confidentiality.....	98
4.10.3	Data management.....	98
4.11	Chapter conclusions.....	98
<b>Chapter 5 Findings from interviews with patients .....</b>		<b>100</b>
5.1	Introduction.....	100
5.2	Participant characteristics.....	100
5.2.1	Reflection on patient interview responses.....	101
5.2.2	Overarching theme: heightened emotions associated with mealtimes.....	103
5.3	Theme: emotional response to the mealtime.....	103
5.3.1	Negative feelings about inpatient mealtimes.....	103
5.3.2	Enduring mealtimes as a physical necessity .....	107
5.3.3	Mealtime experience changes with mental wellbeing.....	108
5.4	Theme: experiencing swallowing difficulty.....	109
5.4.1	Experience of choking.....	110
5.4.2	Medication affects physical mealtime skills .....	113
5.5	Theme: connecting with others through mealtimes .....	114
5.5.1	Mealtimes offer a chance to be sociable .....	114
5.5.2	Mealtimes as a source of friction.....	117
5.6	Theme: valuing choice and autonomy at meals .....	119
5.6.1	Valuing control over food .....	119
5.6.2	Importance of maintaining personal customs at mealtimes.....	120
5.6.3	Inpatient meals feel institutionalised.....	122
5.7	Summary of patient findings.....	124
<b>Chapter 6 Findings from staff interviews .....</b>		<b>125</b>
6.1	Introduction.....	125

6.2	Staff characteristics .....	125
6.2.1	Reflection on staff interview responses .....	126
6.3	Overarching theme: organisational constraints and limitations.....	127
6.4	Theme: mealtimes as a task to be completed .....	129
6.4.1	Staff under pressure.....	129
6.4.2	Institutional environment .....	132
6.5	Theme: importance of personal cultures. ....	136
6.5.1	Emotional loading associated with meals.....	136
6.5.2	Patients' own cultures not recognised .....	137
6.6	Theme: impact of mental health on mealtimes. ....	140
6.6.1	Mental health interwoven with mealtime difficulties .....	140
6.6.2	Stress related to eating with others .....	141
6.6.3	Staff perception of mealtime difficulties .....	144
6.7	Theme: mealtime not integrating with recovery .....	145
6.7.1	Mealtimes detached from care pathways .....	145
6.7.2	Mealtimes as a missed opportunity for supporting recovery	146
6.8	Summary of staff findings .....	149
<b>Chapter 7 Findings from interviews with speech and language therapists</b>		
	.....	<b>151</b>
7.1	Introduction.....	151
7.2	Participant characteristics.....	151
7.2.1	Reflection .....	152
7.2.2	Overarching theme: SLTs' focus on the impact of mealtimes on individuals .....	154
7.3	Theme: patients' personal cultures are important.....	154
7.3.1	Food and control .....	157
7.3.2	Mealtimes involve social contact .....	159
7.3.3	Mealtimes not integrated with recovery aims .....	162
7.4	Theme: ward mealtimes are chaotic.....	164
7.4.1	Dining room as a stressful environment .....	165
7.4.2	Impact on eating behaviour .....	167

7.5	Theme: listening to patients' insights.....	168
7.5.1	Patients' responses to choking incidents .....	170
7.5.2	Patients' insight into swallowing difficulties .....	171
7.5.3	Patients' anxieties and swallowing are linked .....	172
7.5.4	Staff may discount patients' reports .....	174
7.6	Others' awareness of mealtime difficulties .....	176
7.6.1	Raising awareness of mealtime difficulties.....	176
7.6.2	Collaborative approaches .....	178
7.7	Summary of SLT findings .....	179
	<b>Chapter 8 Synthesis of study themes .....</b>	<b>180</b>
8.1	Introduction.....	180
8.2	Reflection .....	180
8.3	Overarching themes: commonalities and differences.....	181
8.3.1	Main themes: synthesis.....	182
8.3.2	Theme: emotional response to the mealtime experience....	183
8.3.3	Theme: experiencing swallowing difficulty .....	185
8.3.4	Theme: connecting with others through mealtimes .....	187
8.3.5	Theme: valuing choice and autonomy.....	189
8.4	Differences and absences .....	190
8.4.1	Mealtimes not part of recovery .....	191
8.4.2	SLT views on others' awareness.....	192
8.5	Findings of literature review.....	193
8.6	Summary of synthesis .....	194
8.7	Overview of thesis .....	195
8.8	Discussion .....	195
8.8.1	Implications for patients .....	199
8.8.2	Implications for SLT practice .....	200
8.8.3	Implications for practice on the wards .....	200
8.8.4	Implications for policy .....	201
8.8.5	Implications for future research .....	202

8.9 Strengths and limitations .....	203
8.10 Dissemination .....	205
8.11 Conclusion.....	206
<b>References.....</b>	<b>208</b>
<b>Appendix A Concepts for literature search .....</b>	<b>224</b>
<b>Appendix B Example search strategy – Ovid Medline database .....</b>	<b>226</b>
<b>Appendix C Worksheet for service user discussions .....</b>	<b>228</b>
<b>Appendix D HRA letter .....</b>	<b>230</b>
<b>Appendix E SHREC letter .....</b>	<b>233</b>
<b>Appendix F Consent form .....</b>	<b>235</b>
<b>Appendix G Patient information sheet.....</b>	<b>236</b>
<b>Appendix H Example of coding using NVivo.....</b>	<b>242</b>

## List of tables

<b>Table 1 Literature search structure .....</b>	<b>23</b>
<b>Table 2 SPIDER framework .....</b>	<b>26</b>
<b>Table 3 Inclusion and exclusion criteria .....</b>	<b>28</b>
<b>Table 4 Database searches .....</b>	<b>29</b>
<b>Table 5 Characteristics of included studies .....</b>	<b>36</b>
<b>Table 6 Case reports.....</b>	<b>38</b>
<b>Table 7 Cohort studies .....</b>	<b>41</b>
<b>Table 8 Literature reviews .....</b>	<b>42</b>
<b>Table 9 Themes and subthemes .....</b>	<b>43</b>
<b>Table 10 Scaffolding the basic ‘components’ of the research process</b>	<b>56</b>
<b>Table 11 Principles of ethical research .....</b>	<b>69</b>
<b>Table 12 Options considered for data collection .....</b>	<b>72</b>
<b>Table 13 Advantages and disadvantages of online interviews.....</b>	<b>74</b>
<b>Table 14 Timescales for study .....</b>	<b>83</b>
<b>Table 15 Eligibility criteria.....</b>	<b>85</b>
<b>Table 16 Interview questions, topic and prompts .....</b>	<b>88</b>

## List of figures

<b>Figure 1 Prisma diagram .....</b>	<b>30</b>
<b>Figure 2 Images of mealtime settings .....</b>	<b>81</b>
<b>Figure 3 Images of coding process, drafting candidate themes .....</b>	<b>94</b>
<b>Figure 4 Example of NVivo coding hierarchy .....</b>	<b>95</b>
<b>Figure 5 Patient group thematic network.....</b>	<b>102</b>
<b>Figure 6 Staff group thematic network .....</b>	<b>128</b>
<b>Figure 7 SLT group thematic network.....</b>	<b>153</b>
<b>Figure 8 Commonalities, differences, and absences in main themes.</b>	<b>183</b>
<b>Figure 9 Positives and negatives at mealtimes.....</b>	<b>196</b>

### List of abbreviations

CAQDAS	Computer Assisted Qualitative Data Analysis
CHIME	Connectedness, Hope, Identity, Meaning in life, Empowerment
COREQ	COnsolidated criteria for Reporting Qualitative studies
ECT	Electro-Convulsive Therapy
ENTREQ	ENhancing Transparency in REporting the synthesis of Qualitative research
EPSE	Extra Pyramidal Side Effects
EQUATOR	Enhancing the QUALity and Transparency of health Research
GRADE	Grading of Recommendations, Assessment, Development and Evaluations
HCPC	HealthCare Professions Council
HEER	Help from Experts by Experience for Researchers
LYPFT	Leeds and York Partnership Foundation Trust
MDT	MultiDisciplinary Team
PPE	Personal Protective Equipment
PRISMA	Preferred Reporting Items for Systematic reviews and Meta-Analyses
QATSDD	Quality Assessment Tool
RCSLT	Royal College of Speech and Language Therapists
RCT	Randomised control test
RTA	Reflexive Thematic Analysis
SLT	Speech and Language Therapist
SPIDER	Sample, Phenomenon of Interest, Design, Evaluation, Research type
SRQR	Standards for Reporting of Qualitative Research
SUN	Service User Network

## **Chapter 1 Background: context, development, and rationale for the research**

*Food and mealtimes are important, culturally, and symbolically, across all people and societies. The variety of meanings associated with food and mealtimes is diverse. (Leslie and Crawford, 2017 p.11).*

Most people consider the consumption of food and drink to be both an enjoyable and a necessary part of a healthy daily life. Much more than just a physical task of nutrition and hydration, mealtimes have a wider role in enhancing quality of life, establishing relationships, and promoting general mental and emotional wellbeing (Leslie and Crawford, 2017). If a person's access to food or drink is restricted, or consumption impaired, the impact on an individual can be wide ranging affecting self-esteem, inclusion, social and emotional wellbeing (Hemsley et al., 2019).

This thesis explores the mealtime experiences of people living with non-organic<sup>1</sup> mental illness (World Health Organisation, 2019a). Mental health conditions as a broader term extending the range of mental disorders, has been defined as:

“A mental disorder is characterized by a clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour. It is usually associated with distress or impairment in important areas of functioning. There are many different types of mental disorders. Mental disorders may also be referred to as mental health conditions. The latter is a broader term covering mental disorders, psychosocial disabilities and (other) mental states associated with significant distress, impairment in functioning, or risk of self-harm.” (World Health Organisation, 2019a)

Clinical experience has prompted interest in how patients on inpatient mental health wards experience dysphagia, choking and mealtime difficulties. There is a need to improve understanding of the mealtime experiences and support needs of inpatients with mental illness to inform recovery and improved wellbeing. However, there is little existing research yet describing how mealtimes may

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<sup>1</sup> 'Non-organic mental illness' will subsequently be abbreviated to 'mental illness' throughout this thesis.



contribute to recovery and rehabilitation for people with mental illness in hospital settings.

UK guidance (including “Report of the Independent Review of NHS Hospital Food”, Shelley et al., 2020; “National standards for food and drink”, Corben et al., 2022) is now beginning to consider the wider aspects of good practice in hospital mealtimes and acknowledges that different settings will need tailored approaches. There is recognition of the importance of enjoyable mealtime experiences:

“Crisp toast for breakfast, a delicious lunch with a friendly word, a cup of tea willingly served in the middle of the night can do wonders. Food is a form of medicine.” (Shelley et al., 2020 p.8).

There is a need for research studies which describe the impact of dysphagia and mealtime difficulties for patients in mental health settings. This chapter sets out the context for this thesis and presents the central concepts of mealtime difficulties and dysphagia, recovery in mental illness in inpatient settings, and the importance of person centred, inclusive approaches supporting each individual patient. Key terms will be defined in this introductory chapter whilst acknowledging that the focus of this thesis is the personal experience of mealtime difficulties rather than an examination of the patients’ medical diagnosis.

### **1.1 Dysphagia in adults with mental illness**

Dysphagia can be defined as an impairment of the process of eating, drinking and/or swallowing. Dysphagia involves difficulties in the coordination of the muscles and structures of the mouth, throat and neck (Royal College of Speech and Language Therapists, 2018). Adverse physical health consequences for the person experiencing dysphagia may include poor nutrition, dehydration, aspiration pneumonia, or choking, and may lead to premature and preventable death (Cicala et al., 2019, Corcoran and Walsh, 2003, Regan et al., 2006, Ruschena et al., 2003). The mental health consequences of dysphagia have (to date) received scant attention in research for people with mental illness. Nonetheless, it is recognised that dysphagia and choking on food are often underdiagnosed for these patients (Guthrie et al., 2015, Guthrie and Stansfield, 2017).

Current research suggests that the experience of dysphagia is common for adults living with mental illness (Aldridge and Taylor, 2012, Bazemore et al., 1991, Regan et al., 2006, Ruschena et al., 2003). Studies have highlighted the prevalence of dysphagia in adults with mental illness with estimates reporting that 46% of this population experience swallowing difficulties (Cicala et al., 2019, Regan et al., 2006, Walsh et al., 2007). However, it has also been reported that there is very limited literature considering the experience of dysphagia in patients with severe mental illness (Cicala et al., 2019, Funayama et al., 2018).

Dysphagia in adults with mental illness may be variable and fluctuating, treatable or deteriorating in nature (Bazemore et al., 1991). Bazemore et al., (1991) proposed five categories of dysphagia in adults with mental illness. In this seminal study, the authors acknowledged the importance of iatrogenic effects and the impact of co-existing conditions in diagnosis of swallowing impairment. Neurological aspects were explored and found to be relevant in determining aetiology and prognosis of dysphagia and the nature of support required by the individual. In more recent research, a phenotype classification describing specific neurological swallowing disorder categories has been proposed (Warnecke et al., 2021). The 'phenotype 5' described by this team relates closely to the presentation of dysphagia in adults with mental illness:

“Phenotype 5: Pharyngolaryngeal movement disorders for example, oropharyngeal freezing, pharyngeal bradykinesia or pharyngolaryngeal tremor regularly occur and interfere with the physiologic bolus transportation” (Warnecke et al., 2021 p.880).

Co-existing conditions commonly experienced by people with psychiatric conditions have further implications for swallowing effectiveness, safety, and mealtime experience. For example, intellectual disability, acquired brain injury and dementia affect the cognitive aspects of eating and drinking. Deterioration in cognition can affect skills such as maintaining the sequence of swallowing movements, self-monitoring for difficulties, sustaining attention to the task of eating or drinking, and awareness of risk may be diminished or absent. Ability to tolerate and respond to caregivers' prompts may also be reduced (Leslie and Crawford, 2017). Respiratory conditions (e.g. asthma) or other neurological conditions (e.g. epilepsy) can also add complexity to the person's dysphagia management.

Psychological aspects of eating and drinking add further complexity to assessment and intervention for people with swallowing impairment. The influence of mental illness symptoms such as manic behaviour, anxiety, phobias and obsessive compulsive disorders affect pace of eating, stress levels, and attitude to others including patients' responses to caregiver offers of support and prompting (Guthrie and Stansfield, 2017). For people with anxiety and heightened stress, there is an established link between stress and gastric flow (Cook et al., 1989, Holtmann and Talley, 2014). However, there is limited research exploring the impact of stress on the oral and pharyngeal stages of swallowing and activities involved in eating. To date, research on this topic relating to people with a primary diagnosis of mental illness focusses on physiology and motility of the oesophagus and stomach. More recently, studies have begun to consider the wider impact of mealtimes and emotions on swallowing for the patient and their social and family relationships (Leslie and Crawford, 2017) but little of this relates to psychosocial aspects of mealtimes for working age adults with mental illness.

## **1.2 Dysphagia and medication**

The impact of medication on the person's ability to swallow effectively and comfortably is particularly relevant for understanding how dysphagia is experienced by people with mental illness (Dziewas et al., 2007, Fioritti et al., 1997, Kulkarni et al., 2017, Sico and Patwa, 2011). Since the advent of antipsychotic medication, case reports and studies illustrating examples of dysphagia associated with specific medications have been documented (Corcoran and Walsh, 2003) highlighting potential side effects of first and second generation antipsychotics, sedative and other commonly prescribed medications (Buchholz, 1995, Dziewas et al., 2007, Massengill and Nashold, 1969). Since the 1950s studies have described the impact of medications on oral, pharyngeal and oesophageal stages of eating, drinking and swallowing with particular focus on extra-pyramidal side effects (EPSE) (Cicala et al., 2019, Hollister, 1957, Hussar, 1962, Mortensen and Juel, 1990).

Carter and Jancar (1983) drew attention to the research increasing understanding of links between medication and asphyxiation. They described the changes in influencing factors for unexpected deaths in people with co-existing intellectual disability and history of psychiatric disorders over the last 50 years.

For older patients who have a history of first generation antipsychotics, there may be a lasting effect from earlier medication despite the current trend to second generation (atypical) antipsychotics (Adityanjee et al., 1999). Other authors have highlighted the effect of medication suppressing reflexes in oral and pharyngeal stages of swallowing, the suppression of motility and timing of the swallowing sequence, and the risks associated with EPSE (Fioritti et al., 1997). In particular, an adverse impact of medication on swallowing has been seen in patients on anxiolytic medication (Chen et al., 2015). Sedative effects contribute to impaired laryngeal function and reflexes, and increased likelihood of aspiration pneumonia (Cicala et al., 2019). For patients experiencing dry mouth, changes to mucosa, impaired reflexes, or oropharyngeal motor dysfunction as side effects of their medication there is also likely to be consequential impairment to their swallow effectiveness and safety (Cicala et al., 2019).

Further compromise of swallowing function has been reported for patients who have multiple forms of medication: polypharmacy has been reported as common practice leading to magnified risk of side effects (Waterreus et al., 2012). Other studies have found that polypharmacy is less significant than higher dosage of antipsychotics (Funayama et al., 2018) however this study acknowledges that higher dosing is also associated with severity of illness (and the latter may itself directly influence the dysphagia). Chen et al.'s (2015) study concluded that pharmacological properties of individual drugs were more important than the number of medications in determining risk of choking and swallowing difficulties. For people with more severe mental illness, other factors may also be affecting swallowing skills and mealtime safety (e.g. manic behaviour in eating, distracted attention, poor self-monitoring, self-neglect). Other neurological conditions such as drug induced Parkinson's, traumatic brain injury, degenerative conditions and epilepsy are also associated with dysphagia and increased risk of choking.

Tardive dyskinesia is described in studies evaluating EPSE in longer-term use of medications such as antipsychotics (Adityanjee et al., 1999). Cicala et al., (2019) discuss the acute dystonic reactions that may occur more immediately after initial doses and are considered to be reversible. The longer-term and tardive side effects of dyskinesia or dystonia may present difficult dilemmas for treatment and care with regard to mealtimes and nutrition generally (Cicala et al., 2019). Other forms of hospital treatment for mental illness include electroconvulsive therapy

(ECT). There is a paucity of evidence presenting the characteristics of timing and duration of dysphagia associated with ECT, but case studies have been presented suggesting delayed deterioration of the swallow and association with motor neurone disease presentation (Mezei et al., 2022). Iatrogenic factors remain a topic of discussion in the research literature and appear likely to be a significant influence on swallow efficacy, safety, and comfort for psychiatric patients.

### **1.3 Choking definition and prevalence**

Choking is defined as

“An acute event in which the patient coughed incessantly or experienced a color change (with inability to speak or cough effectively) while ingesting food or drink. To qualify as an incident, solid or liquid food had to be expelled to terminate the event”. (Bazemore et al., 1991 p.3)

However in much of the dysphagia literature “choking” may be conflated with coughing, with the common description of ‘coughing and choking’ being used to describe people with oro-pharyngeal dysphagia (Hemsley et al., 2019 p.2).

The nature and prevalence of choking has been described in postmortem studies of the general population as well as for people with mental illness (Aquila et al., 2018, Berzlanovich et al., 1999, Berzlanovich et al., 2005, Wick et al., 2006). The term ‘café coronary’ has been used to describe choking on food or drink in a restaurant (often not recognised as choking and treated incorrectly as a cardiac event) (Haugen, 1963, Wick et al., 2006). Early studies of choking in psychiatric settings appear to include mixed populations where people with diagnoses of intellectual disability and mental illness are combined (Carter and Jancar, 1983, Carter and Jancar, 1984, Day and Jancar, 1994). Other studies describe the incidence of choking across specific populations including children (Byard, 1996, Mittleman, 1984), people with intellectual disability (Chadwick and Jolliffe, 2009, Samuels and Chadwick, 2006, Thacker et al., 2008) and older people (Berzlanovich et al., 2005, Hemsley et al., 2019). It has been suggested that fatal and near miss choking incidents related to dysphagia are more common in people with mental illness compared to the general population (Aldridge and Taylor, 2012, Corcoran and Walsh, 2003, Fioritti et al., 1997, Regan et al., 2006, Ruschena et al., 2003, Yim and Chong, 2009). Indeed, mortality caused by

choking in psychiatric patients is reported to be 100 times higher than that in the general population (Regan et al., 2006) with choking known to be a cause of 10% of accidental deaths among psychiatric inpatients (Cicala et al., 2019a, Corcoran and Walsh, 2003, Hwang et al., 2010).

The properties of anxiolytic and sedative medications in reducing levels of alertness and response times have also been described as important factors contributing to choking (Chen et al., 2015, Hwang et al., 2010). Ruschena et al.'s (2003) study reported a high proportion of choking deaths linked to psychotropic medication. Speech and language therapists (SLTs) are the primary profession involved in the management of dysphagia but the majority of research around choking and dysphagia in people with mental illness is considered from a medical perspective with a paucity of research studies from SLT authors (Walsh et al., 2007). Research involving patients and acknowledging or describing the perspective of the person with a mental health condition and dysphagia is very limited. There is equally scant research investigating the characteristics, experiences, and impacts of choking and dysphagia in adults with mental illness. However there are a few studies considering the nature of choking incidents in people with mental illness as precursor to this PhD (Guthrie et al., 2012, Guthrie et al., 2015, Guthrie and Stansfield, 2017) which describe variation in the characteristics, experience, and reporting of choking. There remains an urgent need for further research on the personal impact of choking, the lived experience of the person affected, and any indirect effect on their family, direct support staff and others.

#### **1.4 Assessing dysphagia**

The seminal study by Bazemore et al., (1991) classified five categories of dysphagia in psychiatric inpatients using medical terminology. The clinical criteria described offer an insight into the observable aspects of dysphagia in adults with mental illness as perceived by their clinical staff. However, these do not represent lived experience and Bazemore et al., present no reports of the perspectives of people with mental illness (Bazemore et al., 1991). Recent research in the general population has suggested that personal reports are valuable for clinicians to understand the experience of swallowing impairment and to complement standard assessment resources (Leslie and Smithard, 2020).

For people with mental illness, the problem of diagnostic overshadowing can result in lack of recognition of early signs of mealtime difficulty by the person themselves, their family, support staff, and clinicians. The person may struggle to coordinate and swallow food, drink, and medication until a choking incident or other health concern raises awareness of the need for appropriate mealtime assessment and advice (Guthrie and Stansfield, 2020). Lack of timely access to assessment and diagnosis of dysphagia, limited awareness and understanding in clinical and support staff, and difficulties in monitoring the person for signs of deterioration, are all areas of concern for this population. Self-reporting of dysphagia has been described as a disconnect between the realities of the clinician (i.e. observations of symptoms of swallowing difficulty) and the reality of the patient (e.g. experiencing difficulty swallowing has become normalised) (Leslie and Smithard, 2020). These authors usefully highlight the difference between the clinicians' perspectives and concerns compared to the patients', who may have limited awareness of the consequences of dysphagia.

Dysphagia screening assessments used in acute settings, with patients who have acquired or neurological degenerative conditions, are conducted using bedside clinical assessments (Clavé et al., 2008, DePippo et al., 1994, Kertscher et al., 2014, Martino et al., 2009, Tsang et al., 2020, O'Horo et al., 2015) or via instrumental investigation for more detailed analysis of the functioning of the person's swallowing anatomy and physiology (Bours et al., 2009, Pettigrew and O'Toole, 2007, Warnecke et al., 2021). The narrow focus of instrumental swallowing assessments (e.g. videofluoroscopy) may have limited relevance for understanding the mealtime context and planning for rehabilitation, as these assessments take place away from the mealtime environment (Rommel et al., 2016). Furthermore, instrumental assessment may not be feasible for people in an acute phase of mental illness due to increased levels of anxiety, paranoia or agitation (Kulkarni et al., 2017). Swallowing assessments in the acute hospital setting for physical health conditions, whether clinical or instrumental, are often snapshots limited to a few minutes in duration and detached from the mealtime environment (Bateman et al., 2007, Martino et al., 2004). There is only occasional mention of how the person responds or engages with the assessment process and the findings typically focus on extent and severity of physical swallowing impairment (Guthrie and Stansfield, 2020).

Literature is very limited regarding evidence-based practice and clinical guidance for screening and assessment of dysphagia in people with mental illness. There is a need to understand the context of mealtimes and for dysphagia assessment to incorporate mealtime evaluation and inclusion of patient perspectives (Guthrie et al., 2012, Guthrie et al., 2015, Guthrie and Stansfield, 2017). This is particularly important for people with mental illness as dysphagia may change related to side effects of medication, behavioural changes, or co-existing conditions. Detailed measures of the pace and nature of any deterioration or improvement is needed to inform clinical assessment and allow development of strategies for the patient themselves and their caregivers (Guthrie and Stansfield, 2020).

Commonly used general health related quality of life assessments (e.g. Cieza and Stucki, 2005, Ware Jr and Sherbourne, 1992) make scant reference to swallowing impairment despite the complex psychological and social issues surrounding an impaired mealtime (Leslie and Crawford, 2017, McHorney et al., 2000, Vieira and Antunes, 2017). Ekberg et al., (2002) describe the social and psychological impact of dysphagia but suggest this occurs “mainly in elderly people” (Ekberg et al., 2002, p.139). However, there is growing understanding of the burden of dysphagia and related choking across wider populations. Research and clinical interest in quality of life around mealtimes and swallowing have led to the development of assessment tools to elicit the person’s self-report in different settings. This allows clinicians to evaluate the impact of dysphagia in adult health diagnoses including cancer (Chen et al., 2001), degenerative, neurological, and acquired conditions (McHorney et al., 2000), and for a wider population (Belafsky et al., 2008, Tsang et al., 2020). In addition to these, Colodny (2008) developed a general tool to evaluate caregivers’ perspectives and there has been a series of studies considering the specific perspective of caregivers supporting people with intellectual disability (Ball et al., 2012, Chadwick et al., 2003, Crawford et al., 2007, Crawford and Wilkinson, 2019). There is no equivalent clinical tool to explore the issues specific to people with mental illness and dysphagia.

For people with acquired neurological diagnoses and/or organic mental illness such as dementia, the mealtime context and the impact of dysphagia has been researched from allied health, nursing, and other medical perspectives (Easterling and Robbins, 2008, Swan et al., 2015, Watkins et al., 2017). Reviews



of the literature for dysphagia in older populations have generally focussed on research into supporting behaviours around the mealtime (Herke et al., 2018), modifying diet (Flynn et al., 2018) and adapting nutrition towards end of life (Royal College of Physicians, 2010). However, there is a paucity of studies discussing practice in assessing dysphagia with people with mental illness for adults of working age.

To understand the risks and burdens of dysphagia and/or choking experienced by people with mental illness, it is relevant to consider the whole mealtime (Guthrie and Stansfield, 2017), and the wider impact on family, friendships, and on paid support workers (Leslie and Crawford, 2017). To assess, and to attempt to understand the context of the mealtime, provides a strong foundation for person-centred and inclusive risk mitigation. For recovery to be sustained, personal routines and choices around mealtimes should be considered.

### **1.5 Understanding the experience of mealtime difficulties**

Loss of personal choices, autonomy and impact on quality of life have been highlighted for people with dysphagia (Guthrie et al., 2012). Mealtime difficulties are typically managed restrictively for people on inpatient wards by removing risky menu options, imposing observation and supervision by staff, and reducing patient levels of control and autonomy (Guthrie, 2022). The wider impact of such risk management on recovery and independence during inpatient provision can be devastating for patients and their caregivers (Guthrie et al., 2012). Staff understanding of patient mealtime needs has previously been described as limited (Ball et al., 2012, Chadwick et al., 2003, Crawford et al., 2007) with a lack of caregiver and staff understanding for patients with dysphagia and mental illness and/or intellectual disability. This is particularly apparent in incident reporting around choking (Guthrie et al., 2015, Guthrie and Stansfield, 2017). In one study, staff on inpatient wards described their role in encouraging or modelling behaviours that they perceived as appropriate for shared dining room environments (Guthrie and Stansfield, 2017). However, these were presented from the staff's perspectives and norms, the authors described a lack of autonomy and choice for the patients in these inpatient settings. Multiple potential stressors were described for people with mental illness in shared noisy dining rooms. The importance of staff familiarity and understanding of the individual in

recognising difficulties and needs for support was evident. The impact of dysphagia on people in longer term healthcare provision is little understood (Eslick and Talley, 2008) with the few studies that exist considering people with dysphagia in acquired (and short term) hospital settings for physical health conditions (Bray et al., 2017, Cichero et al., 2009, Odderson et al., 1995). There is currently minimal consideration of quality of life issues for people with acute mental illness and dysphagia on inpatient wards.

## **1.6 Mental illness**

Mental illness affects one in six adults (aged 16 to 74) in England with 39% accessing treatment for mental health (N.H.S. Digital., 2014). This survey based on data from 2014 does not include the additional burden deriving from living with a pandemic in the UK since 2020. At the height of the pandemic, prevalence was reported to increase to 21% of the UK population (Baker, 2021). In the UK, psychiatric hospital wards support adults experiencing a range of acute psychiatric diagnoses but there are many more people living with these as chronic conditions in rehabilitation and community-based mental health care settings.

Historically, mental illness has been categorised as organic and non-organic. The relevance of this distinction has been reviewed in the literature over the last decades with consensus now advocating more holistic approaches acknowledging the complexity of interwoven biological and psychological influences on mental wellbeing (Borsboom et al., 2019, Kendler, 2005, Spitzer et al., 1992).

“Our current knowledge, although incomplete, strongly suggests that all major psychiatric disorders are complex and multifactorial” (Kendler, 2005, p.434).

The World Health Organisation lists the characteristics of non-organic mental illness symptoms which include disordered thoughts, emotions, and behaviours (World Health Organisation, 2019a). Patients can also experience disordered perceptions and impaired relationships with others. Common diagnoses include depression, bipolar disorder, schizophrenia and other psychoses, dementia, and developmental disorders including autism (World Health Organisation, 2019a). Whereas previously assessment and intervention focussed primarily on deficits

and levels of impairment, approaches to recovery now aspire to more holistic and person-centred practices:

“A recovery approach ensures that services place people themselves at the centre of care. It focuses on supporting people to define what recovery looks like and means for them. This approach is about helping people to regain control of their identity and life, have hope for the future, and to live a life that has meaning for them, whether that be through work, relationships, community engagement, spirituality or some or all of these.”  
(World Health Organisation, 2019b p.xi).

Researchers exploring the multiple factors influencing the presentation and recovery of mental illness have thus widened the focus of interest to include a range of biopsychosocial aspects and involvement in decision making (Coffey et al., 2019). For example, the links between deprived environment, poverty and the impact on mental wellbeing have been investigated (Elliott, 2016). Deprivation and adverse psychosocial experiences are increasingly understood to contribute to mental ill health. Specific consequences of deprivation include poor nutrition as an important influence in mental illness (Adan et al., 2019, Lassale et al., 2019, Kris-Etherton et al., 2021, Sarris et al., 2015). The independent taskforce reports (N.H.S. England, 2016, N.H.S. England., 2023) recommend a change in mindset to guide a transformation for mental health care generally and to promote attention to the physical issues experienced by people with mental illness. Mealtimes involve both physical and psychosocial aspects and thus may become pivotal to mental wellbeing affecting safety, nutrition, and quality of life (Leslie and Crawford, 2017).

### **1.7 Recovery and mealtimes in inpatient settings**

Patients with acute mental illness may be admitted to inpatient hospital wards for assessment, treatment and care (N.H.S. England, 2019). Many aspects of the stay on inpatient wards are institutional, routine based and perceived as restrictive to quality of life (Saraceno and Caldas de Almeida, 2022, Taylor et al., 2009). Throughout the acute phase of the mental illness, patients are likely to be supported with day-to-day care including catered mealtimes. These are offered at set times for lunch and evening meal, food is typically dispensed through a hatch onto trays, and menu choices ordered 24 hours or more in advance. Other

routines may be imposed such as a counting process for metal cutlery (so that cutlery is not removed to make weapons), eating in dining rooms rather than lounge or bedrooms due to hygiene and other risks, and limited access to food, drinks, and crockery at other times of day. Little has been written about this process to explore the impact of the restrictive nature of food and drink options for inpatients. Catering is typically provided by external agencies and the meal is reduced to a fast paced nutritional task. Ward staff involvement with the meal is often intermittent, distracted, supervisory and delegated to support workers or volunteers (Cavendish, 2013, Howson et al., 2018).

Person centred care is recommended as a general principle in UK national reports and guidance for healthcare but, as far as can be determined, there is no clinical guidance exploring how this translates to supporting mealtimes for people with mental illness. Recent studies have covered how direct care staff support older adults who have dementia at mealtimes including acknowledgement of the importance of psychosocial aspects (Brush and Calkins, 2008, Douglas and Lawrence, 2015, Faraday et al., 2021, Howson et al., 2018, Scales et al., 2017). For care of people with eating disorders in hospital there is an established body of evidence about the therapeutic mealtime support needed to promote recovery and sustain longer term wellbeing (Hage et al., 2015, Long et al., 2012). In contrast, research and guidance around the mealtime support needs of people with mainstream mental illness are scarce. A literature review explores this in chapter 2 below.

A patient's personal preferences, including cultural aspects of mealtimes, may be known or unknown to the nursing and support staff. The importance of respecting individual choices (including cultural, spiritual and religious aspects) has been described referring to mealtimes in the general population and to people with degenerative conditions (Alhussain, 2017, Leslie and Crawford, 2017). Food and mealtimes for people with mental illness living on inpatient wards can become an important and positive focus offering a highlight in the daily routine (Guthrie et al., 2012). Alternatively, for some patients, mealtimes may become a time of raised stress and anxiety levels (Guthrie et al., 2015, Guthrie and Stansfield, 2017). Ward mealtimes provide an opportunity for social interaction, but people may have limited tolerance for other patients and/or staff when they are acutely unwell (Guthrie and Stansfield, 2017). Studies exploring agitation levels for people with

dementia have described mealtimes as flashpoints for behaviours and incidents (Boronat et al., 2019) but there is a paucity of research exploring similar links between behaviours and mealtimes in psychiatric settings for working age adults.

### **1.8 Person centred inclusive approaches**

Since the publication of good practice recommendations such as “Nothing about us without us” (Charlton, 2000) there is recognition of the importance of partnership and co-production as an essential component of recovery (Clark, 2015, McAllister and Moyle, 2008, N.H.S. England, 2016, Swords and Houston, 2021). An attempt to understand the lived experience and the implementation of a recovery care pathway led by the individual should now be key drivers for clinicians supporting people with mental illness (World Health Organisation, 2019b). Despite the intention for services to move to co-production, the patient voice in this population is seldom described in regard to mealtimes and experience of dysphagia. Friedman et al., (2018) concluded that people with mental illness were less likely to have an active role in decision making relating to their treatment and care, similarly Clark (2015) reflected that the intention to promote co-production is still often not reflected in practice.

Earlier guidance for supporting people with dysphagia described a clinically driven protocol which outlined the benefits of imposing an “anti-dysphagia diet” (McManus, 2001) and other studies which described caregiver “compliance” or “adherence” (Chadwick et al., 2003, Crawford et al., 2007). These suggested a lack of attention to personal preferences and to principles of co-production. The continued use of the term ‘feeding’ in guidance and research studies perpetuates a less person-centred approach, implying less active involvement and a focus on impairment. The research by Smith et al., (2022) highlights the need to consider individualised aspects of dysphagia in terms of the impact on quality of life and to inform the design of management strategies. This study offers valuable insights into the lived experience of people with dysphagia but does not include specific mention of participants with mental illness. The dysphagia experiences described appear stable and longer term in nature, and thus are unlike the dysphagia associated with people with mental illness which is often fluctuating and variable in presentation and experience.

Clinical experience working with staff and patients has suggested that eating, drinking and swallowing difficulties may be affected by both physical and psychosocial influences (Guthrie and Stansfield, 2017). The day-to-day presentation of the patient with dysphagia may change depending on environmental and social factors whilst the physiological and anatomical aspects may remain constant. It is clearly important to understand how hospital settings may influence or exacerbate dysphagia in people with mental illness for the patients, the staff who support them and for wider recovery to be achieved.

### **1.9 Rationale and aims for this PhD**

In summary, research to date has considered clinical symptoms and the importance of medication in understanding dysphagia in people with mental illness. However, the lived experience of dysphagia and choking for adults with mental illness is not clearly understood. For patient involvement to be effective, feasible and sustained, clinicians need to understand the individual patient's mealtime experiences, customs, and choices. As services strive towards more holistic inclusive approaches there is need to identify and then clarify options for mealtime assessment and intervention. In offering shared or supported decision making clinicians need to be able to support each patient to evaluate their options for assessment, interventions, and outcome measures relating to dysphagia and risk of choking.

The patient, their direct support staff and the wider clinical team would benefit from greater clarity regarding identification of the symptoms, risk factors and presentation of dysphagia in adults with mental illness (Walsh et al., 2007). An overview of the individual's perspective of mealtime experiences, swallowing difficulty, and choices would inform improved understanding of the experience of living with dysphagia in this population.

To understand the evidence base for good practice strategies and patient involvement in assessment and treatment of mealtime difficulties, this thesis will explore the literature on dysphagia in adults with non-organic mental illness with a focus on self-reporting and communication of dysphagia. Following a comprehensive literature review, a research study will explore the perspectives of patients and their ward staff to elicit their insights on mealtimes and dysphagia.

To complement this, the perspectives of speech and language therapists will be elicited for further specialist insights.

This study aims:

- to seek research describing the impact of mealtime difficulties, dysphagia and choking on the person him or herself and the experiences around mealtime difficulty reported by this population and/or their families, friends, direct support staff, and SLTs.
- To explore the biopsychosocial influences on swallowing and mealtimes in psychiatric inpatient settings by eliciting insights from patients, staff and SLTs with experience of inpatient mealtimes and of people with dysphagia.

### **1.10 Terminology**

The vocabulary used in this thesis has been discussed with patient and caregiver groups to agree the most relevant and acceptable descriptors for people with mental illness. The use of the terms ‘patient’, and ‘mental illness’ was agreed but follow the guidance of W.H.O:

“The terminology adopted in this document has been selected for the sake of inclusiveness. It is an individual choice to self-identify with certain expressions or concepts, but human rights still apply to everyone, everywhere. Above all, a diagnosis or disability should never define a person. We are all individuals, with a unique social context, personality, autonomy, dreams, goals and aspirations and relationships with others.”  
(World Health Organization, 2019b, p.xxvi).

## Chapter 2 Integrative literature review.

### 2.1 Background

To understand existing knowledge and to situate this PhD it was necessary to conduct a literature review. Thorne (2016) describes this as a critical element of a study to gather current research and explore assumptions allowing the researcher to determine research gaps and orientate study to the needs of clinical practice. To understand mealtime experience on inpatient wards, this review explored and appraised the current evidence. This review was registered with the Prospero international prospective register of systematic reviews (Travers et al., 2019, University of York, 2009) and on completion was accepted for publication (Guthrie et al., 2023). The Prospero registration can be accessed using the link below:

[https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=130630](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=130630)

### 2.2 Methodology: literature reviews

The overall purpose of this review was to understand the existing literature concerning mealtime experience of individuals with mental illness, and how different aspects influence their experience. To this end, relevant approaches and methodologies were considered.

An objective approach such as positivist as described by Lincoln et al., (2011) would be useful if considering a specific cause-effect relationship, for example to determine the causes of choking. However, this review aimed to understand a much wider spectrum of influences in place at a mealtime for someone living with a mental health condition and sought to explore the subjective experience of individual patients.

Constructionist approaches acknowledge the multiple influences of different interwoven personal experiences and contexts that shape an event or activity (Bryman, 2016). Constructionism has been described simply as "understanding lived experience from the points of view of those who hold it" (Ritchie et al., 2014, p.13). Researchers following this approach would consider people in their own settings to understand psychosocial aspects. This review sought any examples of studies describing patient mealtime experience in mental health settings to



afford more in-depth understanding of the human and environmental influences at play (Haydon et al., 2018). To interpret the mealtime experience presented in the literature and offer transparency of analysis, this review included reflexivity acknowledging the expertise and life experience of the researcher.

In social sciences, pragmatism follows a pluralistic approach, encouraging researchers to pursue their topic with an applied focus on the research question and method of investigation, adopting a variety of methods to achieve their objectives (Creswell and Creswell, 2017, Jacobsen, 2017). Ritchie et al., (2014) also suggest that a pragmatic approach can draw on different traditions and, essentially, value the perceptions and interpretations of individuals. This fitted well with the purpose of this review which sought to elicit existing evidence, uncover personal perspectives of individuals in mental health settings and describe the perceived impact of context on mealtime experience.

Preliminary reading suggested the likelihood of gaps in existing research on the topic of interest. The term 'research gap' was explored by Nyanchoka et al., (2019) who identified 12 different definitions in their systematic review. However, Braun and Clarke (2022) challenged the idea of 'knowledge gaps' reframing this as the researcher creating an 'argument' and thus establishing the need for exploration of a topic. Others have used the term 'silences' to represent groups and issues which have not been presented in the literature (Serrant-Green, 2011).

In summary this literature review followed a pragmatic approach to derive information on how mealtime experience is "constructed" highlighting the views of adults with mental illness. To this end, the review included a wide range of sources and databases, seeking any patient stories or narratives, reported experiences and insights from clinicians. Gaps or silences in personal perspectives were identified and described to inform planning for further research.

### **2.3 Reflexivity: the researcher's perspective**

At every stage of the research process, from the inception of the phenomenon of interest to the writing of the conclusions, the researcher's values influence the study (Edgley et al., 2016) whether this is made explicit or not:

“The researcher is a storyteller, actively engaged in interpreting data through the lens of their own cultural membership and social positionings, their theoretical assumptions” (Braun et al., 2019, p.848).

Years of clinical experience working as an SLT with colleagues and multidisciplinary teams in different settings will have influenced the views and insights of this researcher. The clinical perspective is to be valued in a pragmatic approach (Braun et al., 2019, Sackett, 1997). Influences of personal lived experience and wider cultural factors will also be present. Mealtimes are widely varied across and within cultures (Leslie and Crawford, 2017), the experience, choices and culture of this researcher who lives independently in her own family home may not reflect those of someone who is currently an inpatient in a mental health hospital setting. Reflexive thematic analysis was implemented with personal reflections on positionality described throughout this thesis to complement the findings from the literature review and the following study.

## **2.4 Options for methods of review**

Different methods for reviewing a body of literature and evaluating the evidence for healthcare have been discussed over many years (Grant and Booth, 2009). For this review, the most relevant formats included scoping, narrative, systematic and integrative methods. Each of these is considered below evaluating the relevance and feasibility for this topic.

### **2.4.1 Scoping reviews**

Scoping studies offer a means of orienting the researcher around a topic area where evidence is likely to be scant (Colquhoun et al., 2014, Tricco et al., 2016). This approach was considered not sufficient to establish full understanding of current research on this topic, however preliminary searches and reading were conducted to determine the concepts associated with adults with mental illness. Exploring studies in a preliminary review gave rise to concepts and then allowed refining of search terms for the subsequent integrative literature review (below).

### **2.4.2 Narrative reviews and synthesis**

The use of narrative has been described in interpretivist approaches as a means of presenting and/or summarising personal accounts (Haydon et al., 2018).

Narrative synthesis methods have been developed over the last decade with the purpose of reviewing literature where qualitative information is presented as stand-alone or together with quantitative results.

However, following a narrative approach does not offer a wider exploratory focus as it frames interpretation within three dimensions: temporality, sociality and spatiality (Haydon et al., 2018). There is also some concern regarding lack of structure and process affecting transparency, replicability and credibility (Popay et al., 2006). Lucas et al., (2007) compared narrative and thematic synthesis methods and suggested that although both generate similar results, thematic synthesis is more suitable to inform and direct further research by understanding the commonalities of existing research.

### **2.4.3 Integrative reviews**

Whittemore and Knafl (2005) describe the process of integrative reviews as the most wide ranging as it allows diverse reports to be synthesised around a 'phenomenon of concern'. As for all review approaches there is a need to consider bias, rigour, and accuracy in the synthesis. This is closely allied to the format and comprehensive searching of systematic reviews described by Cooper et al., (2018). There is similarity in the methods of searching, quality appraisal, data display and analysis using an iterative process to gain increasing familiarity with the data "to present a comprehensive understanding of problems relevant to health care and policy" (Whittemore and Knafl, 2005 p.552). However integrative reviewing allows inclusion of disparate study methods and diverse perspectives. It offers a robust structure for synthesis and has the potential for structuring findings to be applied to clinical practice.

### **2.4.4 Systematic reviews**

Systematic reviews are considered the gold standard approach (University of York, 2009). They "represent the highest standard of evidence of the effects of interventions and have the capacity to usefully inform clinical decisions, reduce research waste and direct policy making" (Travers et al., 2019, p.1). They offer a comprehensive, explicitly structured approach seeking to present a summary of evidence around a topic of interest with minimal bias (Garg et al., 2008). A systematic review will identify limitations, consider quality of evidence, and

identify gaps in knowledge. These reviews follow clear guidance on design, process, and reporting (Cooper et al., 2018, University of York, 2009). Traditionally the systematic review has been associated with quantitative studies incorporating meta-analysis to build wider understanding. With the increasing use of systematic reviews for qualitative studies the guidance suggests a move to 'meta-synthesis' for homogenous studies (Thorne et al., 2004).

As discussed above, the intention to inform practice underpinned the objectives of this review. A wide diversity of studies was expected (including those presenting qualitative findings) and therefore, this review was integrative in analysing the findings from heterogenous studies of varying quality following a systematic search described below.

#### **2.4.5 Options for methods of analysis**

The methods most relevant to this integrative review were meta-ethnography and thematic analysis. The former is summarised by Bryman (2016) as a procedure translating between different studies, to shed new light on conclusions of the individual studies. Given the anticipated lack of evidence available around patient perspective, mealtimes, and dysphagia in people with mental illness this review sought to conduct a comprehensive and rigorous search strategy to confirm this 'silence' and to understand what other perspectives were present. Meta-ethnography was therefore less appropriate. Thematic analysis was selected as it offers greater flexibility and an open approach for including studies of different designs. By including studies which used different methods and varying levels of evidence this review summarised the context of existing knowledge and established an 'argument' for the area of interest for further research (Braun and Clarke, 2022).

Vetter (2003) cautions that interpretation of data can vary between readers who may reach different conclusions on reading the same data however well presented. Clinical experience, consensus between reviewers, and discussion of themes with service user groups were used to address this concern. Reflexive thematic analysis highlighted the researcher's perspective and experiences. To ascertain relevance, the themes derived for this review were taken to service user groups for their comments and feedback regarding relevance and transferability.

The structured procedure for the literature search and analysis followed the stages defined by Cooper et al., (2018) and Whitemore and Knafl (2005) and is described in section 2.5 below.

#### **2.4.6 Quality assessment**

To assess the quality of each study and its recommendations, different quality assessments were considered. Voss and Rehfuss (2013) evaluated six quality assessment tools looking at both checklists and scales acknowledging that quality assessment is always subjective. The Critical Appraisal Skills Programme (CASP-UK., 2016) and the Mixed Methods Appraisal Tool (Hong et al., 2018) are both checklists which have been more recently updated offering a quick assessment of studies. They are often used by researchers interested in healthcare settings but only offer a binary score to judge each item, thus detail is lost in identifying weaker or stronger aspects of the study evaluated (Voss and Rehfuss, 2013). The Grading of Recommendations, Assessment, Development, and Evaluations (GRADE) system is aimed at more heterogeneous studies as a means of evaluating detailed recommendations (Guyatt et al., 2011). This was not applicable as most studies only gave minimal or vague recommendations. Voss and Rehfuss (2013) advise caution: reliance on a numerical score for quality may obscure the presence of a single major flaw within a study. Also, rigid adherence to higher scoring trials may lose valuable insights by excluding apparently weaker research.

As an alternative to these, this review implemented quality assessment using the Quality Assessment Tool (QAT-SDD) (Sirriyeh et al., 2012). This was devised by a team of experienced healthcare researchers and offers a graded evaluation system (rating from levels 0 to 3) with guidance for each level. It has been validated with inter-rater reliability also established. The guidance notes allow a more transparent approach, and each study is scored against a potential total score.

### **2.5 Method for integrative review**

The key stages are listed below (table 1) showing the structured approach with a description of how these were implemented for this integrative review (Whitemore and Knafl, 2005).

<b>Structured stages</b>	<b>Related activity</b>	<b>Comments</b>
<b>1.Problem identification.</b>	Preliminary review and consultation.	Supported accessible discussion with patients and caregivers to suggest concepts and keywords for search strategy.
<b>Determining the aims and purpose.</b>	To find all relevant papers to give confidence in the findings.	Service user groups were involved in planning and discussion of concepts and priorities.
<b>2.Literature search preparation.</b>	Searching for existing reviews based on similar topics across Prospero, Cochrane and DARE websites.	Literature review focus: dysphagia and mealtime experiences for adults with non-organic mental illness.
<b>Designing the search strategy.</b>	Use of SPIDER format (Methley et al., 2014).  Additional manual citation searches to ensure comprehensive searching.	Concepts for the systematic review were reviewed and defined in light of comments from the service user network meetings and staff training sessions.
<b>Determine relevant databases.</b>	Examination of relevant existing papers to determine most appropriate databases: Cochrane, Medline, Embase, CINAHL, PsycINFO.	Centre for Reviews and Dissemination (University of York, 2009) advise these to be most appropriate sources for healthcare research.
<b>Supplementary searching.</b>	Database searches supplemented by forwards and backwards citation searching from marker papers.	Relevant authors were contacted re any studies in progress. None had any further information to return.
<b>Managing references.</b>	Endnote used for managing and sorting of results from each database.  Deduplication using Endnote and manually.	Spreadsheet constructed for screening results.  Additional spreadsheet for blinded reviewing (interrater reliability established)
<b>Reporting.</b>	PRISMA flowchart completed (Moher et al., 2009)	Transparent reporting facilitates credibility.
<b>3.Data evaluation.</b>	QAT-SDD (Sirriyeh et al., 2012).	Completed by JB, SG, JC (blinded review with agreement of scores).
<b>4.Data analysis and synthesis.</b>	Reflexive thematic analysis.	Analysis completed by SG, reviewed with supervisors.
<b>5.Presentation of results.</b>	Published in peer reviewed journal.	Presented to patient and staff groups for discussion.

**Table 1 Literature search structure**

Given the suspected paucity of evidence, the search was broad with limits only set for age of participant and language. No restrictions on date of publication were set to allow a broad search for review. Search terms were explored, with

reference to keywords listed for marker papers. The research question and the Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) structure (Methley et al., 2014) were used to anchor the search, focus decision making around inclusion of papers, and referred to in discussions regarding relevance of papers located. Papers were not masked for second raters as this has been found to be of limited benefit relating to inclusion (Cooper et al., 2018) and in addition this study subsequently implemented full blinded quality assessment for the included papers.

### **2.5.1 Search limits.**

This search completed full review of the five most relevant databases with further manual citation searching and contact with known researchers to check for ongoing work or publications. This established a comprehensive range of investigation sufficient to allow thematic analysis of current research.

Braun et al., (2019) view the concept of saturation as counter to the process of seeking new knowledge from data sources. They advise that practical considerations may limit the scale of an investigation, but reflexive thematic analysis requires the researcher to become familiar with the whole set of data to develop understanding of patterns and context. They point out that thematic analysis can only occur after data is collected and thus setting a limit to size of sample is presupposition or based on a superficial level of analysis.

Other authors do consider how to achieve saturation (Dixon-Woods et al., 2005). Booth (2010) suggests "for qualitative data: cease searching when new items do not add substantively to understanding of phenomenon" (Booth, 2010, p.433) and he lists further methods for discontinuing a search with strategies including theoretical saturation, comparing known samples, and reduction in yield.

## **2.6 Preliminary review**

Clinical experience and preliminary reading suggested a gap in the evidence relating to adults with mental illness and their personal experience of dysphagia and/or choking. The relevant concepts were drafted as 1) non-organic mental illness and 2) dysphagia and/or choking. Evidence around a third proposed concept – that of the lived experience of mealtime difficulties from the perspective of the adults themselves was also considered. Accounts of dysphagia and self-

reports of mealtime difficulties were investigated in a preliminary search. Patient perspectives were scarce, and the review strategy therefore was widened to include concept 3) experience of mealtime difficulties, to capture relevant aspects and concerns (appendix A).

This preliminary review indicated that there was a need for further comprehensive systematic review of current evidence focussing on the concepts identified above. This would need to include a broad range of search terms expanding the concepts of 'mental health', 'dysphagia' and 'mealtimes' (appendix A). Limitations would be implemented to exclude 1) adults with additional deterioration of mealtime skills associated with ageing and/or dementia and 2) people with primary diagnoses of physical health conditions. The review process would include an assessment of quality of evidence and an evaluation of the perspective of the authors of each study.

## **2.7 Consultation**

To confirm and support the concepts for literature review, the opinions of people with lived experience of mental illness and dysphagia were sought. Relating to scoping reviews, Arksey and O'Malley (2005) and Levac et al., (2010) recommend consumer involvement to direct the focus, to add insight to the findings, and to support dissemination and uptake of any findings. This was equally relevant for this integrative review in light of the focus on patient perspectives and experiences.

City wide service user groups were approached by the author and offered accessible information about the topic of interest. The two local groups for adults with mental illness, (Help from Experts by Experience for Researchers (HEER) and Leeds Service User Network (SUN)), were keen to participate in discussion around their experiences of dysphagia and choking incidents. They confirmed strong interest in the topic finding it relevant to their experience and concerns.

## **2.8 Systematic search method**

The systematic search protocol was drafted in discussion with supervisors. An example search is presented in appendix B. The details of the objectives, method and the findings are described below.



### 2.8.1 Aims and objectives

The overall aim of this review was to appraise and synthesise the current evidence on the nature and experiences of mealtimes and/or dysphagia in adults with non-organic mental illness. Specifically, this review aimed to answer the following research questions:

- a) What are the characteristics of mealtime difficulties and/or dysphagia in adults with non-organic mental illness?
- b) What is the nature of experience of mealtime difficulties and/or dysphagia for adults with non-organic mental illness, from the perspective of the adults with mental illness themselves, family members, direct support workers, and other staff working with these adults?

### 2.8.2 SPIDER framework

The use of clear and replicable structure to define literature searches is recommended to guide investigations of evidence-based practice (Cooke et al., 2012, Moher et al., 2015, Pollock and Berge, 2018, Whitemore and Knafl, 2005). The focus of this integrative review was completed using the SPIDER framework (table 2) to define the topic of interest and key elements (Cooke et al., 2012, Methley et al., 2014).

<b>Sample.</b>	Working age adults with non-organic mental illness.
<b>Phenomenon of Interest.</b>	Mealtime difficulties, dysphagia and choking.
<b>Design.</b>	Broad search, no restrictions aiming for exploratory investigation.
<b>Evaluation.</b>	Outcomes, insights, and information on quality of life associated with mealtime experience/difficulties. Patient and caregiver perspectives.
<b>Research type.</b>	Any relevant qualitative, quantitative, and mixed method studies.

**Table 2 SPIDER framework**

Age related dysphagia has been associated with frailty and older populations (Cichero, 2018, Leder et al., 2016, Leslie et al., 2005, Ortega et al., 2014, Tracy et al., 1989). In order to maintain relevance, this review would only include studies involving adult participants between 18 and 65 years i.e. people who would be

expected to have a mature swallow without the weakening and other influences associated with age. To focus understanding of the nature of dysphagia in mental disorders the review was designed to exclude studies where the patients' primary diagnosis was a physical health condition including patients with neurodegenerative, post-surgery and oncological conditions.

### **2.8.3 Method: search strategy**

Following the discussions with the service user groups, and the findings of the preliminary reading, the three key concepts were refined into search terms: "mental disorders", "dysphagia" and "experience of mealtimes". Each was expanded into lists of relevant synonyms and reviewed with supervisors. Further confirmation was through discussion with University and N.H.S. librarians to ensure relevance, breadth, and feasibility of each concept (appendix A).

The searches under the concept of 'mental disorder' also included "intellectual disability" and related keywords such as "mental handicap" and "mental retardation" (both now outdated) to ensure earlier studies were picked up. Studies describing psychiatric settings in previous centuries may not distinguish people with mental illness or separate these from people with cognitive impairment and/or intellectual disability.

The concept of "dysphagia" was expanded to include "deglutition", "swallowing", "aspiration", "eating and feeding difficulties" although this would be expected to generate some results related to "eating disorders". Studies describing "eating disorders" which had no additional reference to dysphagia were later excluded through screening. It was necessary to retain this term in the full search so that no studies were missed relating to 'eating difficulties' as a synonym for 'dysphagia'. 'Choking' and 'asphyxiation' were also included under this concept. Further terms were added to include "cramming", "gorging", and "bolting". Other commonly used lay terms were added to facilitate the search for patient reported experiences including "stuck in throat"; "café coronary"; "dining".

For the concept of 'mealtime experience', search terms were added to capture the quality of experience and behavioural aspects relevant to mealtimes.

Search terms were entered into the Embase, Medline, and PsycINFO databases on the Ovid platform and mapped to the subject headings using Mesh terms.

These were exploded and the subheadings examined. Relevant subheadings were retained. Following this, synonyms were added into the search as keywords. Inclusion and exclusion criteria are shown in table 3.

Inclusion criteria	Exclusion criteria
Adult (>18 years).	Children/Neonate/Paediatric. Elderly/geriatric (over 65 years).
Dysphagia.	Eating disorder.
Choking.	Postmortem research
Non-organic mental disorder.	Organic mental disorder (i.e. neurocognitive disorders, acquired or degenerative neurological conditions).
Quality of life or mealtime experience.	Studies with physical health as primary diagnosis.
Published in English.	.

**Table 3 Inclusion and exclusion criteria**

### 2.8.3.1 Search techniques

The searches were run for each concept using Boolean operators. These included truncation to allow for variations in word endings of one or more characters. Proximity searching (using *adj3* for Embase, Medline, PsycINFO and *n2* for CINAHL) was used to allow for phrases where search terms might be separated by other words. The searches were designed to locate search terms contained within the title, abstract and keyword for the databases on the OVID platform, and title, abstract, for CINAHL. Synonyms were combined with OR for searches within each concept and then combined with AND.

Following discussion with librarians the use of NOT was not implemented until the final stages of the searches for each database and only to exclude non-human and non-English studies. A trial search using the search terms was run on 3 May 2019 using the Medline database. This located 749 relevant papers for screening. Further checks on the use of the search terms were run with the NHS and University librarians to examine the indexing and keywords for three marker papers (Aldridge and Taylor, 2012, Cicala et al., 2019, Guthrie and Stansfield, 2017) checking that these matched against the search terms used. This substantiated the use of keywords “dysphagia, deglutition, choking, and adult mental illness”.

### 2.8.3.2 Manual searches

The reference lists of the included papers were searched to identify any further relevant papers. A spreadsheet was compiled allowing the references found from this manual searching to be organised and compared with those already identified and included from the database searches. This manual search suggested 13 additional papers for inclusion after deduplication. Following screening of abstracts and then remaining full texts, there were 3 remaining papers which were eligible to be included.

### 2.8.4 Results of database searches

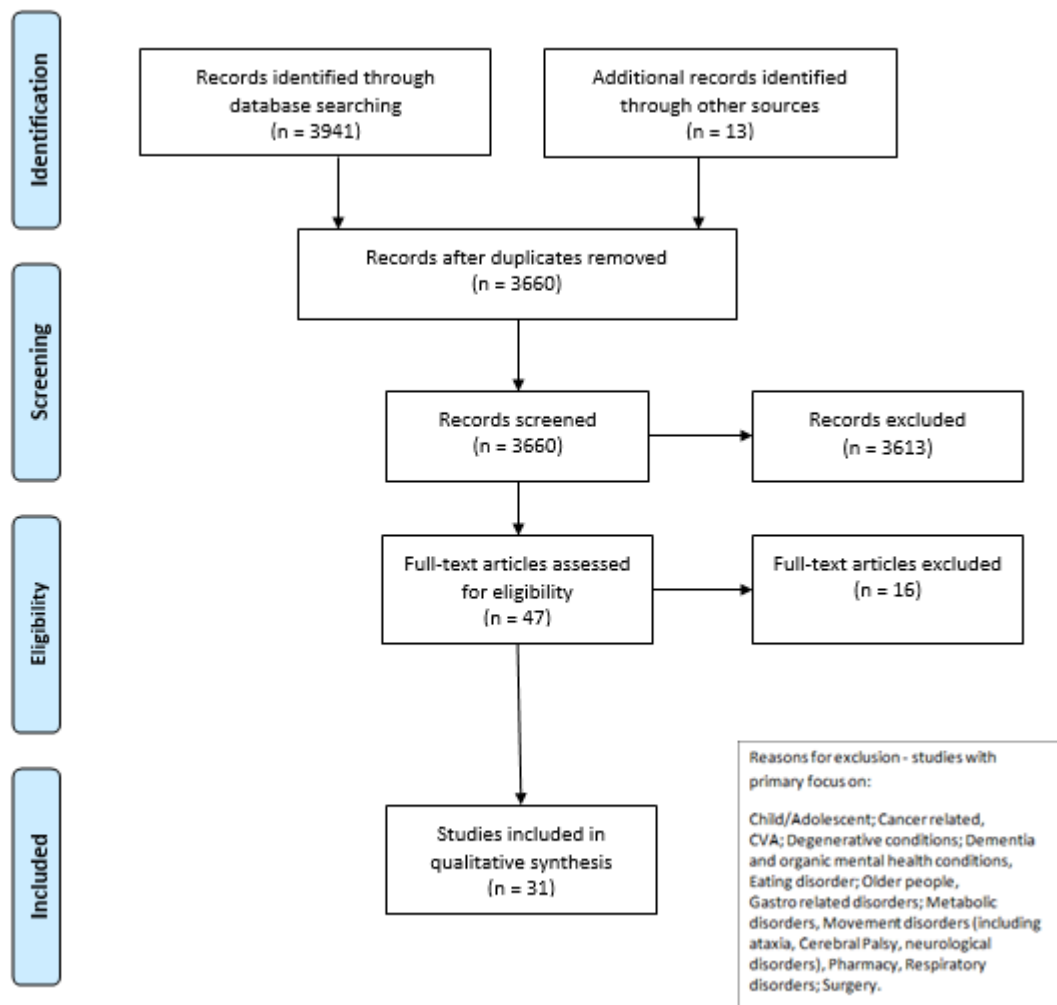
The databases were searched back to the earliest date available for each one. Table 4 describes the date ranges available.

Portal	Database	Date	Search date range	Hits
EBSCO host	CINAHL	9.5.19	1981 to May 2019	250
Cochrane library	Cochrane Reviews + Trials	19.5.19	2005 to May 2019	2 + 47
Ovid platform	Embase Classic + Embase	9.5.19	1947 to 2019 May 03	2333
	Medline MEDLINE(R) and Epub ahead of print	9.5.19	1946 to May 03 2019	749
	PsycINFO	10.5.19	1806 to April week 5 2019	560
Totals			Total	3941
			Duplicates removed	-294
			Manual searches	+13
			Total remaining	3660

**Table 4 Database searches**

The results of all the searches were added to an Endnote library with separate groups for each database. Duplicates were then removed using firstly the Endnote function and then using further manual checking to leave 3660 titles for screening. A flowchart (Moher et al., 2009) was constructed to illustrate the phases of the search (see Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) figure 1 below).

### 2.8.5 Prisma flowchart (Moher et al., 2009)



**Figure 1 Prisma diagram**

### 2.8.6 Screening for eligibility

The PRISMA diagram (figure 1) above illustrates the process of identifying and screening papers for eligibility. The eligibility section summarises the progression from screening titles (n=3660) to reviewing abstracts (n=256) and finally to assessing full papers (n=47). This resulted in 31 papers eligible for analysis and synthesis. The reasons for exclusions are discussed below.

Exclusions were due to the primary focus being on eating disorders (n=1033), paediatric or neonate (n=1163), degenerative conditions (n=310), and dementia (n=84). These were expected but could not be excluded beforehand due to the

potential for studies to combine these topics with non-organic mental illness and dysphagia. Further exclusions included studies focussed on other acquired conditions including stroke (n=133) cancer (n=424), surgery (n=197) and other topics not relevant to the search criteria (n=285).

The titles were screened by the first author and studies excluded according to the eligibility criteria. Next, the abstracts of the remaining studies were reviewed by SG and supervisor JB independently. Agreement was reached for inclusion of 47 papers for full screening. Finally, the full texts of all 47 remaining studies were retrieved for review. Two raters read the full texts separately to decide on inclusion/exclusion. One study was duplicated in two separate papers, (Regan et al., 2006, Walsh et al., 2007). The earlier paper was retained offering greater detail and scoring higher on the quality assessment. For the six literature reviews that were eligible, their reference lists were also reviewed against the eligibility criteria for this integrative review. Single studies within these reviews were considered and included if they offered data relevant to the criteria in table 3.

## **2.9 Literature search results**

Firstly, the characteristics of the papers are described below and secondly the themes within and across the papers are outlined and synthesised relating back to the research question and objectives for the review. Finally, the unanswered questions and any gaps in information are discussed.

A total of 31 papers were included and assessed for quality. Data was extracted and collated into a summary of findings spreadsheet. Dates of publication ranged across three decades with the earliest paper dated 1991. The studies included were heterogeneous in method, settings, and populations. No randomised control trials were eligible for inclusion, the majority of studies were single case studies (n=17) and observations of cohorts of patients (n=9) but there were also four literature reviews, and one prevalence study. Information on the characteristics of the studies is presented below (see table 5).

Although only papers written in English were included, the countries of origin were wide ranging. The majority of authors (n=23) appeared to have affiliation to psychiatry, but other disciplines were also represented. The settings of the studies were not always clearly indicated but most (n=23) included inpatients on psychiatric wards, of these four were described as acute settings and five

included long or short stay hospital wards. Only three papers also included people with mental illness living in the wider community.

## **2.10 Quality assessment**

The papers were assessed for quality using the QAT-SDD (Sirriyeh et al., 2012) (table 5 below). This rated the diverse individual studies against a potential 16 criteria using a scale of 0 to 3 for each. The total scores were calculated as a percentage out of either 42 marks for qualitative studies or out of 48 if quantitative. The majority were qualitative studies (n= 27) with the remainder being mixed methods. The quality scores varied from 7% to 88%. All 17 case reports scored at the lower quality end from ranging from 7% to 40%. Other papers scoring below 50% included some cross-sectional studies (n=5) and literature reviews (n=2). The nine higher quality scoring papers (i.e. 50% to 88%) were cross-sectional studies (n=56) and literature reviews (n=2).

The low scores were partly due to the absence of clear aims and/or research question, and insufficient detail of research setting and sampling methods. This was particularly the case for case reports. Little information was offered regarding specific objectives, assessment of the patient, or justification of analysis and conclusions reached. The style of most of the case reports appeared reflective and essentially based on clinical experience although two case reports added a general literature review to support their findings (Dziewas et al., 2007, McManus, 2001).

Further studies scored low on the criteria of QAT-SDD (Sirriyeh et al., 2012) relating to method and justification of data collection, recruitment and analytical processes. There was no discussion of justification nor reliability of assessment and data collection, no information about triangulation of findings, bias, or user involvement. Some low scoring studies included brief discussion of limitations (Corcoran and Walsh, 2003, Funayama et al., 2018, Nieves et al., 2007, Osman and Devadas, 2016) but the majority scored zero on this criterion.

The studies with higher scores were more explicit in their descriptions of theoretical framework, objectives, and sampling methods. However, justification for data collection and analysis varied widely for the nine studies scoring on or above 50%. Only two studies (Aldridge and Taylor, 2012, Hemsley et al., 2019), a systematic and an integrative review respectively, included justification of their

analytical methods and process. All papers were included in the thematic analysis of qualitative information.

### **2.11 Data extraction process**

Data was extracted through iterative reading of the full papers building a spreadsheet as recommended (Guyatt et al., 2011). This allowed comparison and synthesis of bibliographic information, study types, and participant information as presented in the studies. A further column was added coding for any presence or absence of patient voice or perspective. The characteristics of the studies were extracted for analysis into a database.

Thematic analysis was then conducted with basic codes devised through an iterative process of familiarisation, re-reading and coding (Braun and Clarke, 2022). Superordinate themes were derived by the author in discussion with supervisors. The process of reflexive thematic analysis (Braun and Clarke, 2022) acknowledges the influence and perspective of the researcher. The analysis was orientated by clinical experience and by consultations with the service user groups. Confirmation of themes was reached following discussion with supervisors. Further comments and insights were invited from service user networks and an expert group of SLTs to allow consideration of credibility and transferability.

The different study types are outlined below (table 5) with characteristics described for each to show variations in study design and findings.



<b>Author</b>	<b>Country</b>	<b>Affiliation or discipline</b>	<b>Setting</b>	<b>Study design (duration)</b>	<b>Quality ax score QAT-SDD (%)</b>
Aldridge and Taylor, (2012)	Australia	SLT	Inpatient, acute, short and long stay.	Systematic review.	86
Armstrong, et al., (2014)	UK	Psychiatry	No information.	Case report.	12
Bazemore, et al., (1991)	USA	Psychiatry	Inpatient, acute.	Cohort study (14 months).	43
Bhat et al., (2010)	India	Psychiatry	No information.	Case report.	10
Chen et al., (2015)	Taiwan	Nursing, medical, Psychiatry	Inpatient acute.	Cross-sectional study. Review of choking incidents.	43
Cicala et al., (2019)	Italy, USA, Spain	Medical,	No information.	Literature review.	37
Corcoran and Walsh, (2003)	Ireland	Psychiatry	Inpatient, psychiatric hospitals.	Retrospective study review of choking incidents (10 years).	45
Crouse et al., (2017)	USA	Psychiatry, pharmacy	Inpatient, psychiatry.	Case report.	26
Duggal and Mendhekar, (2008)	India, USA	Psychiatry	No information.	Case report.	16
Dziewas et al., (2007)	Germany	Medical, neurology	Inpatient.	Case report.	36
Fioritti et al., (1997)	Italy	Psychiatry	Inpatient, long stay, short stay, therapeutic community.	Retrospective study. Review of choking incidents (18 months).	50
Funayama et al., (2018)	Japan	Neuro-psychiatry	Inpatients.	Retrospective study: Review of choking incidents (16.5 years).	30

<b>Author</b>	<b>Country</b>	<b>Affiliation or discipline</b>	<b>Setting</b>	<b>Study design (duration)</b>	<b>Quality ax score QAT-SDD (%)</b>
Gregory et al., (1992)	UK	Neurology	No information.	Case report.	26
Guthrie et al., (2014)	UK	SLT	Inpatient, long stay, community.	Retrospective study. Review of choking incidents (12 months).	83
Guthrie et al., (2012)	UK	SLT, Nursing, Psychiatry	Inpatient.	Case report.	40
Guthrie and Stansfield (2017)	UK	SLT	Inpatient.	Retrospective cross-sectional study. Review of choking incidents.	71
Hemsley et al., (2019)	Australia, USA	SLT	Diverse, inpatient and community.	Literature review.	88
Hwang et al., (2010)	Taiwan	Psychiatry	Inpatient.	Retrospective cross-sectional study. Review of choking incidents (3 years).	42
Kulkarni, (2017)	USA	Psychiatry, medic, speech pathology	Patients with schizophrenia.	Literature review, opinion.	11
Leopold (1996)	USA	Psychiatry	Inpatient.	Case report.	31
Lin et al., (2012)	Taiwan	Psychiatry	Inpatient.	Case report.	19
McManus, (2001)	USA	Nursing	Inpatient.	Case report.	7
Mendakar et al., (2010)	India	Psychiatry	No information.	Case report.	17
Nieves et al., (2007)	USA	Psychiatry	Psychiatric clinic.	Case report.	24

<b>Author</b>	<b>Country</b>	<b>Affiliation or discipline</b>	<b>Setting</b>	<b>Study design (duration)</b>	<b>Quality ax score QAT-SDD (%)</b>
Osman and Devadas, (2016)	Ireland	Psychiatry	Inpatient.	Case report.	29
Regan et al., (2006)	Ireland	SLT	Inpatient.	Cross-sectional study, sample of 60.	63
Sagar et al., (2005)	India	Psychiatry	Inpatient.	Case report.	14
Sico and Patwa, (2011)	USA	Medical-neurology	Inpatient.	Case report.	29
Tang and Hseih, (2010)	Taiwan	Psychiatry	Inpatient.	Case report.	21
Varghese, et al., (2006)	India, Scotland	Psychiatry	No information.	Case report.	24
Yim et al., (2009)	Hong Kong	Psychiatry	Inpatient.	Retrospective cross-sectional study. Review of choking incidents (11 years).	64

**Table 5 Characteristics of included studies**

### 2.11.1 Case reports - characteristics

These 17 papers were very diverse offering insight into individual patients (table 6). The majority of these (n=15) focussed on the impact of a specific antipsychotic medication or combined drug therapy. The details of the setting were often unclear with a general reference to the patient “presenting” for assessment by psychiatry. The two remaining papers (Guthrie et al., 2012, McManus, 2001) (written by speech and language therapists and nurses respectively) described case studies where multidisciplinary protocols were the focus for intervention.

Author, year	Patient(s)	MH diagnosis	Medication related to dysphagia or choking	Nature of mealtime difficulty
Armstrong et al.,(2008)	F aged 31	Schizoaffective disorder.	Quetiapine withdrawn. Resolved after 48 hours.	Swallowing difficulty, choking on food, no other EPSE <sup>2</sup> noted.
Bhat et al., (2010)	M aged 37	Schizophrenia.	Haloperidol decanoate, withdrawn. Resolved after 8 weeks.	Increasing difficulty in swallowing liquid, no EPSE, AIMS <sup>3</sup> score 14.
Crouse et al., (2017)	F aged 62	Schizophrenia.	Olanzapine withdrawn. Resolved after 48 hours.	Difficult, painful swallowing, weight loss, increased EPSE.
Duggal and Mendhekar, (2008)	F aged 35	Paranoid schizophrenia.	Risperidone withdrawn. Resolved after 6 weeks.	Difficulty swallowing food, fluids ok. Tardive effect.
Dziewas et al., (2007)	M aged 53	Paranoid schizophrenia.	Haloperidol withdrawn. Resolved after 2 weeks.	Difficulty swallowing food, coughing, mild dysarthria, no EPSE.
Gregory et al., (1992)	F aged 48	Manic-depressive psychosis.	Flupenthixol, chlorpromazine lithium. All withdrawn, resolved after 10 months but some minor involuntary movement remained.	Involuntary movements of tongue, silent aspiration, abnormal oral and pharyngeal.
Guthrie et al., (2012)	M aged 30s	Personality disorder, IDs.	No information	Involuntary movements of tongue, facial, silent aspiration.
Leopold, (1996)	F aged 38	Depression.	Trifluoperazine, paroxetine withdrawn. Resolved after 3 months.	Tremor, sialorrhea, and difficulty chewing. Bradykinesia and rigidity, dysarthric speech. Abnormal

<sup>2</sup> Extra pyramidal side effects

<sup>3</sup> Abnormal involuntary movement scale. (Guy, 1976).

Author, year	Patient(s)	MH diagnosis	Medication related to dysphagia or choking	Nature of mealtime difficulty
				oral and pharyngeal.
Lin et al., (2012)	M aged 54	Schizophrenia.	Aripiprazole withdrawn. Resolved after 3 weeks.	Difficulty swallowing solid and semisolid foods, choking. Slight drooling, no other EPSE.
McManus, (2001)	F aged 44	Bipolar, impulse control disorder, learning disability.	Haloperidol, olanzapine, benztropine, nortriptyline, trazodone.	Coughing on food, fatal choking on food.
Mendhekar and Agarwal, (2010)	M aged 18	Schizophrenia.	Paliperidone withdrawn. Resolved within 1 day.	Difficulty swallowing solid and semisolid food, choking.
Nieves et al., (2007)	1.M aged 50	Schizophrenia.	Fluphenazine decanoate withdrawn, mild improvement.	Difficulty swallowing solids then fluids, coughing, glosso-pharyngeal dyskinesia, EPSE.
	2.M aged 57	Schizophrenia.	Trifluoperazine, withdrawn and swallow resolved (no time details).	Swallowing difficulties.
Osman and Devadas, (2016)	M aged 18	Treatment resistant paranoid schizophrenia, Asperger's syndrome.	Clozapine, dysphagia treated with swallowing therapy.	Swallowing difficulties after 4 weeks, weight loss, no other EPSE.
Sagar et al., (2005)	M aged 24	Bipolar affective disorder, mania.	Olanzapine, resolved on withdrawal.	Difficulty eating and drinking, no signs of EPSE.
Sico and Patwa, (2011)	M aged 58	Schizophrenia.	Risperidone, issues resolved when meds removed (1 month).	Acute onset dysphagia, facial diplegia, no history of EPSE.
Tang and Hsieh, (2010)	M aged 46	Schizophrenia.	Flupentixol, sulpride. biperiden and valproate were discontinued. Swallowing therapy. Amantadine and baclofen introduced.	Swallowing difficulties. Abnormal oral and pharyngeal, involuntary movements, silent aspiration, asphyxia.
Varghese et al., (2006)	M aged 38	Schizophrenia.	Risperidone, reduced dose, and swallow improved.	No involuntary movements, dysphagia.

**Table 6 Case reports**

### **2.11.2 Cohort studies - characteristics.**

Cohort studies are defined as comparing “new rates of incident or disease over time in a group of people with and without a particular well defined exposure” (Jacobsen, 2017 p.59). There were nine studies which may be considered cohort studies under this definition (see table 7). The majority of these (n=7) were retrospective in nature, analysing incidence and potential risk factors (reviewing choking incidents reported over differing periods of time).

The results suggest that research in this topic area is sparse across the globe. The author’s previous work offered two studies based in UK and there were two further studies based in Europe. The remaining work was completed in Asia.

Table 7 presents the diversity of the cohorts presented. The heterogeneity of time scales, length of stay and lack of detailed information about the nature of the setting, make comparison inappropriate. There is generally a lack of significance testing in the studies described which appears largely due to the small numbers within the cohorts, as a result the studies present trends and associations. The high number of people with schizophrenia and with intellectual disability may just represent the prevalence of these diagnoses in psychiatric inpatients. Similarly, the use of antipsychotics with inpatients is common and not compared against a matched control group. First generation antipsychotics are likely to be more common amongst older service users who will have a longer history of use.

Author	Time scales and setting	Cohort size	Matched comparison group?	Source of data	Findings – risk factors identified?	Reliability of results?	Frequency of choking?
Bazemore et al., (1991)	12 months, 400 bed hospital	28 people who choked. Aged 21 to 78 years.	Pre and post dysphagia program.	Retrospective. Choking incident reports, dysphagia assessment and MDT evaluation.	5 categories of swallowing difficulty.	Numbers too small for significance testing.	Increased incidence of death/airway obstruction in psychiatric patients.
Chen et al., (2015)	12 months, 282 bed unit	250 people consented. Mean age 41.8 +/- 14.7. Most common diagnosis: schizophrenia.	2 groups: 1. self-report choking when eating; 2. nurse report choking on medication.	Self-report of coughing while swallowing difficulty, medical records, observations.	Anxiolytics, coughing while eating, and swallowing difficulties remain significant.	Significance testing to examine variables.	Not presented (reviews others' findings).
Corcoran and Walsh, (2003)	10 years, 218 unexpected deaths (Irish psychiatric hospitals)	14 deaths from choking on food. Mean age 51. Common diagnoses: schizophrenia psychosis, LDs.	No control group. Considered asphyxia in psychiatric hospitals against general population.	Retrospective death reports, then questionnaire. Under-reporting.	Most report fast eating, EPSE, obesity. Discuss staff training, supervision, choking reporting, assess swallow, medication.	Small numbers.	11 fold higher rate of asphyxia death for psychiatric inpatients.
Fioritti et al., (1997)	18 months, 97 beds (4 units)	18 people who choked aged 39 to 87. 1 death; diagnoses – LDs, schizophrenia, affective disorder.	No comparison group.	Retrospective review of ward reports and clinical files staff questionnaire and direct examination.	No significance for neuroleptics with abnormal eating. Pharmacological factors, brady-kinetic, fast eating associated with severe or repeat choking.	Significance testing but numbers too small, no association between neuroleptics and choking severity.	1 grave or fatal choking incident for every 249.42 months per person hospitalized, (0.4 incidents every 100 months per person).

Author	Time scales and setting	Cohort size	Matched comparison group?	Source of data	Findings – risk factors identified?	Reliability of results?	Frequency of choking?
Funayama et al., (2018)	16.5 years, (Oct 1999 to March 2016), 1719 patients.	11 people with schizophrenia who choked aged 20 to 75, 2 deaths.	11 choked, 1708 not choked.	Retrospective.	Choking associated with severity of mental health, higher dose medication.	Significance testing for medications and age.	Not presented.
Guthrie et al., (2015)	12 months, 376 beds	Ages 28 to 74. 33 people who choked, 1 death. Diagnoses; LDs, MH, autism.	Comparison with national reporting.	Retrospective review of Incident reports.	Fast eating, time of day, familiar staff, food types.	Qualitative analysis only, description of trends.	435 incidents in UK for 1 year for people with IDs /mental health, 1 death.
Guthrie and Stansfield, (2017)	6 months, 376 beds	5 people who choked, aged 22 to 50. Diagnoses schizophrenia, LDs, bipolar disorder.	Qualitative analysis.	Semi structured interviews with direct support staff, nursing.	Teatime, behaviours, fast eating, agitation, anxiety, physical skills, familiar staff.	Qualitative analysis.	Not presented.
Hwang et al., (2010)	3 years, 210 beds.	11 people who choked, aged 28 to 82. 3 deaths; most common diagnosis schizophrenia.	Comparison with non-choking patients.	Retrospective review of ward reports, clinical files.	Breakfast time. Patients graded as poor/very poor self-care, ageing, Higher dosage hypnotics.	Significance testing described.	5.05 choking deaths per 1,000 persons hospitalised. Men 3 x more likely to choke.
Yim and Chong, (2009)	11 years, Jan 1996 to Dec 2007, 400-600 beds.	17 people who choked aged 18 to 87. 4 deaths, schizophrenia dementia, LDs.	Incidents compared with rates of admissions.	Retrospective review of incident reports, medical records.	Factors included visiting hours, bread, fruit, neurological, fast eating.	Significance testing suggested trends. Also, descriptive statistics.	15 choking deaths per 100,000 patient episodes.

Table 7 Cohort studies



### 2.11.3 Literature reviews - characteristics.

Six papers were identified which reviewed research around dysphagia for adults with mental illness (table 8 below).

Author	Type of study	Breadth of review	Studies located	Findings
Aldridge and Taylor, (2012)	Systematic review	6 database searches.	10 studies relating to dysphagia or choking.	Discussion of dysphagia and choking frequency. No studies evaluating intervention.
Cicala et al., (2019)	Comprehensive review	4 database searches.	45 case reports, 1 systematic review, choking studies, pneumonia studies.	Case reports offer details of dysphagia including tardive dyskinesia and EPSE.
Crouse et al., (2017)	Case report and literature review	No details of search.	14 case reports	Case reports offer details of dysphagia associated with SGA <sup>4</sup> s and management.
Dziewas et al., (2007)	Case report and literature review	No details of search, "relevant literature" summarised.	10 case reports	Bazemore's 5 categories, details of dysphagia assessment and outcomes.
Hemsley et al., (2019)	Integrative review	4 databases searched.	52 studies relating to choking incidents.	5 categories of recommendations to reduce risk of choking: modify mealtimes; oral hygiene; monitor medication; team approach; staff training and risk management.
Kulkarni et al., (2017)	Literature review	No information.	Studies relating to medication. Studies relating to behavioural aspects	Swallowing problems related to the illness itself and to treatment

**Table 8 Literature reviews**

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<sup>4</sup> SGA: Second generation antipsychotic medication

Half (n=3) were informally structured and offered a general overview of the topic but three described the databases searched and specified the search terms used (Aldridge and Taylor, 2012, Cicala et al., 2019, Hemsley et al., 2019). The reviews which included summaries of case reports (Cicala et al., 2019, Crouse et al., 2017, Dziewas et al., 2007) compared the features of dysphagia presented and the variations in dysphagia assessment options.

## 2.12 Reflexive thematic analysis

An overarching theme of 'Predominating medical perspectives' was constructed covering three main themes described below (table 9). The patient voice was minimal and only occasionally reported through staff insights.

Reflection: Clinical interests and experience were intrusive, distracting my focus away from the focus of the literature review objectives. This meant that I needed to keep returning to the aims of the review to anchor the analysis back to the patient perspective and experience. Discussion of the themes with supervisors and service user groups prompted deeper reflection and reminders to focus on seeking any perspectives described and descriptions of the impact of the mealtime difficulties on quality of life.

Main themes	Subthemes
Medical perspectives predominate.	Absence of patients' report of difficulties. Brief reporting of emotions associated with mealtime difficulties.
Lack of patient insights on influencing factors for mealtime difficulties.	Mental health and swallowing. Mealtime behaviours causing concern. Influence of mealtime environment and social aspects.
Lack of patient inclusion	Lack of patient involvement in dysphagia assessment. Lack of inclusion in decision making.

**Table 9 Themes and subthemes**

### **2.12.1 Theme: medical perspectives predominate**

Descriptions of the personal perspective or direct experience of patients were meagre in terms of experiences of dysphagia or choking. Clinical symptoms were presented in the cross-sectional studies and case reports, but psychosocial aspects were not evident. In the studies reviewed, descriptions of the impact of mealtime difficulties on general wellbeing and quality of life were not included and there was little information on the sequelae of dysphagia and choking in terms of physical and mental wellbeing.

#### **2.12.1.1 Absence of patients' report of difficulties**

The studies lacked detail on how the mealtime difficulties were identified and experienced. Self-report of swallowing difficulty was mentioned only briefly in the case reports and with little elaboration (Bhat et al., 2010, Chen et al., 2015, Crouse et al., 2017).

Concerns identified by patients included:

- 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),
- feeling unable to eat (Cicala et al., 2019, Lin et al., 2012).
- complaints of sialorrhea (Osman and Devadas, 2016, Sagar et al., 2005),
- concerns regarding tremor (Leopold, 1996).
- concerns regarding coughing (Chen et al., 2015, Dziewas et al., 2007, Nieves et al., 2007, Tang and Hsieh, 2010).
- difficulty chewing (Leopold, 1996)
- difficulties swallowing medication (Cicala et al., 2019, Gregory et al., 1992, Guthrie et al., 2015, Hemsley et al., 2019).

Studies also identified more general concerns relating to mealtime difficulties:

- 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).

The presence of a mental health condition was considered to have influence on the patient's ability to identify and self-report concerns (Crouse et al., 2017, Guthrie et al., 2012, Guthrie and Stansfield, 2017). Specific examples included delusions, phobias, and anxieties affecting patients' levels of insight (Chen et al., 2015, Guthrie et al., 2012, Hwang et al., 2010, Osman and Devadas, 2016). General aspects of mental illness were also presented as inhibiting self-report, for example manic, psychotic, or agitated presentations (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).

Three studies presented details of staff insights and reflections of how patients experienced difficulties at mealtimes (Guthrie et al., 2012, Guthrie and Stansfield, 2017, Hemsley et al., 2019) and in one study a patient report was invited (Chen et al., 2015). All other studies focussed on clinicians' perspectives centred on their observations of impairments in swallowing.

#### **2.12.1.2 Brief reporting of emotions associated with mealtime difficulties**

The experiences of mealtime difficulties, dysphagia and choking incidents were reported to be associated with emotional distress in 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). Other authors described how the patient appeared embarrassed by their difficulties at mealtimes (Guthrie and Stansfield, 2017, Hemsley et al., 2019) but this was only briefly mentioned. Only one case report presented the patient's voice verbatim: "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 p.3). This was however, subsequently contradicted by the clinician's different perception of significant distress in this patient.

A number of studies highlighted the presence of anxiety in patients concerned about their ability to eat, drink and swallow safely (Gregory et al., 1992, Guthrie et al., 2015, Hemsley et al., 2019, Hsieh et al., 1986, McManus, 2001, Mendhekar and Agarwal,

2010). Two studies suggested that minor incidents such as coughing were less likely to prompt anxiety or concern (Lin et al., 2012; Yim and Chong, 2009). The fluctuating nature of the mental illness, environmental distractions, lack of self-awareness, and difficulties retaining information were described as limiting the patients' ability to understand and then report mealtime difficulties. Inconsistent reporting by staff in one study was described, even for patients who had experienced severe choking incidents (Guthrie and Stansfield, 2017).

Although one study reported how a family member had supported the patient in identifying mealtime difficulties (Crouse et al., 2017), in four other studies the caregivers (staff members) had supported the patient to discuss mealtime concerns (Guthrie et al., 2015, Guthrie et al., 2012, Guthrie and Stansfield, 2017, Hemsley et al., 2019). The staff's concerns and continuing anxiety about risk of choking contrasted with the patients' attitudes: patients were reported to be more complacent and less aware of the potential implications of dysphagia and choking (Guthrie et al., 2015, Guthrie and Stansfield, 2017, Hemsley et al., 2019). Patient inclusion in relation to assessment and intervention was discussed as desirable but uncommon (Corcoran and Walsh, 2003, Fioritti et al., 1997, Guthrie et al., 2015, Hemsley et al., 2019, McManus, 2001; Yim and Chong, 2009).

### **2.12.2 Theme: lack of patient insights on influencing factors for mealtime difficulties.**

This theme captured the absence of inclusive approaches and lack of consultation with patients to understand their perceptions of dysphagia and choking. Mental health, behaviours and environmental aspects were mentioned briefly but physiological observations and assessments predominated.

#### **2.12.2.1 Mental health and swallowing**

Deterioration in mental health was linked to increased likelihood of choking incidents for inpatients. Studies highlighted 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). Hwang et al., (2010) also identified poor self-care as a factor in deteriorating mealtime skills. No direct patient descriptions of how mental health affected their personal mealtime experiences were evident in any of the studies.

All the studies included in this review provided findings on the impact of medication on swallowing and mealtime difficulties. Clinical features associated with antipsychotic medications were highlighted, with side effects reported to include extra-pyramidal symptoms, tardive dyskinesia or dystonia. However, descriptions of the consequences for the patient on their quality of life at mealtimes were scant.

#### **2.12.2.2 Mealtime behaviours causing concern**

Three studies reviewed suggested that behavioural aspects of mental health deterioration could contribute to mealtime difficulties affecting safety in swallowing and risk of choking (Aldridge and Taylor, 2012, Cicala et al., 2019, Fioritti et al., 1997). Cramming and bolting (i.e. fast paced eating styles) were mentioned as concerns (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). One study related this to the effect of institutionalisation and staff pressures (Bazemore et al., 1991). As for the previous theme, no patients' personal insights were evident in any studies, the information on behaviours was presented primarily from psychiatric and other medical staff perspectives.

#### **2.12.2.3 Influence of mealtime environment and social aspects**

The studies focused primarily on clinical descriptions of physiological aspects of mealtime difficulties. For a few studies, the context of the mealtime was briefly considered (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). These descriptions included mention of environmental and social aspects and how patients related to other patients, but only as reported by staff

(Guthrie et al., 2012, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Hemsley et al., 2019). In these few papers there was also acknowledgement by staff of patients' fatigue and the influence of institutional routines and pressures on the long-term wards.

### **2.12.3 Theme: levels of patient inclusion in decision making**

This review sought to elicit information on how patients experienced mealtime difficulties and to understand their insights. Descriptions of patient involvement in assessment and interventions for mealtime difficulties were scant with only three studies suggesting patients were involved in assessment of swallowing (Aldridge and Taylor, 2012, Chen et al., 2015, Regan et al., 2006). One described including patient views in discussions about medication review (Nieves et al., 2007).

#### **2.12.3.1 Lack of patient involvement in dysphagia assessment**

The studies seldom described levels of patients' capacity and their ability to communicate and self-advocate. Clinicians experienced difficulties in attempting to engage the patient in discussion about swallowing difficulty (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). Two papers explored issues around gaining consent and establishing capacity (Guthrie et al., 2012, Osman and Devadas, 2016). One study reported patients contributing to discussions around risk of choking (Hemsley et al. 2019); but others presented descriptions of choking based entirely on staff perceptions of patients' difficulties (Guthrie et al., 2015, Guthrie and Stansfield, 2017).

#### **2.12.3.2 Lack of inclusion in decisions around intervention**

Three studies presented descriptions of staff providing support around developing patient insights into mealtime difficulties (Fioritti et al., 1997, Hemsley et al., 2019, Kulkarni et al., 2017). Studies raised issues around facilitating patient understanding and agreeing adaptation of meal choices to mitigate risk (Aldridge and Taylor, 2012, Guthrie et al., 2012, Hemsley et al., 2019). Occasional reference was made to teaching swallow modification techniques to patients (Dziawas et al., 2007, Kulkarni

et al., 2017, Leopold, 1996, Osman and Devadas, 2016, Tang and Hsieh, 2010) and four studies suggested non-oral feeding (Corcoran and Walsh, 2003, Gregory et al., 1992, McManus, 2001, Sagar et al., 2005). There were no descriptions of the outcomes of these interventions on patients' mental wellbeing.

Interventions to promote mealtime safety were aimed more at staff on the wards with only three offering details of any patient involvement (Bazemore et al., 1991, Guthrie and Stansfield, 2017, McManus, 2001). The impact of restrictions on mealtime choices, and the implications of being closely monitored when eating, were not widely considered in terms of the impact on patient wellbeing and recovery. Three studies acknowledged that outcome measures and evaluation received limited attention (Aldridge and Taylor, 2012, Bazemore et al., 1991, Kulkarni et al., 2017).

Four studies described the importance of support from staff as caregivers on the wards (Crouse et al., 2017, Guthrie et al., 2015, Guthrie and Stansfield, 2017, Tang and Hsieh, 2010). Familiar staff were better able to understand and advocate for patients who struggled in terms of insight and retention of information and guidance on dysphagia or risk of choking (Guthrie and Stansfield, 2017). Wider inclusion of patients, families and support staff was presented as helpful in mitigating risks and promoting safer behaviours at mealtimes (Fioritti et al., 1997, Guthrie and Stansfield, 2017, Hemsley et al., 2019, Kulkarni et al., 2017, Nieves et al., 2007, Osman and Devadas, 2016, Tang and Hsieh, 2010, Yim and Chong, 2009,) but details and outcome measures were again not described.

### **2.13 Discussion**

The case reports, literature reviews, cohort and cross-sectional studies included in this review were diverse in terms of patients' primary diagnoses and swallowing concerns. The settings were predominately inpatient wards and clinical perspectives were presented focussed on impairment rather than function or impact. This review found scant information on patient self-reports of dysphagia or choking and there



was an absence of patient and staff insights regarding the impact of dysphagia on the mealtime experience.

The studies offered clinical descriptions of physiological aspects of mealtime difficulties and highlighted the impact of medication on the patients' ability to swallow effectively. Assessments described in the studies included instrumental approaches (e.g. videofluoroscopy) which do not replicate the mealtime context and may be difficult for patients to tolerate. The absence of information regarding patient reports and their understanding of mealtime difficulties is a concern and surprising in light of current national guidance around person centred approaches (N.H.S. England, 2023). A deeper understanding of how mealtime difficulties affect the person's mental and physical wellbeing is important for offering appropriate support and promoting their recovery. The review suggested a need for better understanding of patients' emotional responses to mealtimes and swallowing difficulties and how these may be interlinked with their mental health.

Based on this review, recognising and identifying mealtime difficulties appears to be the remit of staff on the ward and the patient is unlikely to raise any concerns unless directly supported by staff. The insights of family or partners were not represented in the studies, and support staff were more likely to highlight concerns and offer support. Potential influencing factors were framed in terms of impairment, and defined by medical assessment and observations. This linked with descriptions of how medication and mental health diagnosis overshadowed any consideration of potential other influences. Wider concerns regarding the consequences of mealtime difficulties were not presented but occasionally issues concerning the mealtime environment and behavioural aspects were identified (by staff rather than by patients). For example, fast eating was a common issue described in the case studies, but the underlying causes for this received little attention. Overall, patient insight was not considered or sought during assessment and intervention. The shared decision making advocated in clinical guidance (Charlton, 2000, Marjadi et al., 2023) was not represented in the studies - adaptations and restrictions to mealtime choices were imposed but efficacy in terms of outcomes and quality of life were not considered.

## **2.14 Strengths and limitations**

This review was comprehensive and thorough, identifying 31 eligible papers for analysis. Following guidance ensured the process was robust and transparent (Braun and Clarke, 2022, Cooper, 2019, Moher et al., 2009, Whitemore and Knafl, 2005). Update searches repeating the search strategy for the same databases were conducted in November 2023 but identified no additional eligible papers.

The search for eligible papers was limited by an absence of indexing terms and keywords matching the search terms. This further confirmed the lack of research attention to this topic. Therefore, manual citation searching was implemented to address this limitation. The feasibility of searching is discussed by Booth (2010) who advises that minimisation of bias is the priority and that comprehensiveness may never be achievable. In addition, a clear and transparent presentation of process (e.g. Prisma diagram) will inform the reader of any potential for bias or weakness of search strategy. To promote clarity and replicability, this review reported on process and findings including charting of characteristics and details of thematic analysis.

Inclusion of single case studies and single site cohorts may reduce transferability (Snilstveit et al., 2016) but this exploratory review sought to integrate all information on this topic to understand the need for further research directions. In this review no grey literature or studies not in English were included due to time restraints and feasibility. The studies included were sufficient to offer an overview of current evidence and to direct the need for further research.

Quality appraisal was completed by two raters independently. The appraisal of the researcher's own papers was conducted by the supervisors to ensure independent review (Guthrie, et al., 2012, Guthrie et al., 2014, Guthrie and Stansfield, 2017). Quality assessment using QATSDD (Sirriyeh et al., 2012) evaluated the evidence and synthesised the diverse findings. The quality of the evidence located was poor overall due to the number of case reports, absence of robust studies and lack of relevance to patient perspectives. The findings of this integrative review were published following blinded peer review for an academic journal further confirming the trustworthiness of process (Guthrie, et al., 2023).

To ensure transparent and rigorous process the thematic analysis was led by the researcher but supported by regular discussion and review in supervision (Whittemore and Knafl, 2005). The limited number of studies retrieved restricted the amount of information for analysis. There was scant information conforming directly to the topic of interest. The medicalised view presented in the studies substantiated the concerns that patient voice is not heard in dysphagia assessment and wider decision making around mealtime difficulties for this population. Discussion of the impact of restrictions and adaptations was not found, nor consideration of the efficacy of these and other staff led interventions when implemented. The themes were identified using reflexive thematic analysis by the researcher drawing on extensive experience as an SLT working with adults with non-organic mental illness. The overarching and sub themes reflect this influence and to address this limitation the findings of the review were presented to the service user groups for comment and moderation to discuss wider relevance.

Publication bias may be an unknown limitation on available evidence. Whilst this has been highlighted in quantitative studies this is also a concern for qualitative research (Petticrew et al., 2008). This review concerned an area of neglected interest and a marginalised population. The medical perspectives presented in the studies are likely to have been influenced by publishing constraints and journal conventions. The majority of the patients were living in inpatient accommodation which may account for the lack of information regarding perspectives of family, partners, and wider social relationships.

### **2.15 Implications for further research**

Patient accounts of mealtime difficulties, dysphagia and risk of choking have received little attention in research to date. Current research presents aspects of medical assessment and treatment for dysphagia without consideration of patient perspectives or shared decision making. The potential psychosocial influences at mealtimes which may exacerbate dysphagia and choking for adults with non-organic mental illness are not reported. As patients move back into community life the psychosocial aspects of mealtimes need to be understood and included in assessment and planning to support sustainable treatment recommendations and

recovery (Saraceno and Caldas de Almeida, 2022). The consequences of emotional arousal, behavioural changes, and other aspects of living on an inpatient mental health ward may be important influences on the person's wellbeing and safety at mealtimes and these warrant further investigation.

## Chapter 3 Methodology

*The importance of understanding people's perspectives in the context of the conditions and circumstances of their lives. (Ormston, et al., 2014. p.22).*

### 3.1 Introduction

This chapter outlines the assumptions and foundations of this PhD study. The absence of patient voices in the existing research was a primary concern in determining the adoption of a pragmatic approach and Thorne's interpretive description process for applied healthcare research (Thorne, 2016). The sections below describe the decision-making process in seeking the most appropriate approach to address the gap in knowledge suggested by the literature review.

Establishing the underlying assumptions and beliefs of the researcher is recognised as essential for good practice directing consistent, structured and situated research (Crotty, 1998). Such reflexivity is integral to achieving transparency supporting understanding of the interaction of researcher and researched. Reflections are presented throughout this thesis to highlight the researcher's perspective and assumptions so that the reader may appraise the study process and findings in light of the researcher's personal situation, background, and experience. This chapter identifies the ontological and epistemological positioning of the researcher and then describes the methodological decision-making processes, how they align to this researcher's worldview, and how they directed this exploratory qualitative study. The researcher's clinical perspective motivated the interest in exploring, understanding, and developing the evidence base on the topic of inpatient mealtimes. Parallel clinician and researcher perspectives are described across the conceptual levels. Quality criteria for the choices made within the pragmatic approach are discussed to inform evaluation of trustworthiness across the stages of the study. The chapter then considers the ethical aspects of the study and gives an overview of the method selected.

The different conceptual levels are identified below highlighting the relationship between the levels in relation to this PhD study (table 10).

### 3.2 Reflection on researcher's positionality

My position as a white middle-class female SLT has shaped my experiences working with adults on mental health wards both consciously and subconsciously. Many years of working with service users, inpatients and their caregivers have developed my interests in communication difficulties and in understanding individual experiences of mental illness. Supporting others to express their views is central to my working life and this has been both a distraction and a help throughout the timeline of this PhD. Diverting from a purely clinical focus on assessment of symptoms and planning interventions to follow a more open minded and receptive researcher's role has been challenging. Exploring the different theoretical standpoints has been useful and has informed my understanding of how to explore and give voice to issues raised by participants. I have developed insight into my own views and experiences aiming to describe personal bias and influence on study processes and findings.

Braun and Clarke's guidance offered a useful overview showing how theoretical terms often related to a continuum or spectrum and describing how clusters of ideas were similar or contradictory. Crotty's outline of the hierarchy of elements was also helpful in determining the relationship between the levels. Using a graphic was a useful prompt to map the sections across the conceptual levels. Reading Thorne's work allowed me to combine and value the clinician and researcher roles based on a pragmatic orientation and the values of interpretive description.

### 3.3 Definitions

Definitions of the key terms in establishing the researcher's position are captured by Denzin and Lincoln (2003):

"The gendered, multiculturally situated researcher approaches the world with a set of ideas, a framework (theory, ontology) that specifies a set of questions (epistemology) that he or she examines in specific ways (methodology, analysis) ... every researcher speaks from within a distinct interpretive community that configures, in its specific way, the multicultural gendered components of the research act". (Denzin and Lincoln, 2003 p.30).

The above can be configured as a scaffold (Crotty, 1998) to show the relationships between conceptual levels underpinning the development of the research process. How these components relate to the present PhD study are shown below:

Component	Key question	Relevance to this study	Related task or activity
Ontology	What is the reality?	Understanding through others.	Focus on the event: patients' mealtimes on inpatient wards.
Epistemology	What is known, how is it known?	Constructionism.	Seeking understanding of the experience of mealtimes.
Theoretical perspective	Which orientation underpins the acquisition of knowledge about this?	Interpretive approach.	Focus on interpretation through the patients' insights.
Methodology	What procedure(s) can be used to acquire knowledge about this?	Qualitative research, reflexivity, pragmatic approach using interpretive description.	Seeking the patients' voice. Focus on application to practice.
Method	What tools can be used to acquire knowledge about this?	One-to-one in-depth interviews co-designed by service users.	Supporting patient involvement and communication.

**Table 10 Scaffolding the basic 'components' of the research process**

### 3.3.1 Ontology

Ontology is summarized by Braun and Clarke as referring to “theories about the nature of reality or being” (Braun and Clarke, 2022 p.166). The healthcare researcher’s understanding of the nature of reality is constantly challenged and adapted by personal and clinical experiences. There is an accepted convention of an objective, single truth reality in the medical textbooks of anatomy and physiology (realism) but practice constantly shapes healthcare clinicians’ subjective knowledge and understanding through growing experience of individual patients and procedures. Truth and meaning for this practising clinician researcher are thus filtered, situated, and contextualised leading to uncertainty and subjectivity (relativism). This latter belief directed the route of this PhD study - the researcher is situated in, acknowledges and values context and subjectivity.

### 3.3.2 Epistemology

Epistemology can be summarized as the “assumptions about what constitutes meaningful and valid knowledge and how such knowledge can and should be generated” (Braun and Clarke, 2022 p.175). It includes the relationship between the researcher and the knowledge being sought (Denzin and Lincoln, 2003). Ways of knowing for healthcare are accessed through different routes at different stages of developing practice and clinical knowledge. To achieve knowledge in healthcare initially, novice clinicians will consult empirical studies and teaching of accepted common understandings, with randomized control test studies considered the ‘gold standard’ of evidence (Ebbels, 2017). However learning and wider understanding will be continually adjusted by more experienced practitioners in light of their professional experiences, developing intuition and sensitivity to variation such as the patient’s personal situation, needs, and choices (Greenhalgh et al., 2014, Thorne, 2016).

The work by Sackett (1997) describing the ‘triad of evidence-based practice’ captures this as a three-way basis of knowledge acquisition leading to inclusive, informed, and balanced decision making. More recently the work by Greenhalgh et al., (2014) has updated and reinvigorated this earlier work to campaign for “real evidence based medicine”. This places patients at the heart of decision making with greater recognition of the individualisation needed for each person’s circumstances and choices. SLT and other healthcare practitioners have followed this lead in how they acquire and perceive knowledge and this is now captured in Health and Care Professions Council (HCPC) standards and summarized on RCSLT guidance webpages (Royal College of Speech and Language Therapists, 2022). This focus on the applied use of the knowledge explored, conforms to the pragmatic approach which underpins and directs ‘Interpretive description’ (Thorne et al., 2016).

### 3.3.3 Methodology

This term relates to how the clinician researcher seeks to understand and interpret the issues in healthcare, how to explore and explain using the most effective and robust processes. Thorne (2016) advises that by maintaining an applied orientation, the researcher’s focus remains on describing the data and then ensuring that



interpretation follows from this. Thorne (2020) discusses the moral purpose in the quest for knowledge i.e. that it must relate to patient benefit. Thorne (2016) advocates seeking confirmation of a gap in knowledge, established through literature review, and where relevance is directed by clinical experience and perception of patient need. Transparency is integral in this, allowing the reader to understand the issues around the research context through describing the individual patients or settings presented, to allow others to consider transferability to their own situation. Quantitative terms (such as ‘validity’) relating to quality measures are replaced by values such as trustworthiness, credibility and authenticity (Denzin and Lincoln, 2003, Thorne, 2016). The applied healthcare researcher also seeks feasibility and acceptability (Greenhalgh et al., 2014). Researchers should justify their research process by locating their assumptions against these components – knowledge generated from a study is then perceived as not only “adequate and legitimate” (Crotty, 1998 p.8), but also plausible and helpful.

### **3.4 Considering paradigms**

The nature of (and the distinctions between) paradigms have been a source of great debate in recent decades (Bryman, 2016, Lincoln and Guba, 2003, Patton, 2002). The recent pandemic and crisis in healthcare provision stimulated and accelerated thinking on the relevance of paradigms in applied healthcare (Greenhalgh and Engebretsen, 2022). The term “paradigm” has been defined as:

“The net that contains the researcher’s epistemological, ontological and methodological premises ... an interpretive framework, a basic set of beliefs that guides action” (Denzin and Lincoln, 2003 p.33).

Table 10 above presents the relationships between the components or ‘premises’, mapping each to show the orientation of the current PhD study and the assumptions of the researcher. To design the approach for this study different paradigms and theoretical perspectives were considered and their relevance is discussed below.

### 3.4.1 Positivist vs non-positivist

Positivism has been described in varying ways but is generally accepted as a philosophical position that advocates objective, value-free research looking to generate and test out hypotheses (Braun and Clarke, 2022). Positivist researchers aim to conduct research through an impartial, objective lens, studying data to determine a single reality and thus derive general laws (Ormston et al., 2014). This has been criticised for offering a narrow and superficial focus lacking the personalised detail needed for effective healthcare practice (Bryman, 2016, Greenhalgh et al., 2014, Thorne, 2016).

In contrast to positivism, constructionist researchers reject the idea of defining fixed truths or rules governing the social world – all knowledge is gained through others' interpretations and perceptions (Ormston et al., 2014, Bryman, 2016). Crotty (1998) summarises this as:

“humanly fashioned ways of seeing things whose processes we need to explore and which we can only come to understand through a similar process of meaning making” (Crotty, 1998 p.9)

Crotty suggests that this may or may not involve the object of interest, but proposes that constructionism can allow for partnership and interaction in the generation of meaning (Crotty, 1998). The meaning derived by the researcher may be shaped by “primordial archetypes we locate within our collective unconscious” (Crotty, 1998 p.9) or by more conscious beliefs and personal experiences. Interpretation is situated in, and centred on, the people involved in the research and derived from their interactions. These are the product of historical, cultural and other background influences (Cresswell, 2018). Incorporating reflexivity allows the researcher's influences to be made explicit.

The previous binary division between positivist and constructionist has been further challenged by Denzin and Lincoln, (2003). The boundaries of each paradigm are no longer perceived as impermeable as they continue to be redrawn to reflect the inclusion of wider or ‘softer’ standpoints or worldviews (Cresswell, 2018, Tashakkori and Creswell, 2007). A third option “pragmatic” is now offered for research aimed at informing social and healthcare practice (Cresswell, 2018). Deriving from the

philosophical thinking adopted and developed during the 20<sup>th</sup> century (Campbell, 2015, Greenhalgh and Engebretsen, 2022, Houghton et al., 2012, Patton, 2002) this directs the focus to practical outcomes and steers research towards clinical impact. This is typically at individual rather than a more societal level and thus turns away from the theorizing and abstraction of previous frameworks. In pragmatically oriented research, attention is not framed by a single philosophical direction or assumption but researchers acknowledge the importance of context: truth is seen in terms of usefulness (Greenhalgh and Engebretsen, 2022). The focus is on finding the most appropriate techniques available, offering wider freedom of choice in methodologies, to reach the best understanding of the research topic identified. Patton (2002) describes how he initiated this way of structuring research in order to:

“engage in straightforward qualitative inquiry of this kind without locating it within some major philosophical, ontological, or epistemological tradition. This is not to deny the importance and influence of such traditions, and doctoral students ought to understand how mindsets and perspectives affect inquiry, but grassroots practitioners have concrete questions and information needs that can be answered in straightforward ways through qualitative inquiry” (Patton, 2002 p.3).

The challenge is then to maintain quality and trustworthiness in the face of challengers from the positivist/realist perspectives who would critique the perceived bias and subjective standpoint. Rather, this ‘bias’ is seen in pragmatic (and in qualitative approaches generally) as offering extra information and thus to be valued and celebrated. The inside knowledge and standpoints of the researcher offers greater resource and depth for analysis and with reflexivity can be included in the exploration of phenomena (Thorne, 2016). The inside knowledge and standpoint of the research participants are equally sought out and valued.

Interpretive description follows this pragmatic perspective (Marrocco and El-Masri, 2021). On the first page of the introduction, Thorne (2016) summarises:

“for the clinician researchers the entire point of questing for knowledge was to apply it to real human beings caught in complex and difficult human health

problems so that their quality of life could be improved in some manner” (Thorne, 2016 p.25).

This focus contrasts with that of social scientists seeking to inform and develop theorising relating to groups and to create generalisations summarising human experience (Goodwin et al., 2023, Teodoro et al., 2018). The interpretive descriptive approach consistently directs attention back to the individual and the interaction with the researcher. By understanding variations, patterns and themes in data, clinicians seek to apply their research findings to unique individual situations and concerns (Thorne, 2016).

Braun and Clarke (2022) describe the complexity of discriminating between different theoretical assumptions (Braun and Clarke, 2022 p.156). Their reflexive thematic approach (RTA) offers a structure to explore a situated experience rather than seeking to identify the ‘singular truth’ championed in positivist approaches. They capture their perspective as “mostly relativist-constructionist in orientation” (Braun and Clarke, 2022 p.188) and define ‘interpretation’ as the process of unpacking of meaning in data and exploring the wider context to better understand participants’ meanings.

### **3.4.2 Quantitative vs qualitative research processes**

The terms relating to these conceptual levels is debated by Crotty (1998). He suggests that reducing quantitative and qualitative to a binary distinction allied to theoretical or epistemological perspectives is neither helpful nor justifiable (Crotty, 1998). Researchers may access both options to serve different purposes but will need to consider and justify this in light of their overall approach, theoretical assumptions and purpose in research (Patton, 2002).

Quantitative approaches offering numerically based summaries, experimentation, and evaluations of healthcare, remain prominent in many published studies. Typically based on positivist or realist standpoints, these approaches value objectivity and attempt to control and remove bias from the researcher and/or other variables. Seeking to find cause-effect relationships as a “singular truth”, quantitative researchers aspire to finding generalizable, higher-level understanding by

assimilating and aggregating large numbers and considering how these represent a wider population.

Qualitative research is an umbrella term covering a wide range of approaches which have common ground (Braun and Clarke, 2022). These authors offer the term “qualitative sensibility” to describe the attributes of the qualitative researcher which include at heart “a desire for understanding that is about nuance, complexity and even contradiction” (Braun and Clarke, 2022 p.7). This echoes Thorne’s description of the constant need to adapt knowledge in healthcare: the qualitative researcher seeks more sensitive and detailed personalized knowledge to understand and interpret the individual patient’s strengths and needs (Thorne, 2020). By acknowledging, describing, and valuing the researcher’s perspective, reflexivity as a primary tool in qualitative approaches has grown in acceptance and is integral to making a personalised interpretation of findings.

### **3.5 Theoretical perspectives**

The value of the traditional allegiance to a theoretical position is reiterated by Crotty who reminds the researcher that a robust study needs to have solid foundation and clear philosophical stance. The theoretical position of the researcher anchors the study in terms of methodology and objectives “providing a context for the purpose and grounding its logic and criteria” (Crotty, 1998 p.3). Although interpretive description follows the pragmatic approach and is directed towards applied outcomes as described above, the researcher can determine in Thorne’s (2016) guidance an underlying compatibility with social constructionism and subjective, relativist traditions.

#### **3.5.1 Interpretive approaches**

In determining the relevant and most appropriate approach to make sense of qualitative data, the researcher is confronted by a multiplicity of methodological options and practices with different evaluation criteria (Denzin and Lincoln, 2003). Interpretivism rejects positivism and underpins many of the qualitative research approaches placing:

“emphasis and value on human interpretation of the social world and the significance of both participants’ and the investigator’s interpretations and understandings of the phenomenon being studied” (Ormston et al., 2014 p.11).

Interpretive description has evolved since Thorne’s initial guidance as it develops in its use by nursing and other disciplines (Goodwin et al., 2023, Marrocco and El-Masri, 2021, Teodoro et al., 2018). Based around aims to raise awareness of phenomena and develop insights around complex clinical issues, it offers a relevant methodology for applied researchers. It is particularly appropriate for research seeking to understand perspectives and experiences of patients and their caregivers (Brewer et al., 2014, Teodoro et al., 2018).

Interpretive description is based on foundations of existing disciplinary knowledge and practice. Practitioners and researchers draw on their multiple experiences, knowledge bases, and professional judgement in interpreting new individual presentations seeking insight into the person’s data and maintaining an inductive approach. As an approach it allows researchers to combine elements of different methodologies but this can be challenging due to lack of specific structure or guidance (Marrocco and El-Masri, 2021). The process of analysis needs to reconsider assumptions at every level to ensure a move beyond what is already known and avoid narrow, premature, or obvious conclusions (Chiu et al., 2022, Marrocco and El-Masri, 2021).

In essence, researchers following the Thorne (2016) interpretive description approach:

- value the clinical insight gained from subjective and experiential knowledge,
- pay attention to the context in which the research occurs, although the issues being researched may not be unique to one context,
- acknowledge the inseparability between the knower and known, and the way the researcher and participant influence each other,
- acknowledge that human experience is socially constructed and can involve many contradictory realities, and

- are attentive to the participants' ethical rights and comfort, and undertake research in the most naturalistic setting possible (Brewer et al., 2014).

The degree to which explanation is included in interpretive descriptive studies varies between the proponents of the approach. Current consensus suggests that explanation is not the aim; rather a rich, in-depth exploratory description of data is to be produced with a close interpretation of this as a phenomenon revealing associations, connections, and patterns (Teodoro et al., 2018). This is to be offered as 'interpretive description' of data so that others may understand and apply relevant details to their own practice.

In summary, interpretive description offers the most appropriate perspective for this PhD approach as it allows:

- a functional and applied focus,
- exploration of quality of life and hope in chronic conditions,
- flexibility in choice of data collection and analysis,
- an inductive, and potentially transformative approach appropriate for marginalized, vulnerable populations,
- acknowledgement of the researcher's perspective and existing knowledge,
- co-construction of knowledge by researcher and participants,
- consideration of common patterns of meaning but also outlier information and variation.

### **3.5.2 Defining the research problem**

The research problem for this PhD study was identified and developed through clinical experience and professional curiosity with disciplinary practice as the 'driving force' for determining the research question (Marrocco and El-Masri, 2021, Thorne et al., 2016). The results of the integrative literature review (chapter 2), added to issues raised in the service user group discussions, refined the focus (Cresswell, 2018) perceiving:

- a neglected topic or void in the literature,
- a need to lift up the voice of marginalized participants,

- a ‘real-life’ problem found in the work-place, the home, and/or the community.

Focused on an area lacking information, little existing research, and limited awareness in clinicians, this study explored the phenomenon of mealtimes as a new topic for this population (working age adults with non-organic mental illness) in a specific setting (inpatient mental health wards).

Seeking the participants’ insights and accounts of their experiences aimed to bring greater and more holistic understanding of the different perspectives of the mealtime on inpatient wards. This corresponds with Thorne’s (2016) definition of interpretive description and its integration with informing practice as a guiding principle. The intended focus was on the participants’ lived experiences but the researcher’s interrelatedness as an “insider” was acknowledged and described through reflexivity (Thorne, 2016). The findings are the researcher’s interpretation of participants’ insights through reflexive thematic analysis, the implications for practice are presented at a superordinate level of interpretation reflecting the wider purpose of the study: to seek greater understanding of patients’ experiences of inpatient mealtimes and through synthesis consider transferability and the implications for recovery in mental health settings.

### **3.6 Methodology**

With increasing options for structuring reflexive approaches, the qualitative researcher’s toolkit has become more formalized and robust. Reflexive thematic analysis offers structure and transparency with either inductive or deductive analysis (Braun and Clarke, 2022).

In this PhD project, the research interest was initially directed towards an exploratory purpose given the scant nature of existing research with people with mental illness around mealtime experience and related concerns. Further analysis building on codes, themes and reflection would lead to greater depth of understanding and suggest the direction of future more explanatory work (see Discussion, chapter 8). Braun and Clarke (2022) describe a continuum linking between these two points of orientation: researchers may move from semantic to more latent understanding, and from description of experiences to a more critical and transformative focus.



### **3.6.1 Inductive vs deductive**

Qualitative researchers are likely to follow inductive processes where the data is leading the analysis in a 'bottom-up' process to derive new understanding with reduced influence from established knowledge bases (Bryman, 2016). Some argue that this is oversimplifying as researchers will always bring knowledge and assumptions to the study (whether consciously or otherwise): the process of analysis will therefore always be framed by prior experiences and personal influences (Ormston et al., 2014). Deductive approaches are more allied to positivist traditions and seek to test out hypotheses and theories from 'top-down' perspectives exploring the data as 'evidence'. This PhD involved conducting inductive analysis but acknowledged the researcher's prior experience and culture through reflexivity. The literature review did not suggest concepts for a relevant framework to support analysis informed by existing research. Rather, it showed the gap in knowledge and lack of patient perspectives indicating the need for an inductive approach.

### **3.6.2 Trustworthiness**

As qualitative methodologies have developed, quality checks have been discussed and advanced to determine the trustworthiness of qualitative studies. Considerations of credibility, transferability, dependability, confirmability have replaced the vocabulary from quantitative approaches such as validity, reliability, objectivity (Bryman, 2016, Patton, 2002, Lincoln et al., 2011). More recent reviews of qualitative methods have drawn attention to the need to retain an 'ethic of transparency', including explicit details regarding contextualization and clarity of 'approach to inquiry' (Levitt et al., 2018). Quality checks relate essentially to an evaluation of rigour and coherence across study aims, design, analysis and conclusions determining a clear sense of direction related to the research goal.

The EQUATOR guidance includes checklists relevant to this study including Standards for Reporting of Qualitative Research (SRQR) (O'Brien et al., 2014) and Consolidated criteria for Reporting Qualitative studies (COREQ) (Tong et al., 2007). The COREQ is designed for research using interviews or focus groups specifically

and offers three domains. COREQ was thus more appropriate for this study offering more evaluation of reflexivity in this checklist and with the guiding questions offering helpful advice. This study was mapped to the three domains of the COREQ checklist and was checked against the recent quality guidance aimed at evaluating the use of reflexive thematic analysis and its congruency with the underpinning theoretical assumptions of the study (Braun and Clarke, 2019). The iterative nature of qualitative analysis is in itself an additional quality check (Levitt et al., 2018).

Triangulation is a further measure of quality in study design and conduct. The validation and reliability checks of quantitative approaches are replaced by member-checking in qualitative studies. This is advocated by approaches which seek to hear the voices of marginalized people (Janes et al., 2018, Serrant-Green, 2011) but has some issues in practical application. Bryman (2016) reports potential limitations affecting member-checking which include participant defensiveness, and reluctance to criticize or raise issues against researchers with perceived authority. The concerns for including member-checking in this study included:

- difficulties in returning to the same transient population of patients whose location, wellbeing, and capacity fluctuated,
- difficulties in accessing the same healthcare staff with their own pressures, changing work environments and COVID-19 restrictions,
- difficulties in patients' understanding of the reasons for confirming previous interview conversations – the risk of coercion, suggestibility and compliance or defensiveness and rejection of data. The researcher may be perceived as 'staff' and 'authority' and thus compromise attempted validation.

This study sought instead to review and confirm themes initially through 1) discussion with supervisors and 2) engagement with service user groups (HEER and SUN). This feedback was integrated throughout the study design and analysis by involving the service user group and supporting them to engage using accessible resources and inviting their comments. The discussions with these groups prompted deeper reflection and insight in the researcher developing more latent levels of interpretation.

### 3.7 Ethical considerations

The need for adherence to a strong ethical integrity is well established in research since being formally recognised in the 20<sup>th</sup> century with the Declaration of Helsinki (World Medical Association, 2022). The basic principles of beneficence, non-maleficence, autonomy, and justice have recently been updated and expanded for researchers involved in health and social care settings. Guidance now includes 15 basic principles (the additional principles relating to interventional research were not relevant to this study) and also outlines the responsibilities of researchers (Health Research Authority and the UK Health Departments, 2017). These are presented in table 11 to show how the researcher addressed each principle. The researcher's understanding and adherence to these principles were refreshed through update training in good clinical practice and reviewed in regular (monthly) supervision.

This study recruited patients who were vulnerable in terms of understanding, mental wellbeing and disempowered through living on inpatient wards under restrictions of the Mental Health Act. Gaining informed consent needed careful consideration and support for patients whose mental wellbeing, attention and capacity was likely to be affected by their current episode of mental illness. Any limitations to communication, literacy, and wider intellectual skills were recognised and accommodated throughout the study. The patient information sheet was carefully designed to offer easy read accessible format with images and further details for those who wished (appendix G). Thorne (2016) reiterates the 'fundamental premise [that participants'] interests and needs are respected' (Thorne, 2016 p.85).

Capacity to consent was considered in light of studies that highlight variation in staff skills in estimating capacity due to lack of familiarity or insight into communication difficulties (Jayes and Palmer, 2014, Jayes, et al., 2020). Recent studies have explored the skills of staff in assessing capacity of patients with "mental disorders":

"Professionals without experience of working with people with communication difficulties may make erroneous judgements about these people's mental capacity, based on inaccurate perceptions of their communication abilities, or they may conflate impaired communication with impaired decision-making capacity" (Jayes et al., 2020).

<b>Principles - ethical issues for this study</b>	<b>Actions to address these issues</b>
1 Safety: participant wellbeing.	Potential heightened anxiety in patients and pressures on staff and SLTs were considered and support offered during the interviews. Further support was signposted after the interviews.
2: Competence. 3: Scientific and ethical conduct.	Researcher updated relevant training, competence and conduct was reviewed during supervision meetings throughout the study.
4: Patient, service user and public involvement.	Local service user and caregiver groups (HEER and SUN) were consulted throughout the period of the study. Their advice and insights were incorporated into the study design and format. Dissemination of findings will also include these groups.
5: Integrity, quality and transparency. 6 and 7: Protocol and Legality.	HRA <sup>5</sup> review included protocol and full details of research study (see appendices D and E).
8: Benefits and risks.	The topics discussed (e.g. choking) had the potential to cause distress or anxiety. Participant wellbeing was carefully monitored during the interviews and support offered if required.
9: Approval.	HRA favourable review (see appendix D).
10: Information about the research. 11: Accessible findings.	The patient information sheet was designed in collaboration with the service user groups and contained easy read language, images and details of the research processes and checks.
12: Choice - capacity and consent.	Patients' capacity to understand, retain and process information, and give consent was assessed by familiar ward staff. Consent was supported by easy read information about the study and the secure systems for data storage.
13: Insurance and Indemnity.	Researcher adhered to standards and policies of University of Leeds, NHS and RCLT.
14: Respect for privacy - anonymity and confidentiality.	Confidentiality was discussed with participants along with details of secure storage arrangements for the data. Secure storage on encrypted computer systems complied with University of Leeds and NHS protocols.
15: Compliance - communication and intellectual strengths and needs.	Patients' potential limitations and difficulties in communication, intellectual skills and literacy were considered and supported with accessible resources and adaptations as needed.

**Table 11 Principles of ethical research**

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<sup>5</sup> Health research authority

Jayes' (2020) work recognises that speech and language therapists are expert in capacity assessment and in delivering information at an appropriate level for an individual's level of need (Jayes et al., 2020, Suleman and Hopper, 2016). There was also the potential for coercion or suggestibility as the patient might perceive the SLT researcher as having authority as a member of staff. The relationship between patient and the researcher as "staff" was carefully considered:

"[highlighting] a number of issues, including power relationships between the community and academic sector and issues of accessibility and mutual benefit. In practice, these issues and agendas are complex and intertwined ... Ensuring that people from all sections of society have a voice in health research requires specifically designed research" (Rugkåsa and Canvin, 2011).

### **3.7.1 Risks, burdens, benefits**

These were carefully discussed with service user groups in planning the study. They endorsed the view that the interview experience was expected to be motivating and enjoyable, offering an opportunity for participants to share their views and be heard on a matter of importance to them. Preliminary discussions on the wards and staff groups had suggested a keen level of interest and enthusiasm. Feedback to participants on the findings from the study was requested by the group members. Therefore, at the end of the study, a summary will be offered to all participants using appropriate accessible formats.

The main burden envisaged for participants in this study (patients, staff and speech and language therapists) was time and effort for the interview (estimated to be one hour). The researcher is experienced in supporting communication and has long standing experience (35 years) in understanding people with mealtime difficulties and working on inpatient wards as part of a multidisciplinary team. Interviews were conducted with sensitivity and support aiming to stimulate conversation. However, the topics discussed included 'choking' or other mealtime events which had the potential to be distressing if the participant had personal experience of these. The researcher closely observed participants for any signs of distress, discomfort, or

agitation (verbal or non-verbal) during the interview. If observed or suspected the researcher planned to offer to pause or stop the interview. If this had been the case, the interview would only resume if the participant regained composure and wished to proceed. If needed, patients would be encouraged to approach their ward staff for support and staff participants would be directed to staff wellbeing support provided by their local Occupational Health service. Ultimately, no participants exhibited any distress during the interviews, and none required such support. It was also important to consider overburdening due to COVID-19 pressures and offer sensitivity in recruitment and the interview itself (Nind et al., 2021).

Additional considerations included the researcher's awareness of and adherence to the current levels of COVID-19 restrictions and infection control requirements. Access to the wards during the pandemic was sometimes restricted and patients were faced with loss of regular activities. Staff had increased pressures and concerns from work and home, some were coping with redeployment into unfamiliar settings. Heightened infection control measures including social distancing and wearing of personal protective equipment (PPE), were followed by the researcher for in person interviews. Online interviews were offered for those participants who were comfortable with this option.

### **3.8 Method: rationale for choice of interview**

The options for collecting data on the participant insights and concerns were considered primarily in light of the aims and objectives of the study, but also took account of the researcher's position as 'insider' and clinician and the vulnerabilities of adults with mental illness.

#### **3.8.1 Data collection processes**

Table 12 below shows the options considered for data collection for this study (Braun and Clarke, 2022, Bryman, 2016, Thorne 2016). Offering one-to-one in-depth interviews allowed participants to express their ideas and concerns without influence, suggestions, or pressures from other patients or those with perceived authority. Discussions with service user groups confirmed that asking questions directly to the patients was the preferred choice.

Methods	Summary of process	Relevance to this study
Ethnographic - observation	Observing from the 'outside', exploring wider cultures and beliefs.  Seeks to present whole culture and overview.	Insider role of researcher was already established through clinical role.  Not relevant - this study sought to understand individual perspectives and variations rather than whole culture.
Case studies/series	Following an individual and their caregivers over time to describe different perspectives and experiences.	Less feasible - inpatients have variation in levels of wellbeing; patients and staff may be transient in settings; fluctuation of capacity is expected making repeated and longer term contact difficult to sustain.
Focus groups	Recruiting patients and staff to group discussions.	Not appropriate - patient access to group sessions is variable and potentially restricted. Anxiety affecting in person and online options.  Risk of dominant voices in a group setting, losing contribution from quieter and more anxious patients.
Delphi	Collating views of acknowledged experts, to reach consensus. Typically, through online repeat surveys.	Not appropriate as seeks consensus rather than focus on individual situation/variations. Patients may be reluctant or unable to engage in online format.
In-depth, one-to-one interview	Recommended option for qualitative data collection, flexible and adaptable; offers inductive analysis.	Appropriate for this study: allows individual options (online or in person choices), researcher can provide appropriate support, timing, and setting.
Options for method of analysis	Summary of process	Relevance to this PhD study
Interpretive Phenomenological Analysis	Requires researcher detachment from situation; loss of researcher perspective and experience.	Not appropriate as this study seeks to include and value clinical experience and reflexivity.
Grounded Theory	Focus is to elicit "collective consciousness" and achieve theoretical saturation.	Not appropriate due to focus on abstraction and theorising – this loses the individual perspective and experience.
Reflexive Thematic Analysis	Allows integration of researcher perspective; transparency in presenting researcher and situation.	Compatible with interpretive description and pragmatic approach.

**Table 12 Options considered for data collection**

The questions and prompts were designed using the service user groups' suggestions for topics and accessible information. It was also important to consider how prior contact or relationships may be misleading for researcher and participants:

“Clients within a healthcare or service setting tend to find it highly confusing if the same individual assumes different roles at different times and there is a significantly increased risk of coercion into participation if a prior relationship between the researcher and the clinical team is apparent.” (Thorne, 2016 p.128).

Remuneration was discussed with the service user groups resulting in a consensus that participants would be offered a shopping voucher and a certificate of participation.

Discussion in supervision reviewed recruitment strategies, the format and direction of interview questions, and the support for participants during and after the interviews to counteract the above concerns. This addressed potential concerns that the clinician's skillset and sense of familiarity may lead to misplaced confidence in leading interviews (Thorne, 2016):

“what most health professionals find when they first engage in qualitative research interviews is an uncomfortable sense of ‘nakedness’ without their usual repertoire of conversational tools” (Thorne, 2016 p.125).

### **3.8.2 Online interviews**

The advantages and disadvantages of online interviews are shown in table 13 (Davies et al., 2020, Nind et al., 2021, Pocock et al., 2021). The researcher offered participants a choice between the two methods (online or in person interviews) where feasible. To support the interpretation of the findings, the reflections considered how the interview format may have affected the participants' delivery and content (Pocock et al., 2021).



<b>Advantages</b>	<b>Disadvantages</b>
Can be conducted at home/familiar setting.	Can be difficult establishing relationship, building trust and ensuring non-verbal understanding between participant and researcher.
Allows access to wider geographical sample.	Participants may experience challenges accessing technology, may lack familiarity with online conversations, literacy skills may be limited.
Convenience factors including reduced time, travel, costs etc.	Potential difficulties for researcher in understanding context, loss of understanding and in-depth information, potential for limited recognition of distress in participant.
Easier to discuss sensitive topics and assure confidentiality if alone in room.	Technology issues and anxieties, potential for problems with connectivity, IT skills, navigating screen.
Reduced fatigue.	Confidentiality and privacy if shared space, internet security.
Infection control as no 'in person' contact.	Different demographics, potential younger bias, potential for underrepresentation of vulnerable populations.
	Potentially reduces number of spontaneous comments, turn taking may be inhibited, responses may be shorter in length and depth offering more concrete information.

**Table 13 Advantages and disadvantages of online interviews**

### **3.8.3 Sample size**

Thorne (2016) discusses sample size and limits to transferability in studies of smaller patient numbers and local settings. Qualitative research presents in-depth analysis relevant to a local setting however, with transparency of process described, other clinicians can base their thinking on the findings to consider relevance to their own situation and caseloads (Thorne, 2016). Thus, qualitative approaches can complement empirical forms of evidence by offering insights into patients' personal perspectives and experiences. Checks and balances from these insights (and referencing relevant wider research findings) allow the clinician to adopt the most relevant and useable knowledge to direct their practice (Thorne, 2016). Similarly Braun and Clarke (2022) reiterate the value of 'richness of data' in place of the concept of 'saturation' in study design.

In contrast to more empirical studies, the RTA approach for this interpretive investigation of a gap in knowledge aimed for 'information rich' data from eligible participants (Patton, 2002) to allow in-depth analysis. The size of the sample was sufficient to allow this within the restrictions of timescales and practical for RTA which is essentially led and managed by a single researcher. Smaller samples are typical in interpretive description (Teodoro et al., 2018, Thorne, 2016). As an exploratory study in a new area the number of interviews completed was feasible, it was adequate for in-depth interpretation of data and suggested areas needing further research and explanation (Ritchie et al., 2014). This was adequate for the purpose of this study - an exploratory project aiming to voice experiences of a marginalised population in an unexplored topic area (Serrant-Green, 2011).

#### **3.8.4 Recruitment**

The potential barriers to recruiting effectively in mental health settings are acknowledged; participants' understanding and interest in research may be impaired by mental illness, cognitive and/or communication difficulties. Furthermore, cultural influences may affect willingness to discuss illness and engage with professionals - factors which motivate participants to engage or withdraw may include concerns around ethnic match, age, gender and professional status of the researcher (Rugkåsa and Canvin 2011).

"it is an undisputed fact that the persons whose lives, experiences and meaning-making processes researchers are able to study in interview-based projects are those who respond positively to requests for interviews; the rest remain unknown" (Kristensen and Ravn, 2015).

Building trust, particularly with patients who are acutely mentally unwell, needs to consider anxiety levels, paranoia and perceptions of stigmatisation (Cogan et al., 2021). The potential for acquiescence (Bryman, 2016) was also considered. This was particularly relevant to the SLT group due to participant comments showing awareness of the researcher's publications and expert role in the profession.

### **3.8.5 Analysis**

Reflexive Thematic Analysis (RTA) has been developed and refined by Braun and Clarke (2022) who offer online webinars and publications describing the structured approach. Other forms of thematic analysis were considered (e.g. codebook, coding reliability), but these advocate more deductive approaches with use of pre-informed frameworks or templates. This study did not have pre-existing information to frame the analysis as described above. Instead, this study sought to actively generate codes and themes inductively to ensure the analysis avoided any sense of being restricted by prior conceptualisation. The sequence of RTA phases is listed in Methods Chapter 4 showing how the analysis was implemented.

RTA incorporates subjectivity in analysis and is led by one researcher rather than the team approach associated with other forms of thematic analysis. Using RTA is intended to be tentative - to explore the data is an open-minded process with gradual refinement of the codes and themes anchored back to the research aims and central topic of exploration (Braun and Clarke, 2022). Review and discussion in supervision brought rigour to the process and prompted deeper reflection in the researcher.

Using computer assisted qualitative data analysis (CAQDAS) allowed storage and organisation of the data with fast easy retrieval of text. NVivo software facilitated sharing of processes for discussion in supervision adding transparency. However, Braun and Clarke (2022) caution against overuse of software – there is potential for ‘lazy coding’ where researchers begin to conform to codes already listed rather than devising new codes more closely related to their developing insights into the data. This can result in lost opportunity for constructing new interpretations and insights. Discussion and review with supervisors to air and clarify the decision-making during coding ensured transparency and gave an auditable trail of reasoning and analytical processes.

### **3.8.6 Synthesis of themes across 3 groups**

In seeking methodological options for synthesis using qualitative approaches, the researcher will find resources relating to metasynthesis in literature reviews more commonly than guidance for collating findings within a single research study.

Metasynthesis aims for “conceptual reintegration of diverse findings” (Thorne, 2016 p.273) including patient perspectives and clinical wisdom. Thorne (2016) reiterates that the purpose of interpretive description is to highlight variation and show how individual experiences relate to context. The concern is that this individualisation can be lost if summarising into an overall commonality. Thorne (2020) reminds the researcher to consider absences as well as themes:

“additional critical reflection on what we have and have not got before us. What of the wider clinical world I recognize has not found its way into my study? And does that matter? What would it reflect for my clinical community if I assumed my data set was a reasonable representative of the whole?” (Thorne, 2020 p.1).

Other formats for metasynthesis seek to establish weighting and frequency counts. These can become measures of value and checks for quality but thus lean towards concepts of ‘generalisability’ and narrow down rather than open up thinking around areas of knowledge and practice.

Braun and Clarke’s (2022) approach to synthesis is covered in their discussion of reporting guidance. The focus of this phase is on deeper interpretation and includes acknowledgement of the value of subjectivity during analysis. Rigour through transparent, thorough, and iterative processes includes consideration of the ‘grounds’ for claims and conclusions, while checking that ‘inconvenient truths’ (Braun and Clarke, 2022 p.201) are not neglected in the analysis and synthesis. The synthesis moves on from earlier description of the data (semantic level) to a latent, more conceptual level, considering implications for a wider context or populations.

In addition, it is useful to consider again the EQUATOR guidance and the range of checklists relating to qualitative study quality assessment regarding synthesis. The COREQ (Tong et al., 2007) and the “Standards for reporting qualitative research” (SRQR) guidance (O’Brien et al., 2014) have limited detail in the relevant final checklist items but SRQR provides a general statement expecting a synthesis of findings to be presented in the context of existing research. The checklist ‘Enhancing transparency in reporting the synthesis of qualitative research’ (ENTREQ) (Tong et al., 2012) recommends that synthesis should:

“Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct)”. (Tong et al., 2012 p.4).

This is further discussed by Flemming and Noyes (2021) who highlight the importance of findings and synthesis showing transparency throughout. Transferability is also included on the EQUATOR checklists – the scope of application of this study will be presented in the discussion (Chapter 8) linking to the overarching interpretive descriptive approach (Thorne, 2016).

The synthesis for this PhD study brings together the main and overarching themes seeking a higher order of interpretation, integrating the themes to reach greater understanding of shared issues and concerns for mealtime experience on the wards. This follows the ‘lines of argument’ synthesis proposed by Noblit and Hare (1988) (originating in meta-ethnographic approaches) where the bigger picture is derived from abstracting beyond a basic ‘sum of parts’ (Barnett-Page and Thomas, 2009). This process must continue to integrate with researcher reflexivity as for the planning, interviewing and analysis phases. By combining and integrating the themes from the three study groups, synthesis provides examination of the accepted nature of the mealtime routines and restrictions, seeking to understand the “archeology of taken-for-granted perspectives” (Lawless and Chen, 2019 p.96).

This study followed interpretive description guidance to focus on understanding individual conditions and the importance of context. This required a synthesis that respected subjective individual experience – the patient group themes are thus presented foremost in the synthesis with the other groups’ themes subsequently considered against the patient perspectives. Following on from synthesis of themes it is also interesting to consider outliers, contradictions and absences of data (Lawless and Chen, 2019). Pressures felt as a clinician are to derive findings to inform healthcare practice, and direct strategic planning. Synthesis of the themes will therefore lead on to wider discussion of these and identify gaps in current understanding to inform the need and direction for future research around the varied influences on mealtime wellbeing.

### **3.8.7 Summary of chapter**

This chapter has presented the methodological aspects of the study. The decision making around potential options for philosophical and theoretical orientations has been described to show how the most relevant choices were selected to be consistent with the interpretive descriptive approach outlined by Thorne and colleagues. The use of reflexive thematic analysis has been shown to fit with this approach to include and value the subjectivity of the clinician researcher. Ethical aspects of this study and the evaluation of trustworthiness have also been considered in light of the researcher's position as an insider and an experienced clinician. The methodology chosen to explore this topic has been described and the following chapter will present the methods adopted for the study.

## **Chapter 4 Method**

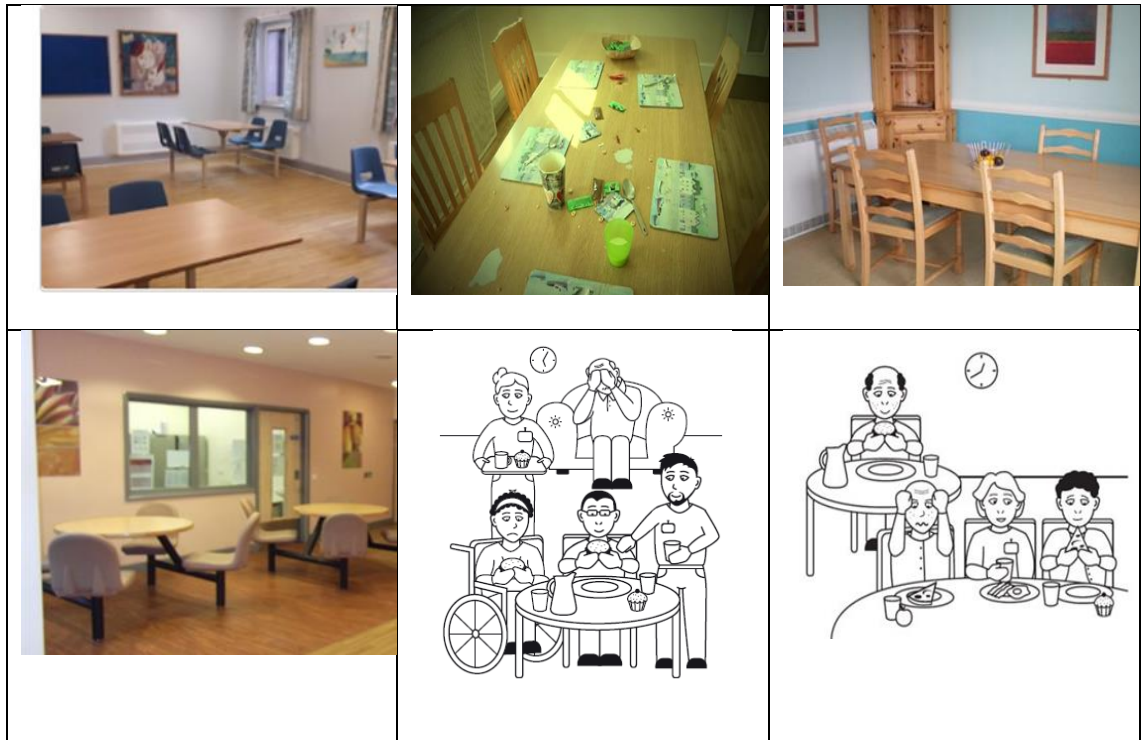
This chapter will present the working methods for the study exploring the patient experiences at inpatient mealtimes. The study design developed from initial planning with the consultation process presented below. Data collection measures are described including details of recruitment and interviewing followed by description of data analysis and synthesis methods. Ethical aspects and governance are presented at the end of this chapter. An active process of reflexivity was conducted throughout, and examples of reflection are presented to clarify the researcher's perspective. The findings from the interviews are presented in subsequent chapters.

### **4.1 Planning the study: consultation**

Following the literature review, local patient and caregiver groups (Service User Network (SUN) and Help by Experts with Experience for Research (HEER)) were consulted to explore their concerns and priorities regarding inpatient mealtimes and to discuss the options for study design. Accessible information was presented to the HEER and SUN groups in January and February 2020 for comment and discussion on study priorities, design, and participants. Further engagement took place in 2021 and 2022 to update group members and seek their insights. To allow the group time to reflect on wider issues around mealtimes, worksheets were offered prompting them to think beyond specific food and drink consumption and menus (appendix C). The worksheets were designed to support those who may have struggled with literacy, vision, or understanding. The format offered accessible language and pictures (figure 2) to support the text. Group members with learning disabilities, literacy or visual impairments were supported by others in the group to contribute their ideas.

The comments showed a sense of keen interest in the topic of mealtime experience on inpatient wards, evidenced by members interrupting each other to suggest questions and topics for discussion. It was interesting to hear the groups' comments about how they viewed the research into mealtimes as important but that they acknowledged they had not thought about this issue until the topic was introduced at the meetings. The comments and suggestions were drawn together by the researcher to summarise as a list of questions with additional prompts for the interview participants if required. The groups agreed that offering images

(figure 2) would help the interview participants to reflect and consider their current inpatient mealtime settings and varied experiences. Confidentiality and ethical concerns were also discussed, and the groups also advised on remuneration for participants.



**Figure 2 Images of mealtime settings**

The group reflected on their preferred terminology for the study and the use of patient related vocabulary generally. Words such as ‘patient’ were contentious (some preferred ‘service user’ or ‘client’) but the consensus appeared to be to use ‘patient’ to refer to people receiving care and treatment on the inpatient wards. Considering how to describe the population, all agreed that using a person’s name was preferable, but they acknowledged that in research confidentiality is important. One person preferred ‘mental health issues’, another ‘mental health difficulties’, but given the research focus on patients in the hospital setting there was consensus for using the term ‘mental illness’. Academic perspectives were considered such as the reasons for using recognised established keywords to support searches, and for use in dissemination across academic and clinical audiences.



#### **4.1.1 Reflection on service user collaboration in research**

Initially I was keen to involve the patient and care-giver groups at every stage including collaboration for interviewing, analysis, and dissemination. Timescales associated with the PhD study, ethical processes and the use of reflexive thematic analysis limited the opportunities to collaborate. COVID-19 infection control measures added further restrictions on movement and contact. In addition, the feasibility of accessing and involving the group consistently was difficult due to the transient and fluctuating membership. The research skills, mental wellbeing and intellectual levels of the group members were varied and unpredictable. By returning to the groups at regular intervals to offer updates and support discussion, the primary focus of the study remained grounded in the concerns of the patients and their caregivers.

Ethical aspects of involving the group as stakeholders were discussed at supervision. Returning at regular intervals to update the group and share findings allowed the members to see the progress and to direct the focus of the research overall. However, collaboration for analysis and construction of themes was not feasible. Learning from this process will inform post-doctoral research activity. In future, without the constraints of the PhD process, I will plan to explore ways to include service user group members more as collaborators throughout.

#### **4.2 Aims and objectives**

Overall aim: to understand inpatient experiences and perspectives regarding mealtimes on inpatient mental health wards for adults with non-organic mental illness.

##### **4.2.1 Objectives for groups: patients and ward staff**

- To seek patient and staff accounts regarding mealtime experiences on the inpatient mental health wards.

- To elicit insights on any stresses, risks and difficulties associated with mealtimes on the inpatient wards including any perceived influences on safety in swallowing.
- To describe perspectives on ‘good’ mealtimes in light of patient experiences, positive aspects and incentives associated with mealtimes and safe swallowing.

#### 4.2.2 Objectives for group: speech and language therapists

The group of SLT participants were recruited as “thoughtful practitioners” (Thorne, 2016 p.93):

- To add SLT insights on patient mealtime experience, quality of mealtime, and the impact on swallowing and safety.

#### 4.2.3 Objective: comparison across all groups

- To compare perspectives regarding mealtime experiences, stresses and insights between patient, staff and SLT perspectives.

Study timescales	
Time period (months)	Task
December 2020 – Mar 2021	NHS, HRA and University application and approvals for patient and staff groups.
May 2021	Patient and staff groups - commence recruitment – attend ward meetings promoting study to inform patients and staff.
May 2021 – March 2022	Patient and staff groups - conduct interviews and begin concurrent analysis.
December 2021 – March 2022	SLT group - local NHS and University checks and approvals.
April 2022 – August 2022	SLT group - recruitment and interviews.
April 2022 – March 2024	Analysis, write up, and dissemination.
November 2022 – April 2024	Presentation of findings to patient and caregiver groups, collaboration with dissemination, designing format of accessible information.

**Table 14 Timescales for study**

#### 4.3 Study design

Ethical approval was sought and confirmed for the one ‘site of investigation’ for the patient and staff groups. The single site was determined due to pragmatic considerations which included:

- The service user groups had suggested the names of local wards that would offer the most relevant information.

- This study occurred during the COVID-19 pandemic and associated lockdown and restrictions on movement and gathering. Keeping the research local ensured feasibility of data collection along with minimal travel for researcher and participants.
- Access to inpatient wards was permitted within local infection control and COVID-19 requirements at the time.
- Adequate numbers were recruited without the need to extend the number of sites for this exploratory study.
- Timescales for the PhD were limited, limiting travel to local wards was more efficient and practical.

The study for patient and staff groups therefore recruited across one NHS Trust following the eligibility criteria and covered the acute and rehabilitation inpatient wards.

During the pandemic, current infection control guidance was adhered to: the researcher wore face mask, apron, and gloves during any interactions where these were required. As the infection rates reduced, guidance altered to wearing a mask without the other PPE. Patients could choose to wear masks during the interviews. COVID-19 restrictions limited access to wards on a few occasions but interviews were rearranged if the participant had chosen to meet in person.

#### **4.3.1 Sample for interview**

To gather a range of perspectives, the convenience sample included patients and staff (from the same site of investigation), and a third group of SLTs (recruited from across the UK). Expressions of interest were checked against the eligibility criteria (table 15 below). Most SLT participants had multiple caseloads covering more than working age adult mental health populations, but their interviews were designed to elicit responses regarding working age patient settings.

Sample size was discussed and reviewed in supervision during the active period of the study. Initially a sample of 15 for each group was intended but this was revised due to the restrictions present during the pandemic. In discussion with supervisors, a decision was made to cease data collection after interviews were completed for 13 patients and 12 staff. The data collected also showed few new insights being obtained in the later interviews suggesting that sufficient richness

of data had been reached at least in some areas of the findings. Recruitment was discontinued from August 2022.

#### 4.4 Recruitment

Access to the wards was straightforward due to the researcher's familiarity as a clinician, however this also brought potential challenges that needed to be addressed. There was a need to reiterate the information on the role of the researcher on those wards that had prior contact with the researcher as a clinician (appendix G).

<b>Patient group - eligible</b>	<b>Not eligible</b>
Adult patients aged 18 – 65.	Adults aged over 65.
Primary diagnosis of non-organic mental health condition.	Primary diagnosis of organic mental health condition.
Current inpatient on LYPFT <sup>6</sup> inpatient ward.	Patient on current speech and language therapist caseload.
Having capacity and able to consent to participation including audio-recording.	Staff advise patient not capacitous.
	Patients with eating disorders.
<b>Staff group - eligible</b>	<b>Not eligible</b>
Current staff on LYPFT inpatient wards for adults with mental illness (non-organic).	Not working for LYPFT.
Agreed consent to participation including audio-recording.	Not giving consent.
Working with adults aged 18 to 65.	Not working with adults.
<b>SLT group - eligible</b>	<b>Not eligible</b>
Working as SLT in the UK.	Not working as an SLT in the UK.
Experience of inpatient wards for adults with mental illness (non-organic).	Experience only with organic mental illness.
Working with adults aged 18 to 65.	Not working with adults.
Agreed consent to participation including audio-recording.	Not giving consent.

**Table 15 Eligibility criteria**

All the patient participants opted for in person interviews, these took place in a quiet side-room on the ward. Staff support was offered if required by patients during or after the interview. The majority of staff agreed for online video

<sup>6</sup> Leeds and York Partnership Foundation NHS Trust

interviews, preferring this to occur from home. Staff participation was permitted to be within work time. Occasionally, staff were called away during the interview due to incidents or meetings on the ward. In recognition of the potential for staff anxiety from witnessing near-miss choking or choking death, local staff wellbeing support networks were available if required. All the speech and language therapists chose online video interviews, they were guided towards their local support networks if required following the interviews.

#### **4.4.1 Group: inpatients**

Recruitment information was circulated as a flyer emailed to wards, multidisciplinary team members, and given out on in person visits to promote the study. This was designed to attract interest with colour images and a concise amount of easy read basic information. Attendance at patients' 'your views' groups gave further opportunity to build rapport and trust (Perez et al., 2022). The potential for coercion was recognised when there was an existing relationship between participant and researcher (Thorne, 2016). This also had the potential to lead to confusion as to the role of the researcher, so care was taken to explain the nature of the interview to each participant at the outset when confirming consent to participate. The principles of confidentiality were reiterated during the interview when responses indicated anxiety or concern.

#### **4.4.2 Group: inpatient ward staff**

The researcher circulated details of the study sending the flyer by email and hard copy to the eligible wards and staff groups. The study was presented at staff meetings on different wards and details were also offered during clinical visits. At the time of recruiting on the wards, the COVID-19 pandemic was at its height with staff appearing pressured by redeployment, unpredictable schedules, and reduced capacity due to colleagues' sickness. One to one discussions were more successful in disseminating details of the research and recruiting staff participants. Staff were keen to offer their perspectives suggesting they saw the topic as of interest and value (Jacobsen, 2017) however the challenges of staffing pressures and competing work demands meant some were unable to participate after expressing an interest and others were called away unexpectedly during the interview.

#### **4.4.3 Group: speech and language therapists**

A flyer was circulated by email to relevant SLT networks through RCSLT and social media posts tagged with #SLTsinMH were sent to the network on Twitter seeking a snowballing effect. The total number of SLTs working in relevant settings in the UK is unknown (Guthrie and Leslie, 2023) so a response rate could not be determined. The target groups included RCSLT Clinical Excellence Networks with interest in people with mental illness and relevant other populations including Criminal Justice Sector, Adults with Learning Disability and Autism. Establishing rapport and offering reassurance was necessary as there was no direct previous relationship with these participants and some expressed being unsure as to whether they could contribute useful information to the study (Ritchie et al., 2014).

#### **4.5 Data collection**

The use of interviews offering one-to-one contact allowed the researcher to support each participant and to reassure and build confidence for the more reticent or anxious participants. During the interview, the researcher provided photos of different mealtimes so as to support reflection. The researcher was aware of the potential for a) coercion given the clinical role of the researcher on the wards and b) suggestibility of individuals with mental illness. However, the researcher is experienced in supporting people with communication and cognitive difficulties and was careful to reduce any coercion or suggestion in the interview. The complexities of supporting patients and staff (some of whom were colleagues and thus already known to the researcher) were acknowledged and recorded as reflections.

##### **4.5.1 Interview guide**

Using the findings from the literature review and the suggestions from patients and caregivers groups, the topic areas and prompts were listed (table 16) to frame the in-depth interviews. The interviews took the form of guided and supported conversations facilitated with empathy and sensitivity from the researcher (Thorne, 2016). The sequence of questions was designed to be flexible following each participant's lead with the list of additional prompts as an aide-memoire. Aiming to retain spontaneity as far as possible (Ritchie et al.,

2014), the discussions were adapted each time to respond to the individual's insights and comments and also allowed the researcher to redirect gently if the participant's responses moved away from the key topic areas.

#### 4.5.2 Interview structure for speech and language therapists

The SLT interviews were conducted and transcribed after the first two groups of interviews (i.e. the patient and staff groups) were completed. The interview topics for the SLT were adapted from the patient and ward staff groups questions to make them relevant for the clinicians' roles. The process and reflection when coding the patient and ward staff groups suggested further adaptations to the questions and topics, to ensure that the questions related closely to the patients' perspectives and insights. The coding for this third group was completed after the first two groups were analysed.

Questions for patient and ward staff groups	Adapted questions for SLT group
<p>Warm up item 'describe your favourite meal'.</p> <p>1) Can you tell me what it's like on this ward at mealtimes?</p> <p>Prompts: to expand on setting, staff activity, atmosphere at mealtimes, social aspects.</p>	<p>1) Can you tell me what it's like on the wards at mealtimes?</p> <p>Prompt re social aspects and engagement at mealtimes, how do patients feel about other people around them at mealtimes? What are staff doing while patients are eating – what do patients think about this?</p> <p>Mental health care: How does mealtime fit into recovery generally, discuss relationship or links with care pathway?</p>
<p>2) How does this compare to having a meal at home?</p> <p>Prompts: to expand on 'normal' compared to ward meals, own cultures, and behaviours</p>	<p>2) Normal ('usual') mealtimes: discuss cultures, background, family aspects of meal and impact on patient mealtime experience.</p> <p>Have you seen any impact of trauma history affecting mealtimes or swallowing?</p>
<p>3) Have you ever worried about personal safety at mealtimes? Have you seen anyone have difficulty?</p> <p>Prompts: to expand on any concerns or anxieties, any comments on how to improve the experience</p>	<p>3) Safety aspects: Mealtime difficulties - what have you noticed? Do you think staff notice swallowing difficulties or choking? and do patients seem aware?</p> <p>What are staff observing for? (what signs of difficulty are recognised?)</p> <p>What would patients find stressful when eating? What effect does that have on their meal or swallowing?</p>

**Table 16 Interview questions, topic and prompts**

#### **4.6 Interview process - Developing interview skills**

The first three interviews were reflected upon in supervision to fine tune the questions and prompts and to review the researcher's style and skills in interviewing. Subsequent interviews were adapted accordingly to promote more open requests for information and to ensure the responses were not distracted by clinician's perspective or judgement. The use of open and closed questions and pace of moving between topics was considered and techniques to improve in-depth extension and probing were adopted. The researcher continued to add to the reflective journal following each interview, after transcription and during coding to capture ideas as these developed.

Supervision discussions focussed on differentiating between clinical practice questioning and research questioning. Initially the years of experience as a clinician appeared to be influencing the researcher's delivery of the interview (e.g. responses affirming the participant's contribution and using closed questions). With supervisor feedback and reflection, the format of the interviews became more open, and more time was allowed for participants to consider their responses. Hesitations, unclear comments and emphasis on specific topics were noted during the interview and these topic areas were then repeated in the second half of the interview to allow participants to reflect further and clarify their perspectives as recommended (Davies et al., 2020).

Learning to direct and support the participants in the interviews included consideration of:

- variations in confidence and mental wellbeing in patient participants,
- influences of clinical roles and relationships with ward staff (whether familiar or unfamiliar with the researcher's clinical SLT role),
- redirecting the conversation back to mealtime topic if the participant became distracted.

Introducing the topic 'mealtimes on the wards' in the interviews provoked a sense of heightened emotion in the participants as they sought to find the words to describe their feelings about the mealtimes on inpatient wards. The emotions associated with the inpatient mealtimes were entirely negative for some participants, but others attempted to find and describe positive aspects or appeared more relaxed and positive in their accounts. Following more in-depth



questioning participants offered insightful comments and concerns raising topics that suggested common patterns of interest and concern across the interviews.

#### **4.6.1 Reflection on developing research interview skills**

The entries in the reflective journal following each interview captured the issues and concerns.

##### **Reflection on my skills and approach to interviewing**

- 1) It was useful to read Thorne (2016)'s advice on the impact of "value laden prompts" which signal approval to the participant and subtly direct the subsequent content of conversation. I had to become more aware of this tendency and also limit my use of yes/no questions to develop a more open style for prompting further reflection and depth of insight from participants.
- 2) My skills as a researcher interviewer (as opposed to a clinician interviewer) continued to develop over the course of the PhD. I progressed with my ability to reflect, learning through discussion with supervisors, NAT-CEN SRA training, further reading (Ritchie et al., 2014, Thorne, 2016, Braun and Clarke, 2022) and by offering presentations for discussion with a UK community of practice webinars. Reading around the Silences framework (Serrant-Green, 2011) and discussion with HEER members also helped to build my awareness of clinician vs researcher perspectives.

#### **4.7 Transcription and analysis of interviews**

Access to an online interview for patient participants was offered with support from ward staff if required. Staff and SLT participants were assumed to be familiar with online options through regular professional use during the pandemic (Nind et al., 2021). The patients all opted for in person interviews and were interviewed concurrently with the staff group. The staff were interviewed in person or online according to their preference. All SLTs were interviewed online using MSTeams. The participants' interest and familiarity with online video conversations varied.

The analytic coding began after the first three interviews to inform the questions and prompts of subsequent interviews. Consideration of these preliminary codes then directed probing towards greater in-depth discussion in subsequent interviews. Examples included expanding discussion of personal background, culture, and preferences at mealtimes; exploring participants' attitudes to other people at mealtimes; and perceptions of choice and autonomy around meals (on the wards and prior to admission). As the interviews progressed there was less need to focus on a warmup item 'describe your favourite meal', as this was not necessary (participants were keen to contribute from the outset) and for some this appeared overwhelming as a first question. This was replaced with 'can you tell me what it's like on this ward at mealtimes?'.

#### **4.7.1 Audio recording and transcription**

Audio recording allowed the researcher to give full attention to the participant during the interview (Arthur et al., 2014). The influence of the recording device on a participant's contribution to the interview has been raised as a potential limiting factor on confidence and willingness to offer information (Rutakumwa et al., 2019). There was a need to build rapport and trust during the interviews and the researcher was conscious of how the recorder was perceived by the participants. The dependence on audio recorded data can lead to a narrower focus on the spoken word at the loss of wider meaning expressed in intonation and facial expression (Rutakumwa et al., 2019). The researcher conducted and transcribed all the interviews and completed field notes immediately after the interview reflecting on non-verbal and situational aspects of the interview. This brought deeper understanding to the interview responses and comments and allowed the process of coding to start during this familiarisation process. The researcher's transcription was soon after the interview offering a close link between the recording, field notes and reflexive journal. This facilitated attention to the 'story' and initiated the analysis of the data (Swain and King, 2022).

#### **4.7.2 Transcription**

Online interviews were transcribed using MTeams automated online transcription facility which was then checked by the researcher. The in-person interviews were transcribed manually by the researcher from the audio recording

which helped with familiarisation of the content. The transcripts were created as MSWord documents (as table format with a column for preliminary comments and codes) and then uploaded into NVivo as files and classified regarding demographic characteristics. Training in NVivo hosted by University of Leeds and thematic analysis (online webinars) were attended by the researcher during the analysis phase to develop the relevant skills and familiarity with the software.

During the interviews, words and phrases that were emphasised or appeared in need of clarification were noted concurrently. This allowed the conversation to flow and allowed the researcher to return to these points at an appropriate opportunity aiming to encourage the participant to add more in-depth reflection. To support the interview data and transparency in interpretations, the researcher kept a reflective journal and made notes immediately after each interview. These were added to during transcription to include reflection on the researcher's perspective and that of the individual participants' also noting repetition, recurrence, and emphasis of insights from the participant (Owen, 1984). Pauses and hesitations when present were transcribed in the format '...' and this was also used to show when redundant words were removed due to off topic comments and distractions.

## **4.8 Data Analysis**

Analysis was inductive and used constant comparison focussing firstly on the patient group and then the other two groups. This was done to give primacy to the patient voice in the data. The phases described by Braun and Clarke (2022) were followed to give transparency and replicability to the process of analysis and these are described below.

### **4.8.1 Phase 1 Familiarisation**

Iterative reading of transcripts and listening back to the recordings helped the researcher to achieve immersion. Comments and insights that were emphasised in the recording were underlined so that the text remained prominent in the transcript. Reflexive journalling helped to capture the main focus of the conversation and the tone of the participant. These helped distil the key points of the participants' insights and explore the 'latent' underlying aspects behind the words.

#### 4.8.2 Phase 2 Coding

The transcripts and audio recordings were examined for salient words and phrases relevant to the topic of ward mealtimes and patient mealtime experiences. Initially coding was conducted using MSWord and then by moving transcripts into NVivo to facilitate cross referencing and listing of relevant elements of data. The researcher drafted code labels to apply to units of meaning within the data for further consideration in subsequent stages. Analysis of staff and SLT groups followed, and the codes drafted for patients were considered and applied to the data. Further codes were added to describe new areas of understanding and meaning for these groups.

##### Reflection on coding

It was helpful to talk through examples of the coding at supervision and re-ground myself in reflexive analysis. Clinical SLT skills such as noting emphasis, non-verbal cues and intonation threatened to dominate and risked clouding attention to content. In addition, I had been distracted by considerations such as the interpretation of the participants' hesitations, caution, and reticence – all relevant to a clinical assessment but less so for thematic analysis which typically orientates more towards semantic and latent content. It was helpful to read Owen (1984) who suggests noticing repetition, recurrence, and forcefulness can facilitate deeper understanding of the latent meanings.

I found that initially I was categorising and describing at a surface level; but as the codes increased in number and were listed as subsets of related codes, it became easier to reflect on deeper, underlying meanings at a 'latent' level as described by Braun and Clarke. Returning to the transcripts and listening again to the audio-recordings helped me to reflect on the prominence of certain topics for the individual participant.

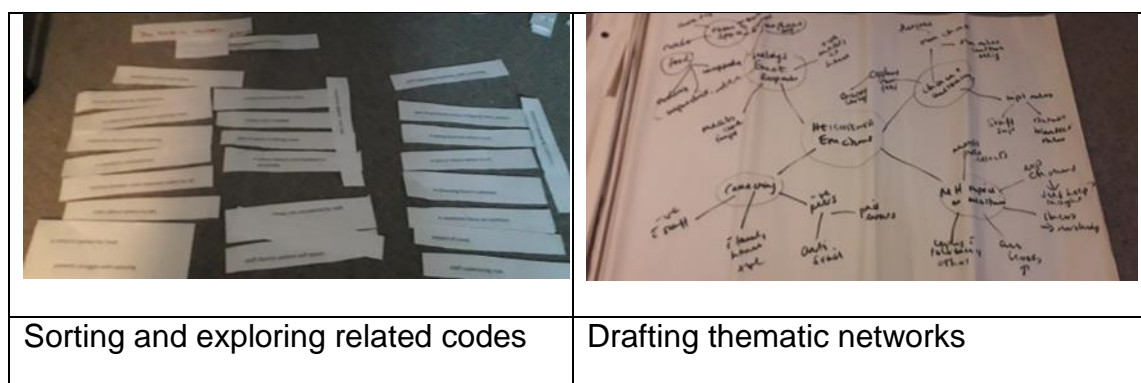
#### 4.8.3 Phase 3 Generating initial 'candidate' themes

Using NVivo to organise and combine codes into clusters (candidate themes) with related meanings was helpful. Care was taken to ensure that the context of a word or phrase was retained - the software shows the retrieved data highlighted

as part of a whole response or conversation. This was iteratively reviewed to check that coding and themes were consistent with the participant's intended meaning as perceived by the researcher. The data had multiple examples of commonly shared insights on mealtimes but also included single examples of comments from participants as outliers. Thorne (2016) advises on the importance of considering data which gives insights into "rare and relevant variation" (Thorne, 2016 p.180).

To facilitate open exploration of the codes and their interrelationships, manual paper-based sorting of codes into common topic areas and draft hand drawn networks were created (see images below, figure 3). The links between the codes were adapted and themes developed further following discussions in supervision (figure 4). It was important to go back to the research question and study aims to consider the relevance of all the codes. Clinical interests were also considered and needed to be set aside, particularly when participants commented about the physiology of swallowing and suspected choking. Discussion of candidate themes in supervision ensured the construction of themes was based on inductive analysis.

Analysis started with the patient group – constructing themes, finding links and commonalities and clustering into networks. Analysis then moved to the staff group to complete the same process separately and then finally the SLT group transcripts were coded, and themes constructed.



**Figure 3 Images of coding process, drafting candidate themes**

#### **4.8.4 Example of coding and theme development**

An example of the process of clustering codes and drafting candidate themes is presented here to illustrate the process of theme construction.

1. The patient interviews included many comments about food choices and menus coded initially on NVivo as:



○ lack of personal choice in food & time options	26	81	15/08/2022 2:53
○ choosing food in advance	19	35	15/08/2022 2:50
○ flexibility in food choices	29	79	15/08/2022 2:52
○ menu choices not displayed or accessible	15	35	02/09/2022 1:53

**Figure 4 Example of NVivo coding hierarchy**

2. These were clustered into a candidate theme of 'lack of personal choice at mealtimes'.
3. With further reflection this was retitled 'valuing control over own food'.
4. This was then grouped under a main theme of 'valuing choice and autonomy'.

An example of how multiple candidate themes were organised on NVivo is shown in appendix H.

#### **4.8.5 Phase 4 Developing and reviewing themes**

In this phase the themes were developed and reviewed with reflection and discussion in supervision regarding boundaries and overlaps across the linked codes and themes. Thematic networks linking themes within each group were constructed. These are presented and discussed in the findings chapters for each group. Rereading transcripts ensured themes were checked against the codes and data set and noted any repetition, recurrence, and forcefulness (Owen, 1984). A central organising concept for each group i.e. 'overarching theme' was drafted with further consideration of the relationships between the themes. Reflexive journalling continued as the researcher reflected on the analytic process and decision making.

#### **4.8.6 Phase 5 Refining, defining and naming themes**

Finally, definitions for superordinate themes were written to delimit the scope of meaning for each of the themes with iterative reference back to the focus of the research questions. The themes included both surface level (semantic) and latent (underlying) meanings (Braun and Clarke, 2022). Writing the definitions of the

themes and finding a concise name for each, helped to clarify and limit the scope of each one. Using NVivo the themes were collated and reconsidered. Discussion with supervisors helped to conduct more in-depth reflection and clarified distinctions between the themes. Determining an overarching theme for each group was helpful in checking relevance with research aims and building more in-depth understanding.

## **4.9 Synthesis**

The separate analysis of each participant group was completed sequentially in a constant comparison method using the phases described above. The analysis of patient experiences was conducted first, the other groups' themes then were determined before synthesis brought the themes together for comparison and evaluation of commonalities, differences and absences (Barnett-Page and Thomas, 2009, Thorne, 2016).

### **4.9.1 Synthesis process**

1. Map findings from staff and SLT groups to patient themes to find common themes.
2. Determine absences – themes not present in patient group.
3. Describe partial commonality or differences in themes across groups.

The thematic networks were compared across the three groups and similarities with patient group themes described and discussed. The synthesis considered “Who said this, and why does it matter?” (Lawless and Chen, 2019 p.96) to ensure context and relationships were reflected. A figure was devised (figure 8) to show commonalities, and differences in themes or sub themes across the three groups and to illustrate themes that were absent or had limited reference from the patients' perspectives.

Reflexivity complemented this analysis by highlighting the researcher's position, perspective, and experience. The discussion (chapter 8) will expand beyond the synthesis of the study's themes to consider the existing evidence base and wider context relating to the synthesis and establish areas where further research is needed. This process of the analysis and synthesis method ensured the patient perspective was presented as the primary source of interest and the themes related back to patient perspectives following the research aims and objectives.

Presenting the candidate themes to the service user group prompted further researcher reflection by listening to comments from ‘user voices’ in this group of experts by experience (HEER).

#### **4.10 Ethical considerations**

The HRA favourable review was confirmed in March 2021 (REC reference: 21/YH/0038; protocol number: N/A; IRAS project ID: 270116) appendix D. The local NHS Trust gave approval for the study to recruit patients and staff from wards across the Trust. The interviews for SLTs were approved by the School of Healthcare Research Ethics Committee (SHREC) in March 2022 (appendix E). For the SLT group interviews, there was approval from Royal College of Speech and Language Therapists (RCSLT) as gatekeepers to the network #SLTsinMH to recruit from this network. No NHS approvals were required for the SLT group as recruitment was via Twitter and the RCSLT network and this group did not include patients. Research integrity was addressed through regular discussion and review with supervisors.

##### **4.10.1 Consent and capacity**

Informed consent was requested from each participant and involved giving both verbal and written information at the start of the interview (appendices F and G). Patients were supported to understand the information about the study by their ward staff. The accessible patient information handout contained easy read vocabulary and images to support the conversations. Staff assessed the patients’ capacity to ensure they were able to give informed consent and their mental wellbeing could support the one-to-one interview.

To address any potential participants’ concerns, the researcher’s neutral status was emphasised, and the interview topics were introduced with a ‘warmup’ topic to promote confidence and ease as needed. Salient insights, hesitations or unclear comments were returned to later in the interviews so that the participant could clarify or correct their accounts as their confidence increased. Appropriate reassurance and encouragement were offered throughout the interviews. The researcher monitored the participants for any signs suggesting a wish to opt out or pause the interview. Support was offered for those who wished to leave the interview (e.g. some patient participants asked to terminate the interview



prematurely and they were reassured that they were free to leave without censure or adverse comments to ward staff).

#### **4.10.2 Confidentiality**

Details of confidentiality and anonymisation of data were presented to the participants. The possibility of a need to waive confidentiality was discussed in the case of any risks or safety issues being raised during the conversations. This may have been patients' personal experience of choking or of witnessing other concerns on the ward, and any staff accounts of unreported risks or concerns. In the event no concerns or unreported risks were raised but patients were advised to share any general anxiety about choking with ward staff.

Participants were supported, by use of verbal and written information, to understand that their data would be anonymized and stored securely. Given the small population (for all participant groups), all personally identifiable data was removed.

Consent to participate and for data to be stored for the duration of the study was audio recorded and saved into secure folders. Consent was sought for retaining anonymised transcripts of the interviews 1) for the period of the study in the researcher's secure folders and 2) for additional retention in the University of Leeds data repository (this was optional). The audio recordings were destroyed at the end of the study.

#### **4.10.3 Data management**

The audio files and transcripts were stored electronically onto cloud storage using an encrypted NHS laptop and secure password protected server files. Electronic secure storage and governance complied with University of Leeds and NHS guidance. Names of participants were anonymised using a personal reference number. This allowed quotes to be distinguished and compared in the analysis. Personally identifiable information was retained for the period of the study in a separate secure folder then destroyed.

#### **4.11 Chapter conclusions**

This chapter has described the method for design and completion of the interviews with patients, ward staff and SLTs. The themes and subthemes are

presented in the next chapters covering findings for each group and then across the three groups. The subsequent 'Synthesis and discussion' chapter 8 explores the commonalities and differences between the groups and the individual accounts relating this to current knowledge and clinical practice. This leads into consideration of mealtime practice and implementation of findings.

## Chapter 5 Findings from interviews with patients

*It's stressful and it shouldn't be stressful. Patient 12.*

### 5.1 Introduction

This chapter presents the findings of the interviews with patients. The patients' comments relating to mealtime experiences were coded and themes were constructed for this group before moving on to analyse the other groups' data for content themes which are described in subsequent chapters.

Participant characteristics are described below, followed by a reflection on the participants' engagement, responses, and interaction during the interviews. This reflection gives context to the participants' interactions during the interviews. A thematic network is presented below to illustrate the themes and subthemes (figure 5). This is followed by an in-depth analysis exploring the main themes and subthemes constructed for this group.

An overarching theme of 'heightened emotions associated with mealtimes' encapsulated the four main themes:

- Emotional response to mealtimes
- Experiencing swallowing difficulty
- Connecting with others through mealtimes
- Valuing choice and autonomy at mealtimes

A definition of each main theme describes and delimits the scope of each main theme (Braun and Clarke, 2022). Details of subthemes are then reported to clarify and expand on the content of each theme. Following a report on the analysis for other groups in Chapters 6 and 7, a comparison and synthesis of themes across the three participant groups is presented in Chapter 8.

### 5.2 Participant characteristics

The patient group consisted of thirteen inpatients from a range of mental health acute, forensic and rehabilitation wards. These included both locked and open access accommodation.

#### Demographic information:

- The 13 inpatient participants were aged between 20 and 60 years.
- 5 participants identified as female (8 identified as male).
- 8 participants reported active adherence to a religion.
- Ethnic/cultural backgrounds were reported as African (n=1), Afro-Caribbean (n=2), Asian (n=1), Gypsy (n=1) and white British (n=8).

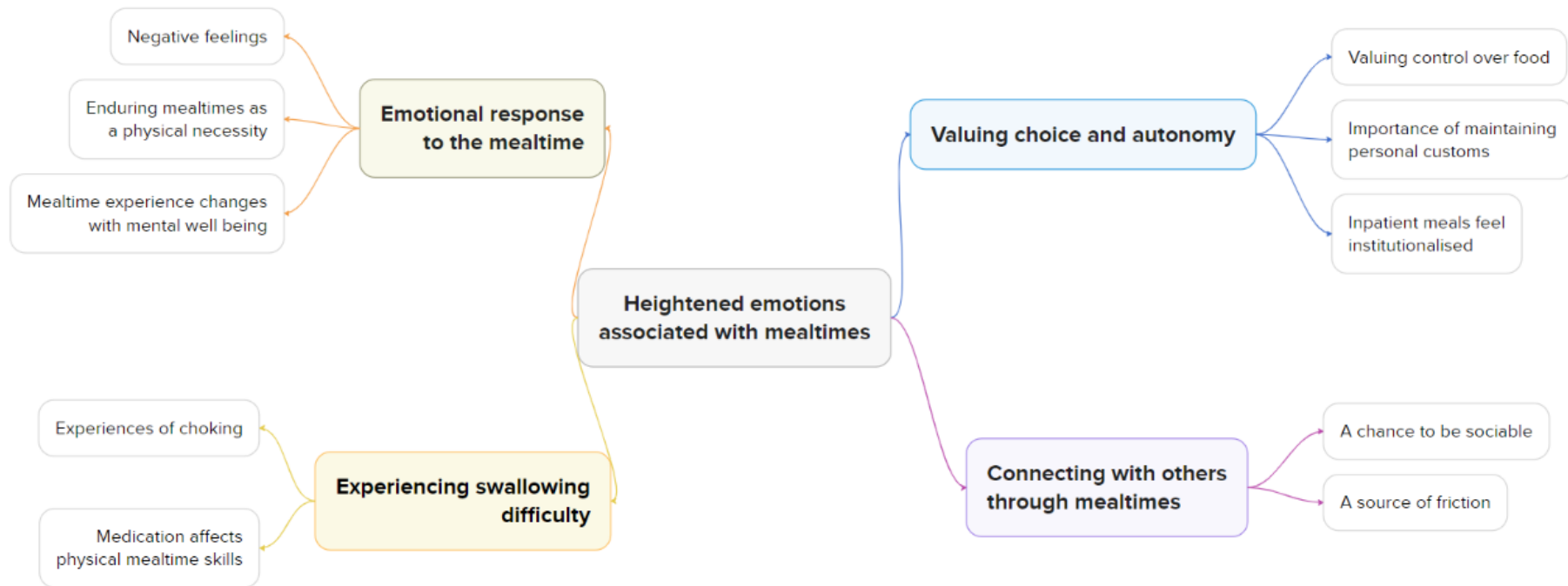
Given the small number of participants no further demographic details were recorded to maintain anonymity. Although background information from case notes was not accessed, some patients volunteered details of their mental illness diagnosis or physical health conditions during the interview discussions. The interviews occurred between May 2021 and July 2022; the duration varied from 6.04 to 41.58 minutes, (total data time = 251.29). Reference codes for each participant are given following each quote, in the format 'patient number'.

#### 5.2.1 Reflection on patient interview responses

##### Reflection

Participants showed varying levels of confidence and trust in their responses and their expressive styles varied. Some appeared very confident with a rapid flow of comments, while others were more reticent and appeared anxious. During the interviews some patients' responses suggested manic aspects of their mental illness were present: these patients were excessive in the amount of information offered, and their delivery was fast paced and prolonged. Other patients were slower paced and cautious (for example expressing comments such as "I don't know anything ominous").

All participants exhibited heightened emotions in their comments about mealtimes and their experiences on the wards expressed through patterns of emphasis and repetition of certain words.



**Figure 5 Patient group thematic network**

### **5.2.2 Overarching theme: heightened emotions associated with mealtimes**

An overarching theme of 'Heightened emotions associated with mealtimes' was determined for the patient group. This captured their descriptions of wide ranging and intensified emotional experiences triggered by mealtimes on the inpatient wards. It also captured the emotional aspects of patients' reflections on home and/or family mealtimes prior to admission. The overarching theme connected four main themes relating to these heightened emotions associated with mealtimes. Each of these themes is described in more detail below and expanded into underlying subthemes.

### **5.3 Theme: emotional response to the mealtime**

Definition: This theme captured the patients' views on how mealtimes raise intense emotions. Patients felt the pressure of restrictions, lack of choice, and issues not present at other times of the day. Subthemes included how frustrations and anxieties intensify at mealtimes, particularly when choices of food and environment are not available as expected. Experiences of swallowing difficulties and choking were highlighted, for some this led to further anxiety and distress at the mealtime. Patients described their mental health being variable at mealtimes with deterioration in mental wellbeing related to institutional practices and by the proximity of other people in the room. Patients reflected how the importance of eating conflicts with the desire to avoid others on the ward. Further stress was expressed when comparing ward negatively with home mealtimes and the disappointment felt when food is not appealing. Home mealtimes were important events associated with wellbeing, autonomy, identity, and cultural norms not experienced on the wards.

#### **5.3.1 Negative feelings about inpatient mealtimes**

For many of the participants, the first comments offered in the interview concerned frustrations and tensions associated with the ward mealtimes. Spontaneous (unprompted) introductory comments gave a sense of generally unpleasant experiences:

"Well, there was a problem again ... Just looks disgusting ... so I walked out with the comment that I wanted beef ... you wait for 15 minutes and

then you're confronted with food that you haven't ordered ... it's not good ... doesn't put you in the best of moods". Patient 02

The patients' accounts often reflected intensely felt frustration and annoyance relating to the ward mealtimes. There was disappointment and a sense of hopelessness as patients faced the dining room and the meal:

"Well, it makes me feel 'shall I bother?' ... it really does ... but if you're hungry you've got to eat, but it does put me off." Patient 12

These frustrations and annoyances then affected their engagement with the meal and their emotional levels afterwards. Patients reflected on how the setting for the meal affected their wider experience on the ward, describing the wards as detached from previous and future lives. One participant described the mental health wards as being "places where you can't live your life" (Patient 01). Patients repeatedly described mealtimes as a catalyst: feelings of frustration, stress and powerlessness were triggered and escalated by the dining room set up and the routines in place. These emotions extended beyond the mealtime into their day-to-day mood and contributed adversely to their general wellbeing.

The negative emotions often related specifically to environmental aspects of the dining room. Patients' tolerances for the mealtime setting varied and this included attitudes to the people present and the place itself. The environment provided for the mealtime on the ward was typically a dining room, with seating around shared tables, but for some patients a self-catering kitchen was an option. The food was served usually from a metal hatch which opened for the meal with a loud noise and patients were directed to queue by the staff supervising. For many participants the lack of space and crowding during the mealtime were a primary concern. The crowded dining rooms resulted in close contact between patients during the mealtimes and lack of choice for where to sit. For those patients preferring more space or quieter environments this became intensely stressful. In describing the ward mealtime environment participants used vocabulary such as "busy" (Patient 01); "crush" (Patient 09); "hectic" (Patient 13). When asked to describe their feelings about this, patients repeatedly used words such as "stressful" (Patient 12); "uncomfortable" (Patient 09); and "nervous" (Patients 06,11). As participants discussed the crowding in the room, they described their dislike of the resulting noise levels:

“It makes me feel that I can’t eat me dinner cos I’m being distracted with the noise.” Patient 12

These environmental concerns led to some patients wanting to avoid the mealtime due to their particular dislike of the dining room setting. Opportunities to find a comfortable space to eat were limited and unpredictable. Participants had insight into their needs in terms of mealtime environment and there were clear accounts of how they attempted to seek out quieter times and settings with more space. Outside the mealtime periods, patients could avoid others on the ward by spending time alone in their individual bedroom or finding other quiet spaces. The difficulties tolerating others in the dining room are further discussed in the other themes, as other patients and staff contributed to many aspects of emotional difficulties experienced in the dining room setting.

The queuing system at mealtimes presented additional emotional challenges for patients with increased frustration related to the challenges of getting the correct food as ordered and finding a space to eat the meal. The descriptions of queuing gave a sense of pressure to keep a place in line, and of having to be close to other patients which for many was a particular source of distress. Participants also reported on their anxiety if at the back of the queue and worrying about missing out on meal options:

“Queuing up ... and it’s like ... first come first served ...Yeh so everyone’s rushing in to ... queue and it’s like ... you would get what’s left over.”  
Patient 03

Following the accounts of finding the crowded dining rooms challenging, and indeed aversive, some described rushing through the meal to avoid being in the dining room any longer than necessary. Participants explained that they would give up on a partially completed meal rather than prolong the emotional difficulty of being in the room with others on the ward, other patients described eating in their bedroom separately or missing the meal entirely to avoid the close contact with other people. The concerns related most often to uneasiness around other patients but in some cases, participants voiced concerns around staff who were watching and supervising:



(Researcher asks, “what do you think the staff are watching for?”) “I don’t know ... to make sure nothing gets out of hand, or nobody can be themselves or something ... they don’t like it if you be yourself.” Patient 05

This participant showed disquiet regarding the restrictions perceived on the ward at mealtimes and described staying in the bedroom to avoid contact with both patients and staff throughout the day, but this became difficult at mealtimes due to hunger. Due to not liking the food, Patient 05 would access snacks to eat in the bedroom in preference to coming into the dining room for the catered meals. In effect, this participant described avoiding the mealtime setting to the extent of replacing most meals with snacks.

A further source of stress was the unpredictable and unappealing nature of the food itself. Participants described the lack of flavoursome food:

“... it’s the quality of the meal ... They all have that overlying taste, like somebody’s sprayed it with a taste you know.” Patient 02

For many the food was repetitive, lacking in variety and represented the institutional setting which they found unpleasant. The patients emphasised their concerns about the food options but with a sense of hopelessness at any change being possible. They often continued at length to describe the lack of interest and appeal in the meal itself:

“Oh, it’s just not worth going in for ... everything tastes the same.” Patient 02

The typical routines were for food choices to be made and requested by the patient through staff the day before. Part of the stress experienced was related to the variation in availability and the failure for food to be provided as ordered. Many participants voiced their dislike of the unpredictable menu options, but these descriptions were offered with an air of resignation and acceptance.

Some patients emphasised the differences between home and the inpatient ward at mealtimes:

“It’s stressful and it shouldn’t be stressful ... cos it’s not stressful at home is it where your family brought you up from ... they could make it a bit nicer.” Patient 12

The impact of the setting and the people present at the mealtime at home were again key to the experience. This linked with the theme of mealtimes offering connections and confirming relationships.

Occasionally, emotional aspects of mealtimes were commented upon negatively in relation to earlier home life and childhood experiences. For one participant this included breakdown of relationships:

“They [mealtimes] can be awkward, weird family, ... even though ... broken families and stuff.” Patient 01

Clearly, for some patients, mealtimes at home were also difficult emotionally with the absence or presence of other people influencing how the mealtime was experienced. Mental health issues would come to the fore at mealtimes, particularly for those with experience of eating disorders. For many participants their anxiety levels would increase at mealtimes, and this is discussed further in theme “experiencing swallowing difficulty”.

### **5.3.2 Enduring mealtimes as a physical necessity**

The participants reflected on the importance of balancing the emotional issues described above with the physical need to eat, particularly focusing on hunger and nutritional needs. They were clear that the meal was necessary in terms of nutrition and physical health, but they did not associate the mealtime with enjoyment - rather it was a routine task to be completed. There were occasional comments suggesting that participants appreciated having a meal provided, but others perceived this as stressful compared to cooking a meal themselves:

[Researcher asks: “what might be stressful at mealtimes?”] “Everything really when you think about it, unless you’re cooking, unless I’m cooking for myself.” Patient 12

There was a tension in the accounts between what the patients acknowledged as the physical importance and social potential of the mealtime and the disappointing reality of mealtime-related frustration and stress. The ward mealtimes typically bore no relation to the positive emotions felt during home mealtimes. These tensions are also reported in the other themes (i.e. patients not connecting with others through mealtimes and frustrations with lack of autonomy and choice on the wards at mealtimes).

### 5.3.3 Mealtime experience changes with mental wellbeing

Participants varied in their ability to describe their perceptions of mealtime difficulties associated with deterioration in mental health. Some patients were able to reflect on how their mental illness affected their mealtimes, both in general terms and more specifically around their physical skills in swallowing food and drink. One participant described how acute mental illness had reduced his interest in meals:

“I’d gone really low you know in bipolar terms ... I couldn’t ... swallow at all ... but it were physical as well as mental ... and I were like a broken-down horse you know ... you could see me ribcage.” Patient 02

This participant could reflect on experiences of mealtimes on the ward. Mental illness had prevented engagement in all aspects of eating including physical swallowing ability. Patient 11 described how a recent decline in mental health led to emotional difficulties with the dining room setting finding it hard to explain:

“I feel like I right rush it really somehow and feel like I’ve got to rush ... I don’t know what ... whether it’s a nervous thing ... I don’t really know”. Patient 11

With limited levels of insight, Patient 11 could not identify further details of anxieties around the meal and the dining room setting. In contrast, Patient 07 used an analogy of driving to explain the feeling of being out of control when mental health deteriorated:

“... it’s like suddenly a ten year old has got behind the wheel ... they’re not aware of anticipation, they’re not aware of road skills, they don’t know cos they’ve not been taught ... as an analogy.” Patient 07

Patient 07 went on to explain how this lack of control affected the ability to cope with the meal and swallowing. Other participants also described how specific aspects of their mental illness impacted on how they could engage and cope with the mealtime. Participants described their observations of other patients whose confusion and disorientation affected their mealtimes:

“... the only thing I can think of is, some of them eat their custard and sponge before the main meal and they’ll eat everything in the wrong order which is typical of bipolar behaviours cos they’re confused with the

mechanics of 1-2-3 ... soup comes first, then the main meal, then the custard.” Patient 11

Patients focused repeatedly on the need to leave the dining room, and this desire appeared to increase in intensity when their own or other patients’ mental health deteriorated. Crowding and mealtime behaviours of patients were a particular concern as described in the previous themes relating to the mealtime environment. Access to quieter spaces was seen as important but was usually not available to many of the participants. The role of the staff in the dining room was described by some as supportive and helpful in relation to the management of the mental health condition and behaviours:

“... one particular person that’s really kind, she’ll come and sit with me when I’m eating, she’s called [name]... she’s one of the dinner ladies with [Catering service], and when I’m eating, she always comes to join me, not always, just if she’s free and she’s working ... but that helps ... you know it does help.” Patient 12

However, patients also described staff lacking recognition of individual patients’ needs and anxieties. The staff needing to follow routines, cover other duties, and respond to emergencies could disturb the mealtime experience:

“Yeh because [catering] want to wash up and they want to go, like... when alarm goes off, yeh ... the staff have to run off the ward and go on a different ward.” [Researcher asks: “so what happens if you’re in the middle of your dinner?”] “Er, we have to leave it ... Not nice.” Patient 08

Patient 08 gave a sense of the organisational pressures overriding individual attention. Patients perceived that staff’s other commitments and duties took precedence over mealtimes. There was an underlying sense of patients needing extra space and time when their mental illness was acute but that this was not recognised or understood by staff.

#### **5.4 Theme: experiencing swallowing difficulty**

Definition: this theme included insights around difficulties in eating, drinking, and swallowing. Patients described the details of food getting ‘stuck’ and the emotional impact of this both as immediate and as longer-term effects. Insights were clearly articulated by some, others appeared more dismissive and

complacent. There were frequent concerns about anxiety: the physical processes of eating and drinking were interlinked with mealtime stresses. An escalation and interaction between the levels of anxiety and rushed eating led to increased risk of choking, and also brought further anxiety into the mealtime experience. Medication for mental health was described as a further concern affecting mealtime skills and experience.

#### **5.4.1 Experience of choking.**

Some patients reported that they had no difficulties in swallowing, others readily offered their own experiences of coughing or choking on food. Past experience of a choking incident had a lasting effect on the emotions at mealtimes for some patients:

“The only thing that’s bothering me is that choking thing, I feel like I’m going to ...if I choke then I’m not going to be able to control it.” (Patient 06)

There were contradictory reports of how often choking occurred on the ward, some patients had no reports or observations of difficulties. Others, who had observed others having difficulty with swallowing and symptoms of coughing and choking, described heightened anxieties. Patient 02 showed awareness of the seriousness of the choking risk:

“Oh, it’s a close call ... if you don’t get it out, you’re dead ... can’t breathe.”  
Patient 02

Some showed interest in first aid responses for choking describing back slaps or the abdominal thrust albeit with limited understanding:

“... have to do that hyphen thing [sic] ... I had to do that on myself once a long, long time ago ... I just wanted to say you know ... erm mainly ... if we could all have an update first aid course?” Patient 12

Other participants described how staff responded to a choking incident:

[Researcher asks: “So you say an apple got stuck one time? what happened?”] “Someone had to slap me in the back ... yeh one of the staff.”  
Patient 01

For Patient 01, the choking incident was described casually with some detachment. However, other participants recalled their choking experience as being more distressing and were explicit in explaining the experience and the level of distress choking produces:

“... it’s not often it happens ... or if it happens twice or three times in my life ... it’s a bloody horrible feeling.” Patient 02

Patient 02 was able to give a detailed account of his experience of choking, describing shock and panic:

“I didn’t chew it properly ... Swallowed it ... and it got stuck right across my throat ... and I couldn’t (gestures to neck choking) ... It’s gone down as far as bottom of me throat ... I felt where it was, and it were bottom of me throat ... Horrible ... you think you’re gonna die ... You think you’re gonna die ... it were down there for about a minute and a half ... now I were gasping.” Patient 02

Other patients described their fear of choking and that this meant they anticipated problems with swallowing their meal. Their accounts showed clear levels of insight into the choking experience listing food types and describing the textures that might present difficulty. Descriptions of choking included awareness of difficulty in the sequence of swallowing processes with mention of “back of the throat” and “gagging” (Patient 03) and comments that the oral process was impaired “me mouth struggled” (Patient 07). This was linked with difficulty in self-monitoring. There were also accounts of reduced control over the mechanics of introducing food into the mouth “shaking with my hands, I can’t use my cutlery properly” (Patient 10) and reduced efficiency at the oral and pharyngeal stages:

“I was swallowing bigger and bigger bits ... I wasn’t really processing it down very well.” (Patient 07)

Patients also showed awareness of the importance of posture but explained that this was difficult to maintain when their mental health declined. Sitting upright at a table was physically difficult, uncomfortable, and unfamiliar for some with descriptions of leaning forwards and resting on the table linked to feeling unwell. Others described how their interest in food declined with deterioration in mental illness and this led to difficulty consuming adequate nutrition:

“I couldn’t ... swallow at all ... but it were physical as well as mental”.

Patient 02

There were repeated accounts linking mental wellbeing with swallowing skills and effectiveness, improved mental health was associated with improved physical skills in eating and drinking:

“Once I got into my new rhythm ... everything was ok”. (Patient 07)

Some participants reflected further on choking at mealtimes and how to mitigate the risk offering information on how to alleviate their difficulties and describing self-monitoring during mealtimes. Strategies suggested by patients included adjusting the timing and pace of eating as well as the importance of food consistencies and textures:

“You get drawn to other foods ... cos they look good ... but erm you’re better off staying with the smoother.” Patient 10

Patients described preferring softer foods when they felt unwell, they could also suggest foods they preferred to avoid due to the increased difficulty in oral processing experienced for tougher textures.

Mental wellbeing was linked to level of choking risk, patients highlighted the importance of a relaxed, slower pace of eating along with attempting to reduce anxiety:

“I take me time to eat me dinner, relax, don’t rush - that’s important.”

Patient 08

Patient 08 appeared to be remembering words from staff, repeating advice previously received. Patients’ accounts of how to mitigate or respond to the risk of choking often showed awareness of the risks associated with speed of eating and the need to be able to concentrate on the task of swallowing. The word ‘anxious’ was repeated by patients explaining how their mental illness affected their physical mealtime skills and stamina. The feelings of stress and anxiety were described clearly as an impetus to speed up the process of the meal. Many referred to self-imposed reasons for rushing their food e.g. to enable them to leave the dining room and the crowded setting. Others reported that staff prompted faster eating due to the need to attend to other duties or emergencies. The anxiety that led to faster pace of eating was then exacerbated by anxiety

about choking. Patients were aware of when their mental illness deteriorated, and they were conscious of their difficulties in self-regulation for pacing their eating:

“I found when I was eating, I was filling my mouth faster than I could chew it and swallow it ... like an automatic reflex ... of shoving food in my mouth ... and I kept eating at that pace but me mouth wouldn't [cope].” Patient 07

Patients' descriptions showed awareness of the impact of eating too fast, however they also reflected that they were unable to modify or control their speed of eating at times when unwell or stressed. Patients' accounts suggested that they did not raise concerns about pacing the rate of eating to staff and that they were not supported to slow down at the mealtime. Rather the accounts suggested that the staff were unaware of individuals' difficulties with pacing during the meal.

The pressures and anxieties felt by patients when supervised by staff were acknowledged but patients were also aware of the risks of eating and potentially choking alone. Patients reflected on their goals for independent living in the future relating to mealtimes, considering the risks and benefits of eating alone – and how mental wellbeing was central to mealtime safety and enjoyment.

#### **5.4.2 Medication affects physical mealtime skills**

In addition to identifying difficulties around mealtime skills resulting from mental illness, patients also reflected on how medication affected their oral skills and mealtime behaviours:

“I was having a problem with drooling ... it felt like the muscle was tired, the swallowing muscle was tired .... Some days it was better than others.”  
Patient 10

However, these side effects became another source of anxiety for patients relating to the theme 'experience of choking' above. Patients explained how they felt about side effects of medications such as drooling and spitting during the mealtime and described feeling self-conscious at mealtimes:

“I think it's [drooling] something to do with the Clozaril cos I've never done it before, ... I know it's not pleasant [for others at the table].” Patient 12

Despite the concerns described, these patients showed no reluctance to taking these medications, their accounts appeared accepting and resigned. In contrast,



some patients described how their current medication had improved their mealtime skills:

“It’s really good now ... I do get diazepam ... that helps a bit as well.”

Patient 10

For example, side effects such as tremor were reportedly reduced when the medication was successful and appropriate. However, these discussions about medication were infrequent - patients reflected more on their emotions, social aspects, autonomy, and anxiety than on the specific aspects of treatment for mental illness.

## **5.5 Theme: connecting with others through mealtimes**

Definition: This theme of connection through mealtimes describes how participants expressed their emotional response and connectedness to other people present at the mealtimes on the wards. Subthemes included how sharing meals usually consolidates relationships with family and friends. Participants described how mealtimes on the wards are typically restricted to dining rooms shared with others. Occasionally, this might be a welcome social opportunity but for the majority this is an unwelcome pressure raising anxiety levels. Interactions during ward mealtimes were not generally felt to be supported by staff engaging with patients. Patients who have avoided others during the rest of the day, are faced with the need to tolerate other patients and staff for the duration of the meal. Issues between patients were felt to escalate in the close environment.

### **5.5.1 Mealtimes offer a chance to be sociable**

Patient participants highlighted the important role of mealtimes facilitating connections with others. This included building and maintaining relationships with other patients, staff, and between family and friends. For some patients, the positive mealtime experience was due to the people present in the room offering potential social opportunities:

“Well, I’ve got more sociable since I’ve been here, I haven’t had a girlfriend since I was 19 so it’s just me ... when it’s just you it’s easier to get a takeaway isn’t it.” Patient 04

One participant shared a positive memory of how a family member had been included in the ward mealtime as a visitor. However, this was the only account of family inclusion in a mealtime and this patient reflected that this was no longer an option for visitors. The majority of the participants discussed their feelings about other patients on the ward and no others described having visitors at mealtimes. Most patients described similar preferences for eating alone and not interacting with others during the meal. The participants made it clear that the mealtime environment in their current inpatient ward did not encourage them to be sociable or chat to others:

“I always try and be polite you know when I go in my first thing is ... you get the juice you know and need to get some drinks so I always ask politely can I have the jug ... I don't know why the staff don't do it, but I always ask as well ... do you want me to pour you a drink? There's nothing wrong with that but it's always me that does it ... you know goes round the tables.”

Patient 12

Participants valued the opportunity to show care for others by offering food or drink. There was a strong sense of how this had been an important part of maintaining relationships and personal wellbeing prior to admission. They described previous experiences of cooking and caring for family and parental roles at mealtimes, but this was contrasted to the sense of isolation for mealtimes on the ward. It was clear that participants perceived inpatient mealtimes as an essentially individual experience:

“You go into the kitchen, or the dining room and you put the kettle on, and you just make a cup of tea [Researcher asks: “does that kind of bring people together do you find ... in there?”] No, no ... it's solo experience.”

Patient 02

Participants expressed that the opportunity for personal choice in choosing, cooking, and eating was an essential part of everyday life, however this was not available as part of inpatient routines. There were occasional descriptions of increased choice when recovery was progressing sufficiently to allow kitchen access. Including others on the ward was not generally considered for self-catering sessions - the majority expected to cook and eat alone.

In contrast to the negative emotions of ward mealtimes, family mealtimes were described as positive emotionally. For the most part, patients described their experiences of family mealtimes affectionately: the meal was described as a time for family to be together and seen as a highlight of the day. This compared negatively to inpatient mealtimes:

“For me ... it’s never been the same since I’ve not cooked for me children.”

Patient 12

There was an emphasis on connections and relationships between patients and their friends and/or families established through coming together for the meal. Social connections were validated and confirmed by home mealtime routines with the mother often identified as central to maintaining the mealtime culture and customs. This is discussed further in the subthemes below exploring the importance of personal cultures associated with mealtimes.

In contrast to the comments about relationships during meals at home, the patients seldom discussed connectedness or positive relationships during mealtimes on the wards. Most did not appear to relate any aspect of mealtimes to improving their current relationships – nor did they consider that mealtimes could contribute to recovery or progress in mental wellbeing on the ward. The ward mealtime was perceived as a hiatus between other daytime activities and once complete the patient would return to being alone in their room.

Occasionally participants mentioned interacting with other patients, however fewer described contact and social exchanges with staff during mealtimes. Generally, participants were unclear about the role of the staff present at mealtimes. They described the staff sitting at separate tables, supervising menu choices for the next day, and organising queuing systems. Typically, the staff present at the mealtime were not eating their own meals at the same time as the patients. One participant described seeking company from staff successfully during the meal, but others did not feel the staff were available or interested in social connection during the meal. This was interpreted by some as influenced by pressures of work, but others saw this as staff actively choosing not to engage in communal eating:

(Researcher asks: “So do they [staff] sit down with the patients then?”)

“What do you think? They sit on their own table don’t they, course they do.

I wouldn't ... if I was staff, I would quite willingly sit with people." Patient 12

Participants perceived the staff role to be more about monitoring adherence to safety protocols, behaviour management, and maintaining mealtime routines:

"They just watch, just watching to make sure everybody's ok, basically yeh [Researcher asks: "So what's it like when they're watching do you think?"] They don't watch me, they just make sure that I'm ok, cos its metal [cutlery] and cos it's forensic, part of a low secure ward." Patient 08

This patient rephrasing "watch me" to "make sure that I'm ok" reflected awareness of the complexity of the staff role and how it is perceived both in terms of being watched (potentially a restrictive practice) but also for reassurance of that safety and the need for support.

Social interactions with staff during the meal were not routine experiences but there were occasional reports of staff showing greater involvement in attention to and support for patients during the mealtimes following identified nutritional or weight concerns. There was a sense of distance perceived between staff and patients with no coming together over drinks or food to support social interaction for regular mealtimes. Rather the staff role at the mealtime was depicted as supervisory and restrictive rather than an opportunity for considering connections and encouraging wider recovery and mental wellbeing.

### **5.5.2 Mealtimes as a source of friction**

A key problem with mealtimes on the ward was associated with difficulties in patients relating to other patients on the wards. Patients described how close proximity of other patients triggered negative emotions including disgust, anxiety, and/or fear. Being near to someone with deteriorating mental health was difficult and patients commented on others' personalities and behaviours:

"... the only available place [in the dining room] was with somebody who wants to fight all the time and uses F words all the time, so I thought I'll go and try eating in my room." Patient 07

Other patients' behaviours at the dining tables were described as unpleasant and difficult to tolerate:

“Like blowing their nose ... and that put me off me meal ... and they cough ... I just eat, but it really not right [sic].” Patient 09

Some patients were self-conscious about their own behaviours at mealtimes making them feel embarrassed to be with others at mealtimes. Others described their wider anxiety relating to deteriorations in their own mental health:

“I just, I get right nervous in front of people’s company ... I just get really really clammy hands and that ... don’t like meeting lots of people.” Patient 06

As outlined in previous themes, the patients often had anxieties being near to others and this was a particular issue for mealtimes, in part related to the environmental aspects above. At other times of day (i.e. outside of mealtimes), it was possible to avoid others by being in the bedroom or by going off the ward if permitted. Mealtimes was the only time that patients had no choice in this - if they wished to eat, they felt they had no option but to enter the crowded, noisy dining room.

The patients described how any difficulties in relationships on the ward could be intensified at a mealtime. Previous interactions and social difficulties could not be avoided when the meal was on offer in one room only:

“... with that woman, I was just like treading on eggshells ... there was one time when, like, I sat near her and stuff and then it, like, it escalated into, like, an argument and stuff like that.” Patient 13

The consequences of difficult relations with other patients in the dining room were repeated by many participants showing insight into risk and concerns about how arguments could escalate:

“I wouldn’t like to think that someone was having a really bad day and ... they’d picked up a big knife.” Patient 06

There were more accounts of difficulties with other patients but occasionally the relationships with staff were highlighted as an issue and this affected the mealtime process and experience. One patient described speeding up her eating to get away from the room where there were staff she disliked, and another focused on her feelings of irritation and exclusion relating to staff sitting together and chatting nearby.

Patients reflected on their anxieties about sharing a meal with other patients who were struggling with their own mental illnesses; this triggered concerns about personal safety and conflicted with personal and cultural preferences. These difficulties were in stark contrast to the relaxed and positive connections associated with home mealtimes as described above. The accounts suggested that mealtimes were viewed by the patients as an important part of everyday life but the mealtime experiences on the ward led to increased tension and anxiety affecting their mental wellbeing outside the mealtime.

## **5.6 Theme: valuing choice and autonomy at meals**

Definition: the theme of ‘valuing choice and autonomy at meals’ covered insights on independence of choice around food and drink and mealtime customs – these being keenly valued and important for personal wellbeing. Subthemes related to ward restrictions and rigid routines which were sometimes understood as necessary from an organisational point of view but remained a source of frustration and annoyance when conflicting with individual preferences and customs. Patients described dislike of the institutional routines and a contrast between ward and home cultures.

### **5.6.1 Valuing control over food**

During the discussions about food and mealtimes, the issue of choice and access to preferred options was a frequent concern. Patients reflected on how cooking their own food brought emotional benefits and certainty as well as improved tastes:

“I prefer me cook my meal myself ... Cos I just cook, and I know it’s ok.”

Patient 09

Many expressed strong preference for accessing the kitchen to choose and cook their own meals to avoid the uncertainty of ward menus. Patients also described the emotional benefits of being able to cook their own choice of food and making it precisely to their individual preference:

“... its comfort food you know, soothing food .... Soothing food, tastes nice, and gives you a warm feeling ... Yeh, gives you a warm feeling when you eat it ... it’s what you want if it’s the right type of food.” Patient 02

Patient 02's account highlighted the comforting and emotional aspects of self-catered eating and drinking in contrast to negative emotional experiences at ward mealtimes. Preparing one's own meal allowed for more personalised choice of textures, individual combinations of flavours and wider options for additional dishes. Participants who preferred and were able to prepare their own meals, conveyed a sense of wellbeing related to the food offering more than just nutritional value – the food chosen and cooked by patient 02 brought “comfort” and was “soothing”. There was a sense of improvement in mental wellbeing and recovery not seen in the accounts of shared dining rooms and hospital foods provided on the wards. In addition, being able to cook was valued in terms of exerting and enacting choice and control over the timing for preparing and eating food:

“Me have more space and time [sic] ... more space and time ... Yeh ... that's important ... When you're cooking ... you can sit down, you can do ... you can turn off the stove, go back or do what you want to do ... you have more space and time.” Patient 09

The repetition of “space and time” emphasised the strength of feeling in patient 09's account. Cooking food offered more than just access to food and nutrition; such accounts highlighted the importance of flexibility in the meal and having choices and control over food options, timing, and place to eat.

Patients described the restrictions in access to food and drink on the wards and how they felt about this. Having to seek permission for accessing food or drink, asking for kitchens and utensils to be unlocked, and requesting staff presence to supervise kitchen access, gave a sense of dependency:

“You don't want to be disturbing them ... and asking them ‘can you make me a cup of tea’, like a five year old child” (Patient 02).

Patients reflected that, as adults, they would normally be able to choose time, place, and food to eat as a last-minute decision or be able to change their minds about mealtimes. Many patients described how, in hospital, this autonomy is lost.

### **5.6.2 Importance of maintaining personal customs at mealtimes**

Patients commented on difficulties in maintaining personal mealtime customs and routines and compared the restrictions of the inpatient wards negatively with life

outside the ward. Comments suggested a loss of personal cultures, preferences and choices that impacted on their wellbeing. For many of the patients, including those who were initially reticent in sharing their stories, the information about their way of life at home flowed more easily than when asked about life on the wards. Many described, with some nostalgia, having their own chosen routines for mealtimes when in their own home:

“You see I like to eat at the table because me bread and butter were there – all laid out ... what I mean is ... it would cheapen the meal I were eating by having it on me knee on the sofa ..... and I wanted to eat it in a proper way with a knife and fork.” Patient 02

The use of the words “cheapen” and “proper” indicated patient 02’s strong preference for his own mealtime routines and customs. Other patients described their own ‘rules’ from when they were growing up that were still a conscious and important part of their mealtime experiences relating to different aspects of the mealtime. Participants described their views on appropriate settings for a meal and reflected that eating at a table (not on the knee) was a strict family rule. Family customs governed the sequence of the meal and how the meal was eaten:

“... Sunday lunch was a big event you know and we would have ... the first thing we would have would be the Yorkshire pudding separate on the plate without the main meal, and then we’d eat that, get fresh plates, cutlery, and then have the main meal, and then we’d have what me mother used to call a ‘finish off’ which is the dessert.” Patient 07

Patients recalled these memories and customs from earlier life with affection. These rules relating to what was perceived as appropriate and acceptable for mealtimes appeared deep-seated and retained into adult life. On the wards however, individual rules that were important to patients were not feasible being replaced instead by a communal approach and hospital routines.

Patients acknowledged that ward catering services did consider religious dietary needs in menus, however these were not always implemented and were unpredictable and uncertain in practice. Individual patients described how they had adhered to religious customs (e.g. to pray before meals) and beliefs prior to admission to the ward. However, there were comments that the following of



religious routines and practices was difficult on the ward due to social pressures or lack of active encouragement and support from the staff:

“I know if you've got someone that wants to like, pray just before when they've received a meal or something, they might not feel comfortable to do that. Because there is like peer pressure in hospital kind of thing.”

Patient 13

Participants' comments showed that individual customs, whether based on religion or personal cultures, were not considered adequately and individuals did not feel able to raise or maintain these in the shared dining rooms. Religious aspects were perceived to be recognised by the organisation in terms of menus and food options, but these often failed to materialise and individuals' needs for mealtime behaviours and practices were not understood or supported by staff or patients.

### **5.6.3 Inpatient meals feel institutionalised**

Patients' experiences of the routines and systems in place for mealtimes related to feelings that the meals were part of an impersonal, institutional system. Their descriptions suggested a sense of resignation and dependency in relation to mealtimes. Participants described routines for queuing and waiting for food to be served suggested these were immutable practices with little or no variation:

“Everybody knows 5 o'clock teatime, I think most people have got an internal clock you know, ... 5 o'clock, its teatime ... you queue ...patients and staff they keep 2 metres apart.” Patient 04

The queuing and waiting routines were rigid and unquestioned and suggested distance between patients and staff. The comments suggested that the patients felt helpless in terms of achieving the food items they had ordered despite the system offering a choice of menu options listed the day before:

“Yeh, the food ordering is ridiculous because either they haven't got it the next day, they run out of the amounts they've ordered the next day... or it's promised to somebody else ... another patient.” Patient 02

This situation linked to the frustrations discussed above regarding choice of food at mealtimes. Patients perceived that staff offered support to them as a whole

group based on common areas of need, rather than attending to individual choices:

[Researcher asks: "Do you think they take account of what individual people might want?"] "No, they just bring whatever they think is good for the patients ... maybe I'm right or wrong." Patient 01

This patient was cautious in offering comments and appeared reluctant to sound critical of the system. Other patients were more explicit and disapproving of the practices in their comments:

"... generally speaking, it's only certain staff who behave, as I say, with this despot attitude, you know." Patient 07

Referring to staff as "despot" and having "prison mentality" (Patient 13) added to the sense of patients' powerlessness on the ward. Some participants reflected on the staff roles at the mealtime with an air of hopelessness:

"Er ... staff are not really good they don't really help. .... but the staff they don't really talk ... they don't really talk to patients ... no idea...it's sad."  
Patient 01

Participants' accounts presented critical views but were also passive and accepting of the situation, and no participants outlined pursuing these issues through patient groups or in discussion with staff.

Patients' comments described how staff controlled the timing and options for the meal giving an impression of dependence. For some the system offered protection and safety, for others the impersonal mealtime routines and supervision created an impression of constraint with the needs of the organisation superseding the individuals' needs. This led to descriptions of feeling restricted and contained. The emotional reaction to staff supervision and control was clearly voiced by some showing frustration and annoyance:

"It makes me wound up, it makes me want to say something ... I want to say to that person [staff] 'Listen, wind your neck in, it's part of his illness' ... just be polite and speak in a soothing tone". Patient 07

The distance that participants perceived between patient and staff interests was apparent across the interviews. This perception of staff-patient distancing at mealtimes linked with the prior themes described, particularly with regard to

emotional reactions and difficulties with relationships at mealtimes. There was again a sense from the participants of the mealtime viewed by patients and staff as a task rather than a positive, comforting, and valued part of the day.

### **5.7 Summary of patient findings**

The overarching theme of 'heightened emotions associated mealtimes' has been discussed with reference to four main themes considering the emotional aspects of inpatient ward mealtimes which are in turn influenced by practical and logistical aspects such as the environment, timing, swallowing difficulty, choking experiences and related anxieties. Social aspects such as mealtime companions, staff presence, and the limited nature of any support provided were highlighted. Each theme captures how the patients experience the mealtimes on the wards and highlights the aspects which are of most concern from the patients' perspectives. Patients expressed dislike for the inpatient dining rooms and food options, with a preference for quieter places to eat on the ward or to prepare their own food. The variation between choices and reactions to the ward routines is contrasted with their individual and more favourable home settings, where they experience more relaxed familiar routines and preferences and could exercise more choice and control improving their mealtime experiences. Although the mealtimes on the ward offered connections and social opportunities with other patients and staff, this was experienced as being difficult to tolerate and something to be avoided. The home routines were described as flexible, comforting, and offering independence to choose foods, times, and places to eat in contrast to the ward routines which were described as prescriptive, restrictive, anxiety-provoking, and rigid or institutional. The impact of noisy, crowded, and somewhat chaotic ward dining rooms was highlighted as a negative influence on mental wellbeing escalating anxiety and stress. Patients described how stress and anxiety can lead to rushing the meal with consequent increased likelihood of choking and distress.

The following chapters will describe the themes derived from staff and SLTs views of the patients' perspectives of inpatient mealtimes.

## Chapter 6 Findings from staff interviews

*well ... everybody knows that mealtimes is tough ... right?* Staff 02

### 6.1 Introduction

This chapter presents the findings from the staff interviews. Staff participants included those who were working as allied health staff, nurses, or catering staff. Participant characteristics are described with a reflection on their engagement during the interviews and their interest in the topic of mealtimes and mental health. Reflexive thematic analysis was conducted for this group separately following the analysis of the patients' interviews (Braun and Clarke, 2022). A thematic network illustrates the themes and subthemes (figure 6). Definitions are presented to describe and delimit the scope of each main theme. Within these, details of subthemes are described to clarify the content.

An overarching theme of organisational constraints covered four main themes:

- Mealtimes as a task to be completed.
- The importance of personal cultures.
- The impact of mental health on mealtimes.
- Mealtimes not integrating with recovery.

These themes are presented highlighting the staff perspectives around the ward mealtimes. The themes from all three participant groups are discussed and synthesised in Chapter 8.

### 6.2 Staff characteristics

The participants consisted of 12 staff from a range of mental health acute, forensic and rehabilitation wards. These included both locked and open access accommodation. Participants had a wide range of professional experience working on mental health wards in terms of years (experience ranged from six months to 20 years), and locations. The relatively high proportion of female to male participants in this group reflected the workforce in mental health services being primarily female

(W.H.O, 2019c). Current engagement in religion was not common with only four participants reporting active or lapsed religion (all were Christian). Further details are not reported to maintain anonymity. Reference codes for each participant are given following each quote, in the format 'staff number'.

Demographic information:

- The 12 staff participants were recruited from acute mental health wards (n=4), forensic wards (n=1), and rehabilitation wards (n=7).
- Their roles included occupational therapy, nurse, dietitian, recovery worker, catering services.
- The participants' ages (in decades) ranged from 20s to 60s.
- Of these 10 identified as female and 2 identified as male.
- Ethnic/cultural backgrounds were reported as a majority white British (n=9) with the others African (n=2), and Asian British (n=1).

The majority of staff (n=10) were interviewed online, two participants opted for in person interviews. The interviews were completed May 2021 to August 2022 in wards across Leeds, UK with the duration of the interview ranging from 16:34 minutes to 46:05 minutes (total data time = 373:20 minutes).

### **6.2.1 Reflection on staff interview responses**

Recruitment resulted in swift return of interest and participants all presented as keen to offer their insights and concerns regarding the inpatient mealtime processes and practice. Duration of experience on the wards was very varied but many had spent additional time as students or as support workers in mental health settings.

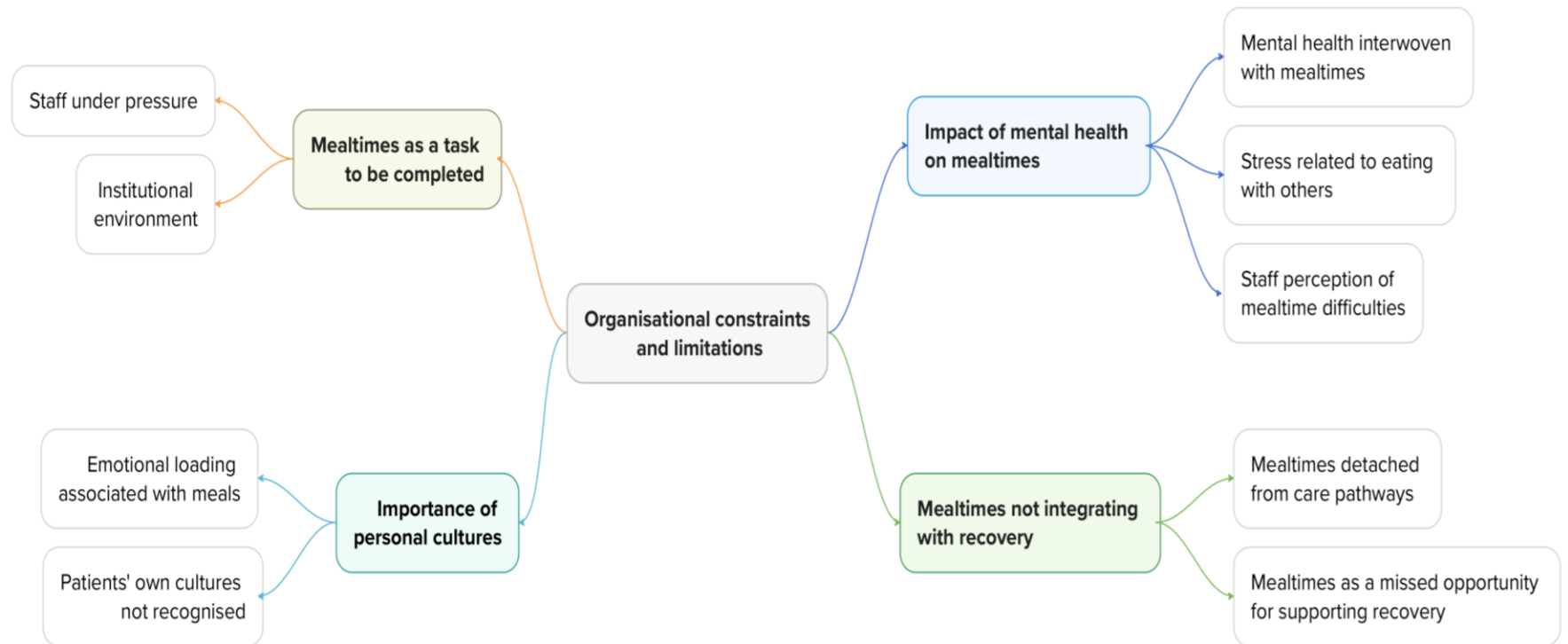
Staff introduced the mealtimes as a negative experience both for the patients and themselves at the beginning of the interview. The comments were carefully tempered using subtle, cautious vocabulary often offering phrases starting with "not ..." for example: "It's not an enjoyable experience, I don't think" Staff 03; and with qualification "it's not particularly great" Staff 11.

Over the course of the conversational-style interview staff gradually developed and expanded on their insights adding further comments while reflecting on their experiences. Many expressed empathy for the patients and offered their suggestions

for improvements in the way mealtimes are managed on the wards to improve patients' experiences. However, some instances of guarded phrasing of the comments and hedging of the difficulties suggested some degree of reluctance to criticise higher management and possibly a loyalty to colleagues and the organisation. The overall impression was one of concern for limitations in mealtime practice.

### **6.3 Overarching theme: organisational constraints and limitations**

The overarching theme 'Organisational constraints and limitations' reflects the staff's perceptions of the organisational systems controlling and influencing mealtimes on the inpatient wards, particularly for the catered meals supplied by staff. Staff interviews reflected a wide range of perceptions including restrictions in time, food choices and settings that staff considered could not be altered. They presented mealtimes as a 'nutritional task' to be managed and controlled in the day's routine. Staff acknowledged the impersonal and predictable nature of the processes in place and discussed how this challenged the potential opportunities and benefits of mealtimes. They reflected on how mealtimes might represent more than just a means to fulfil a person's nutritional needs. Indeed, many staff aspired for mealtimes to be improved to offer wider and more personalised opportunities for supporting recovery. Although they described valuing social and emotional benefits of enjoyable mealtimes, these were not viewed as achievable due to the organisational constraints. Within this overarching theme there were four main themes capturing the difficulties resolving individual needs with organisational pressures. These main themes are described below and summarised in a thematic network with further detail presented as subthemes (figure 6).



**Figure 6 Staff group thematic network**

#### **6.4 Theme: mealtimes as a task to be completed**

Definition: This theme captures the sense that the mealtimes were pared back to a routine, functional task with the primary aim of supporting nutrition. Patients attended mealtimes to access food and satisfy hunger in a safe environment described as being under careful supervision of staff. The mealtime environment, personal customs and social aspects were limited by the organisational systems in place, and this was perceived to have an adverse effect on patient independence and mental wellbeing. The organisational processes were implemented as blanket rules – with the patients perceived to have little to no control over their mealtimes. Staff participants also identified additional pressures from the people present and the physical setting of the mealtime making reference to noise levels and crowding.

##### **6.4.1 Staff under pressure**

Staff described the mealtime as a necessity, a task to be completed primarily for the nutritional needs of the patients. Some described their role with detachment, explaining “one of the jobs that I do is meals” (Staff 02) and focusing on the nursing role. The choice of vocabulary suggested an impersonal approach. There was a sense of the patient as a passive recipient at the meal, perceived by staff as one of many rather than an individual. Others described how the mealtime routine had become embedded in terms of patients following the same patterns of behaviour:

“... it feels here that people come in, they get their meal, they eat, they leave.  
... That's one thing I've noticed is it's very ... uniform, but I think that kind of says a lot ... potentially about the type of service users that we see because a lot of people are very institutionalised and regimented.” Staff 04

Staff described both the structure and organisation of mealtimes, and patients' behaviours as ‘uniform’ and ‘regimented’ and they related these to institutionalisation. The patients were described as a group entity without discriminating between individual preferences and concerns and as such the mealtime task was associated with achieving speed and efficiency in nutrition for the patients as a group.



This theme included concerns about the lack of social and emotional benefits in the current mealtime routines. Interviews reflected that little happened during the mealtimes that was deliberately designed to increase enjoyable social interactions between patients or patients and staff. Participants described how individual choices were reduced to a common solution:

“[rather than individual orders] the staff ordered so many of each meal, meaning the majority of the time people just didn’t get what they really wanted ... that wasn’t good at all, and you’d try and bring it up with ... you know senior staff management and it was always ‘oh well its easier you know’ and ‘we haven’t got time to go round asking people what they want the day before’.”

Staff 09

Staff made it clear that the task of getting through the meal in such a fashion was implemented without question, and without considering ways to vary or change the routine:

“On the ward, it’s just one of those things that has to happen, and nobody gives it a second thought.” Staff 09

Some staff did reflect on how patients might view the function of the mealtime as providing food and drink, as opposed to being a social opportunity to be welcomed and enjoyed. Staff expressed feeling pressured in managing the mealtime routines and the patients’ access to the dining room. This was a challenge for staff in a busy day with many other tasks competing for their attention:

“... there's a bit of a culture I think of staff wanting for meal service to be done as fast as possible because then they can crack on with other things.” Staff

11

The mealtime was perceived as an additional routine task in a sequence of duties waiting for completion during the day. Other staff saw the mealtime as a means of occupying patients’ attention, giving staff the opportunity to concentrate on other tasks. The number of tasks to juggle during the mealtime both in the dining room (e.g. sorting menu choices, supervising behaviour) and duties elsewhere on the ward, meant that those staff who might seek to interact were constrained by other

demands and any aspiration to sit and chat during the meal was not realised. Staff could reflect on how a shared mealtime would also be of practical personal benefit since many explained that they did not have a meal themselves during the working day, due to the pressures of work and no opportunity to eat with the patients.

Staff participants described their supervisory role in the dining room with their attention focused on managing risks around behaviours and conflict between patients. However, supervision relating to specific support needs of individual patients was rarely mentioned and few related any concerns about patients' mealtime risks or swallowing difficulties. The act of supervising in the dining room brought an impression of distance between staff and patients during the mealtime.

"I've kind of noticed in other services when staff have kind of been stood up kind of near the door, it does feel a bit more kind of almost like a prison guard."

Staff 04

Staff reflected on how this surveillance might be experienced by the patients:

"... yeah, if I was thinking of it from the service user's perspective, I think I'd feel uncomfortable with it." Staff 04

Staff recognised that sustained observation throughout every mealtime could become a source of difficulty for the patients – some participants reflected that patients might experience this as controlling and oppressive. Staff used negative vocabulary to describe their attitudes to, and experiences of mealtimes on the ward, examples included "nerve-wracking" (Staff 04); "encroaching", "hostile" (Staff 06); "frustrating", "intense", (Staff 11) conveying a sense of difficulty interacting with patients. They gave examples of how mealtimes were associated with particular 'triggers' for individual patients resulting in risky behaviours that needed supportive management. Several participants described mealtimes as a "flashpoint" (Staff 03), with their concern being to de-escalate any issues between the patients, offer assistance, or restrain the patient in some way. Others agreed that the mealtimes appeared to be a trigger for tensions and frustrations which may have built up over time on the ward and be related to interpersonal relations:

“I suppose from a staff perspective, you're sat in there and you've got to manage that. You have to be prepared to respond, and I think ... Some days it can be much more monotonous and relaxed. Uh, and I think those days definitely do exist ... But by and large mealtimes have always been a bit of a time of tension, ... you just you never know what's gonna happen. And often things come to a head within mealtimes, I'm not sure why, but I always kind of felt like they did.” Staff 07

Staff 07 contrasted the unpredictable responses from the patients with the sameness of the routines describing previous events, tensions, and difficult relationships that “came to a head” in the close proximity of the mealtime setting. Other staff described how they would approach a patient who was struggling to manage their behaviours:

“I guess one of the things to look out for is kind of behaviour. So, I would kind of, if someone is, you know, saying things that might be distressing to others. I might just kind of have a quiet conversation with them.” Staff 01

Occasionally staff explained how they would encourage patients to take time out to settle if the mealtime was difficult for them. Escalation of behaviours in the somewhat aversive and ‘triggering’ mealtime setting appeared to be an ongoing concern and the potential for conflict ever present in the supervising staff’s minds.

#### **6.4.2 Institutional environment**

Staff described the routines associated with mealtimes as being rigid with no options to adapt to patients’ needs or preferences. The “rigid rigidity of the time frames” (Staff 11) reflected lack of flexibility which was also not appropriate to patients’ individual needs and choices. Participants described the experience of patients who missed a mealtime and were then not able to access a meal until the next official time, expressing concerns on the impact of this on recovery and general health. The staff also reflected on the patients’ habits and personal routines. They were aware that patients had different needs, customs, or an idiosyncratic way of life in relation to meals so that the rigidly imposed mealtimes were perceived as unhelpful, insensitive, and overly restrictive:

“We’re not a ward of early risers, so then that automatically kind of puts them on the back foot in terms of having their meals. You don't want to wake up at like half 11 and then go have a like a full on dinner at 12:00 o'clock. And so, I think it is really restrictive.” Staff 12

Staff questioned the reasoning behind the mealtime schedule and suggested that the organisation had determined the times for reasons that were unclear to them. Some felt that the timing suited the organisations’ needs rather than the patients’:

“I'm not sure kind of where that came from, almost ... whether it's what the food service provider can work with, whether it's more of an organisational choice. ... yeah, I don't ... I've never known where that's coming from.” Staff 04

Staff acknowledged the practical difficulties of offering mealtimes for large numbers within an organisation. However, for some there was a wish to offer mealtimes more in line with life outside the hospital environment, linking to the theme of integrating with wider recovery. The concerns regarding neglecting individual choices and preferences also linked with themes below.

Staff reflected on the dining room itself and how this environment affected the patients before and during the mealtime. There was general concern that the setting was not welcoming or comfortable. Details such as décor, table layout and the serving hatch were all aspects seen as clinical, functional, and missing any homely or appealing characteristics:

“There’s some notice boards up with menus and things but I’ve never seen anyone look at it and its just kind of there and it’s not very nice to look at ... I think the walls are very bare ... and it’s not a very nice room to be in.” Staff 09

The setting out of tables and chairs was described as “claustrophobic” (Staff 01), with a sense of crowding. The serving out of the food through a serving hatch felt impersonal and functional. Forming and waiting in a queue was perceived as an issue for patients leading to stress building from the start of the mealtime:

“They find it very difficult waiting for the meals ... they all come at the same time right at the beginning you know ... they’re kind of queuing for a long time. Obviously, it’s not an ideal situation.” Staff 01

Staff considered the impact on patients, but were conscious of organisational constraints:

“I think this is probably organisational ... and we only have so much staff time? So, I think it is kind of weighing up ... What is good in an ideal world and what is doable in reality?” Staff 04

Staff identified the noise levels in the dining rooms as a particular issue for some patients and felt the setting was “chaotic” (Staff 01). Some staff’s duties (e.g. on the forensic wards) included insisting patients remain in the dining rooms for the mealtime for supervision. There was discussion on how this did not suit individuals who sought to sit in other areas for their meals or eat in their bedrooms. There were further concerns about how the layout and crowding in the dining room felt like a deterrent for socialising between patients. Despite this, staff described how some patients attempted to initiate conversations with their other patients:

“It doesn’t feel like a social environment ... I know a lot of people kind of just sit there ... not really talk. Or if you do talk, you’re kind of the odd one out and so I feel like that’s quite a jarring experience.” Staff 08

Socialising during mealtimes (i.e. having conversations with other patients or staff) was not sustained due to the unwelcoming environment. Staff commented on the silence of the other patients but also suggested that the elevated noise levels and commotion in the room limited interactions. The staff presence did not typically include encouragement to converse during the mealtimes:

“We just kind of sat in the corner just watching them eat ... which feels a bit uncomfortable.” Staff 01

The staff pressures of time and organisational protocols were acknowledged and ever present in the accounts of the staff. COVID-19 brought further specific challenges to managing the environment and promoting safety, particularly in relation to social distancing. Some participants appeared to reconsider their current

practice and processes describing how they would like to improve the setting and the flexibility of how the meal was presented and delivered.

Following the descriptions of the institutional approach to mealtimes, participants also commented on the food lacking appeal or taste:

“They may be not the best of cooks and ... you know it's not actually quite nice. Whatever the cooking or like the meals aren't nice on, you know, the [caterer] meals ... or they're cold? Or they're just unpleasant.” Staff 12

Staff described foods being “slopped” or “plonked” on the plate when the food was served and considered the meals lacked visual appeal. There was a lack of sensory stimuli associated with the meal generally and this affected engagement with the meal, staff commented that the food aromas gave no hint of the different items on the menu:

“They're cooking five different meals, but it's almost just this one ... cooked, you know, reheated smell ... the smell of food is just like the rest.” Staff 11

Staff participants suggested that the institutional mealtime approach actively affected the emotional wellbeing of the patient due to the lack of positive choices in the food offered and eating was a ‘chore’ for patients. Without access to personal choices, the mealtime became a task to be endured. Many staff described menus being offered the day before the meal was consumed providing limited and repetitive choices. The resulting frustrations meant staff had to deal with the patients’ reactions to unexpected changes:

“I think people can get really distressed when the meal orders change at the last minute... And I know it's easy to kind of dismiss it and say, ‘oh, you know, it's not a big deal’, but actually, you know, I guess in somewhere like this you have so little control over everything else ... that's going on in your life. You know your choice ... that what you want to eat is probably important.” Staff 01

Staff felt this was a difficult and stressful aspect of the mealtime management. They expressed sympathy with the patients and showed understanding of how this was distressing and frustrating for them.

## **6.5 Theme: importance of personal cultures.**

Definition: this theme focusses staffs' insights on the need for supporting individuality at mealtimes, particularly in relation to cultural aspects of mealtimes such as religious observances and personal routines and practices. Again, this theme reflected the prior findings of unchanging institutional restrictions and blanket group level processes. Personal aspects of mealtimes could not be supported, and this was viewed as being to the detriment of patients' wellbeing and recovery. Staff described their own preferences and customs for meals at home as an important part of their personal culture and wellbeing. Some described religious observances associated with mealtimes and how this underpinned their sense of community and belonging. For others, the same sense of belonging was achieved through family customs and personal rules for the mealtimes. Emotional wellbeing was closely linked to being able to observe these preferred mealtime processes, and many staff described social connections through sharing food being an important part of their mealtimes.

### **6.5.1 Emotional loading associated with meals**

This subtheme relates to the mealtime experiences of staff at home providing some insight into the lens by which they observed patients' mealtimes on the wards. Staff ascribed importance to understanding patients' individual preferences and customs so that mealtimes could be more therapeutic and mutually enjoyable.

Staff reflected that for their own mealtimes at home there was a sense of being able to relax, mealtimes were a focal point of home life, building emotional wellbeing, and connecting with others. Staff described their own mealtime cultures as satisfying a deep-seated emotional need:

“Emotionally food is so ... it brings me like joy to eat, to eat well ... to eat good food ... and cook good food and eat good food. So, I just feel like sometimes there's the emotional response as well.” Staff 05

The benefits to mental wellbeing derived not just from the act of eating but also from cooking and sharing the meal, particularly at the end of a busy day, helping the staff member to settle back into the home and recover from the stresses of work. Staff

reflected on their own personal preferences and habits around mealtimes highly valuing personal freedoms to choose how they would arrange their own mealtime environment so that the setting was exactly to their liking. Such preferences might have related to or evolved from long standing family traditions and were seen as important for enjoyment of the meal:

“I personally wouldn’t like to sit in the dining room on the ward and eat my dinner ... cos that’s just not how I’ve ever done it ... I’ve never sat at a dining table to eat so it would be quite strange for some people I think.” Staff 09

Others explained that, as independent adults, they had adapted their mealtime routines and that these were not adhering to previous family rules:

“My normal yeah, it’s terrible ... It’s absolutely terrible ... I was brought up totally differently and my mother would be appalled if she saw what I do ... Mom would have wanted me sat at the kitchen, sat in the kitchen at a table with all the family around us and we would be having a meal together and that was how I was brought up.” Staff 03

Some staff recognised that they broke from custom, and “broke the rules” from their upbringing, describing what was considered appropriate mealtime behaviour and comparing this with their present-day routines.

### **6.5.2 Patients’ own cultures not recognised**

Staff perceived differences in patients’ cultures and customs at mealtimes, with some appearing more aware than others of how patients’ cultures could align or conflict with ward routines. A few participants described their experiences of supporting patients from different cultural backgrounds, giving examples of patients being unsettled by the unfamiliar mealtime routines and expectations imposed on the wards. They emphasised the importance of pro-active measures to understand a patient’s personal mealtime routines:

“Actually, I still don’t think we ever ... ask people outright. Like what do you prefer? Would you like me to sit with you? Would you like me to talk or not talk.” Staff 12



As well as being aware of the cultural needs of the patients, Staff 12 considered it important to understand in detail ways to make a mealtime safe, comfortable, and appropriate to the patient's individual customs and preferences with a view to sustaining recovery in mental wellbeing. Participants also measured the patients' behaviours against their own routines and experiences:

"One of the staff members has said 'ohh, ... he's not even using a knife and fork', but actually like that culturally, that is, you know, for this guy, he would ... when I used to take him on home visit [what] he'd eat was a lot of finger food and eating curries with chapati ... people have their own perceptions, don't they? And then when those ... aren't met by other people you might hear sort of comments or like inquisitive thoughts about the differences." Staff 11

Staff also varied in how they described the religious aspects of mealtimes for patients. Levels of attention to this varied between participants. Some staff described other staff members' practices and commented on limited attention to specific religious observances:

"I think again that's that the conversations we're not having. So do people, some people like to pray before they eat? Do some people need to observe certain practices, and I think again those are conversations that we need to be to be mindful that people may have. But they also may not feel comfortable telling us." Staff 12

Staff 08 commented on the importance of adherence to religious beliefs associated with mealtime practices and how this impacted on the patients' wider mental wellbeing and recovery:

"If it's being missed out, there's a potential that they could either stop eating, or they could eat something that was completely against their beliefs, which then could impact their mental health enormously." Staff 08

The organisational processes and rigid routines did not appear conducive to either recognising or supporting each patient's personal customs and preferences. The communal dining rooms were perceived to be a source of concern and staff felt

constrained by what was feasible in the shared setting. This need to work at a group level was at odds with the promotion of individual recovery:

“I just think it's a real one size fits all. I don't think there's many options for people to ... have just a bit more of an individual take on the mealtimes really, so.... I see it is still quite institutionalised part of our service, I see it as a bit of a standout kind of like perhaps a bit different to the way we do with the other things.” Staff 08

Describing the mealtime settings, the organisational processes, and the associated limitations, staff highlighted the impact on the patients. The requested menu choices did not always materialise at the mealtime and the staff showed frustration at being unable to support this need. Patients' choices were seen as not respected and staff described patients' negative reactions to this lack of autonomy and control:

“You can have ordered something the previous day ... and it won't matter. Your choice consistently does not matter because it is probably subject to change.” Staff 07

Staff explained how mealtime changes and food choices came to rest on staff rather than patients who were disenfranchised from and disempowered in relation to mealtime decisions. In addition to organisational determiners and staff acting as decision makers, mealtimes could be dominated by more assertive patients making their needs known which could impact on the choices of other patients:

“I think for me the most significant thing, is that people don't really have options so they're always kind of ... having to tolerate the environment that the loudest person or the most confident person has asked for or wants.” Staff 01

These comments reflected that patients lacked autonomy, choice, and control over mealtime decisions regarding the environment, food, timing, and other people in the room. Hence, recovery and individual decision making appeared to be on hold for the mealtime, constrained by the need to manage the group of patients and by organisational constraints. Staff expressed regret, empathy, and frustration on patients' behalf, and most found it stressful as a task.

## **6.6 Theme: impact of mental health on mealtimes.**

Definition: This theme reflects the reciprocal association of mealtimes with mental wellbeing. As described in previous themes, mealtimes can elicit a wide range of emotions. Some patients may come into hospital with anxieties and stresses around mealtimes and eating as part of their mental illness. For others, the negative emotions associated with inpatient mealtimes contrast with the positive emotions associated with mealtimes at home. The institutionalisation of mealtimes within the mental health ward can exacerbate the stresses related to social, sensory, or historical influences including trauma. The presence of other patients and staff, particularly those in a supervisory role, can escalate the patient's distress and reduce tolerance of the dining room. Staff participants recognised that understanding the nature of these issues can be difficult for the patient (who may be lacking insight) and also for the staff (who may be lacking awareness and/or opportunity for providing individual support).

### **6.6.1 Mental health interwoven with mealtime difficulties**

Staff commented on the patients' previous histories and how they coped generally with everyday routines around food and drink on the ward. Some staff described supporting individuals to engage with ward mealtimes and that this could be problematic if the food, place, and/or routines were not familiar or comfortable for the patient. Mealtimes were often a stressful experience:

“... the lady who really hates the dining room and will pull back from it. She's the one with a history of eating disorders but it's not really been considered in her diagnosis and her care. She has restricted eating, she's quite chaotic in the kitchen and finds it quite stressful - and I see her mental health impacting on how she eats quite a bit.” Staff 08

Staff emphasised that individual difficulties and issues at mealtimes were not widely recognised in terms of overall mental health. Even if the mental health or emotional difficulties related to mealtimes were recognised, staff described colleagues as not being confident enough to respond appropriately:

“They [staff] just really didn't get it ... they just don't get it and I just don't know if they [staff] know what to do, or what's best.” Staff 08

Other staff described some patients having specific phobias or fixations about food in a communal area, for example fears of poisoned food or anxiety about people. The mealtime experience could result in patients becoming more unsettled and distressed:

“I know if she felt rushed that would not only impact her mental health, but kind of ... other people there, and sensory stuff, her eating experience. She really found that really hard to focus. It would take her an awful long time to eat, and she would often ... kind of drop things and stuff 'cause she felt a little bit, you know, flustered ... It just completely ruined that meal for her.” Staff 08

Staff accounts highlighted that mealtimes were more tense and anxiety-provoking than other situations or activities in the day's routine. Staff reflected on the need to take time to understand the reasons behind an individual patient's mealtime anxiety – and how this might present or escalate as behaviours in the dining room affecting other patients and staff.

### **6.6.2 Stress related to eating with others**

Staff considered that for some patients, the dining room was an intimidating environment prone to intensifying anxiety due to fear of other patients or staff observing them. Staff 09 gave a specific example of mealtime experiences that patients found frightening:

“... the noise and being around other people who may be experiencing psychotic symptoms ... it's not something that they're [i.e. other patients] used to, people find that quite difficult, especially if some of them are shouting and experiencing delusional beliefs that they're shouting about, talking about, it can be quite anxiety provoking.” Staff 09

Staff showed empathy for patients in this, acknowledging that such behaviours are difficult to tolerate and outlining their own difficulty in managing these behaviours in the dining room. The most difficult behaviours described by staff, were those which

originated outside the dining room and caused a build-up of tension prior to the meal. This could escalate in the confines of the dining room, however patients typically had no choice but to eat in this one location. The mealtime was the only time during the day that patients were obliged to meet other patients, at other times difficult situations could be avoided on the ward. Those who wanted to eat had little choice but to enter the dining room and face the person who they perceived as “hostile” or feared a confrontation “kicking off” (Staff 06). Staff therefore understood and empathised with patients who left the room or avoided the meal entirely:

“I’d probably just go ‘I’m just gonna leave it. I can’t be bothered with that today. I’m just gonna get some cereal’. And you know, I mean, I think that those things aren’t considered and because we don’t have the flexibility, I think people get a bit stuck.” Staff 08

Occasionally staff had the option of supporting patients to eat away from the ward dining rooms and they described offering a more individual approach. The benefits of a quieter space and personal attention were emphasised.

Staff also commented that the more severe triggers provoked by mealtimes were associated with patients who had previous traumatic experiences. Staff reflected on how mealtimes on the wards presented adverse stimuli for these patients:

“... that ‘come on, let’s hurry up’ and that sort of pushing and actually, when you think about that trauma informed care model, that’s not really that fantastic for somebody who might have as a child experienced that - through to somebody who maybe they were abused by ... not saying it replicates anything you know to that extent, but it I think that could be quite triggering and stressful for people definitely.” Staff 11

Other aspects of mealtimes directly relating to the patients’ mental health were described, for example the messy eating styles of some were highlighted as being particularly stressful for patients with obsessive compulsive disorder (OCD). For those patients with strong reactions to untidy eating behaviours this added further stress and anxiety:

“My service user [patient] with OCD, he could not eat in the dining room, and he said ‘I’m not being horrible ... I’m not judging him. I just can’t. I can’t eat my food, not looking at him’ and that was that was quite difficult.” Staff 08

Staff 08 went on to explain that the disgust and avoidance of this patient became known to the messy eater who then experienced deterioration in self-esteem and mental wellbeing.

Staff reported that patients needed support to voice their concerns and feelings about the stresses at mealtimes. They observed that some patients chose to avoid the other patients in the dining room and that this was part of how they coped in order to get their meal. The pressures of the dining room were also seen to result in patients rushing their meal to leave the room as quickly as possible. Occasionally staff recognised that this could result in unsafe eating patterns putting some patients at risk:

“If people are feeling rushed or feeling like they need to eat faster, ... if you’ve got somebody that is predisposed to risk of choking, is that going to have an impact?” Staff 11

The need to consider wider recovery was raised and participants reflected on how much staff colleagues were aware of the individual patient’s needs. Staff 01 commented on the need to support patients who were avoiding the dining room:

“We don’t kind of say or you know ‘why is it that you’re not coming? Is there something about going to the dining room that you find difficult? Or is that you don’t like the food? Or is it ...?’ You know, we’re not necessarily always delving into that. ... we haven’t really necessarily always understood the problem that’s underneath.” Staff 01

There was an overall sense that staff would respond sensitively to patients who voiced their anxieties about the mealtime but if not initiated by the patients, staff would generally not seek to discuss mental health issues related to mealtimes or other mealtime difficulties.

### 6.6.3 Staff perception of mealtime difficulties

Staff discussed what support they typically offered during the mealtime for patients who were experiencing difficulties in eating, drinking, or swallowing. Their understanding was variable, a few staff could describe signs of difficulty in the act of eating and drinking and consider the person's ability to swallow:

"What I'd be looking for is coughing, spluttering kind of eyes watering ... that sort of thing would signal to me that someone is struggling with their food or kind of ... how they're sitting: if they're kind of particularly hunched over, or I don't know, abnormally moving." Staff 04

The descriptions of risks and concerns about choking suggested lack of awareness and confusion. Others reported that they had little experience of patients' choking on the wards and thought that the incidence was minimal. Some staff were fearful of supporting people at heightened risk and described their attitude to mealtime observation:

"Choking is something that absolutely terrifies me. Like, I hate it. It really scares the ... It absolutely terrifies me ... Awful, awful." Staff 12

Participants had concerns on how anxiety could accelerate speed of eating, consequently impacting on the ability to swallow safely, and potentially leading to choking. Comments suggested particular concerns with patients who crammed or overfilled their mouths during the meal. However, staff also reflected that the risk of choking was not something they had considered previously:

"Up until this conversation actually that I had never even thought about. Or clocked with her the whole ... the way she would drink and smoke and drink and smoke and it just being very very rapid, like I'd ... I'd never even thought about it up until this point, to be perfectly honest." Staff 12

There were occasional descriptions of patients who had more severe levels of coughing and choking but generally lack of awareness in both staff and patients was a concern for participants.

## 6.7 Theme: mealtime not integrating with recovery

Definition: This theme captures the perceived gap between recovery pathways and mealtimes. The ward mealtime routines and dining room settings were perceived by staff as being at odds with patients' mental wellbeing and autonomy. There was a sense that not only were mealtimes detached from the process of recovery planning and pathways, but they could become actively harmful to mental wellbeing through the stresses and specific triggers of the mealtime setting. Developing social aspects of the meal and connecting this with life outside the ward were seen as important for the patients' sustained recovery. Eating socially on the ward was seen as a starting point for recovery and allowed staff insights into how the patient was progressing.

### 6.7.1 Mealtimes detached from care pathways

Participants reflected on patients' wider recovery and how mealtimes affected rehabilitation:

[Researcher: "So, thinking about recovery and care pathways, how do you think mealtime features in the person's care pathway or recovery?"] Staff: "It doesn't really, it doesn't fit, it just feels like a thing that has to be done and it's never really thought about." Staff 09

This separation of mealtimes from other aspects of the recovery pathway was seen as concerning. Staff lacked opportunities to address issues around the mealtime experience and support patients' skills for future wellbeing:

"I just think it's an environment for a little bit of stagnation if I'm honest. I think things stay the same, and I don't think staff are given the tools to kind of make it better, and make it more pleasurable experience, but also incorporate into people's care ... we don't have to wait till someone leaves hospital ..., for that work to begin." Staff 08

There was a sense of lost opportunity to consider mealtime experience and develop skills and independence. Staff described how patients became "institutionalised" so that their understanding and expectations of mealtimes were limited and framed by ward routines. As a result, support for mental wellbeing around eating and drinking



was not incorporated into treatment planning and staff raised the consequent impact on sustained recovery:

“So, if we're getting them into one [routine] here and then all of a sudden, you know they can't translate that into their outside world. Automatically, like we're setting up a little bit of failure there for them, because how do we get them to adjust to that?” Staff 12

Staff were keen to suggest improvements but were very conscious of mealtime restrictions present on the ward. Reduced staff capacity was viewed as limiting opportunities to include mealtimes in rehabilitation. Flexibility and choice for mealtimes was seen as an important part of developing independence, and staff emphasised how this should be considered when planning for leaving hospital. The sense of contrast between mealtimes on the wards and mealtimes at home was clearly expressed underpinning concerns about integrating mealtime experience with recovery.

### **6.7.2 Mealtimes as a missed opportunity for supporting recovery**

Staff discussed their ideas on how mealtimes on the wards could be adapted to work towards improving and sustaining mental wellbeing. Key to this was integrating emotional and social aspects into mealtimes:

“We were worried about ... kind of social isolation because he was spending all his time in his room and we thought you know one of the ways we could get him out of this room was to kind of to encourage him to at least spend a meal a day, you know, in the dining area.” Staff 05

Understanding the potential for triggering distress and the underlying mental health issues associated with mealtimes was recognised in patients with specific known mealtime difficulties (e.g. eating disorders) but for the majority, mealtimes were not integrated into the recovery pathway. Staff associated recovery with access to choice at mealtimes. This included recognition of the importance of supporting individual access to culturally important food choices (also raised in the theme above ‘Importance of personal cultures’). The difficulties in maintaining cultural and

religious mealtime practices on the wards were described as potentially impacting on connections with home and community life outside:

“... there could be various guilt, there could be not feeling embedded with the community .... Yeah, for some people they might feel like they really have been pulled out of the community and just maintaining the ... eating kind of thing that links with that culture may just be enough to make them feel linked with that culture or religion, ready for when they're out of hospital.” Staff 08

Improved social aspects and interest in cultural adherence of the meal would also help to measure improvement in mental wellbeing. Recovery was associated with more sociable mealtimes as patients became more able to tolerate others when eating together:

“[This patient had] difficulties just generally sharing a space with people when eating and there was a lot of defensiveness around food consumption generally. And me and [patient] go for lunch now. It's quite nice. It sends a very powerful message to me of how far [patient]'s come.” Staff 07

Meals at a shared table and staff eating with patients were described as helpful in several ways. Firstly, the benefits were seen in building relationships and trust:

“I think it's a really positive thing and I think it, you know, it reflects that everybody's, you know, the same ... I think it supports development of relationships. I think people are generally more relaxed when they're eating. So actually, from a clinical perspective ... it's a really good opportunity to actually just get to know people.” Staff 11

Staff described how sharing a meal table offered a more relaxed opportunity for building relationships between staff and patient. Participants perceived a contrast between clinical tasks during the rest of the working day and more informal interactions at mealtimes. Secondly, staff described how mealtimes at a shared table could support development of interactions and relationships:

“It's an important kind of social space as well, so it's often the time when service-users see each other ... it can be quite a spread-out unit and

everyone's doing different things, so I do think that it is an important place where people meet each other and have some food.” Staff 01

For patients choosing to eat in isolation, staff considered that this would limit their recovery in the longer term. Thirdly, staff described the benefits of staff sharing a meal with patients in terms of understanding and monitoring the individual's mental wellbeing:

“Gathering that informal information about somebody's interests ... that would be a normal thing to ask people over a meal, you know, ‘what have you done, what would you like to do at the weekend? What things have you previously enjoyed?’ ... opening up conversations.” Staff 11

Some staff described how they would be interested in promoting shared mealtimes where staff could eat at tables with the patients but were concerned that this was not authorised “it's now a little bit frowned upon” (Staff 09). Organisational policy was frequently repeated as a reason for not sharing meals. However, some staff offered personal reservations about sharing the table with patients, describing personal eating styles as “shovelling in their food” (Staff 08):

“I think some staff would be put off by eating with other service users because of the nature of the way that they eat ... when there's food flying, you know, there's food flying over or the tables and erm ... mess.” Staff 11

Staff were clear that the process of rehabilitation needed to include support for developing appropriate social and physical skills at mealtimes. This acknowledged the impact of mealtime behaviours on others – the patients may need support to self-monitor for appropriate ways of eating in social settings.

Mealtime preparation also featured in the staff interviews. Staff 04 described how groups of patients cooking together could offer a therapeutic opportunity for supporting connection and building relationships between patients giving examples of breakfast clubs and other shared cooking activities. Offering a departure from the usual routines and organisational constraints, preparing food together in self-catering sessions promoted a more informal mealtime atmosphere offering positive

interactions between patients and between patients and staff. There were reports of seeing sustained improvement in self-esteem linked to developing skills:

“So, we've got a couple of guys that are going to a cooking course ... It was like ‘I cooked this, and it was amazing’ and it's like that's almost a week that's gone by and they're still feeling like ‘this is a really good thing that I've done’ ... self-worth I guess is what it is ... things that we cook because it's something that we create. It's almost a projection of who we are.” Staff 04

Staff commented on how cooking and then sharing the food provided a sense of pride, identity, and improved self-esteem in patients. The positive aspects were also rewarding for staff themselves, who described improved rapport and connections in these sessions. The benefits afforded longer lasting experience so that the positive effect was perceived beyond the mealtime itself.

Participants reported that staff sharing tables with patients at regular mealtimes could provide opportunities to model appropriate eating behaviours and to build wider relationships important for rehabilitation. The institutional setting was constantly felt to be a barrier in terms of promoting such informal mealtime approaches and developing skills for future life. Staff described the recovery focus on the wards as currently disconnected from mealtimes but clearly felt this as a missed opportunity.

## **6.8 Summary of staff findings**

The overarching theme of ‘Organisational constraints and limitations’ has been discussed with reference to four main themes. This chapter captured staff’s insights into the nature of the mealtime experience for patients on the mental health wards, and for themselves as staff.

The staff accounts reflected their desire to understand and respond to the individual needs and preferences of their patients, including attention to cultural practices and personal routines. However, this contrasted greatly with their described reality of mealtimes being a task to be completed with inflexible restrictions placed upon patients. The lack of choice and control, and lack of autonomy for patients who were not involved in decisions relating to many aspects of the mealtimes, was frustrating

for staff who struggled to identify ways in which they could improve the mealtime experience within the organisational restrictions.

The staff were engaged and motivated to present their views and their understanding of how patients perceived the hospital mealtimes. The descriptions of mealtimes as a task to be endured were in contrast to their desire to understand and recognise the importance of individual mealtime preferences and cultures. Staff highlighted the potential beneficial impact of positive and personalised mealtimes on patients' mental wellbeing, particularly in developing and supporting relationships and creating opportunities for social interaction and conversation. However, there was no connection of the mealtimes to recovery pathways and no consideration of providing support for improved mealtime independence, behaviours, or enjoyment. The stresses associated with ward dining rooms were presented as counter to recovering mental health and developing skills and independence within and outside the hospital environment.

## Chapter 7 Findings from interviews with speech and language therapists

*It's so much more than just eating and drinking ... For me, I think it's really important. I think we do forget that when we put such a clinical slant on it.* SLT 06

### 7.1 Introduction

This chapter presents the findings from interviews with speech and language therapists (SLTs). Participant characteristics are described followed by a reflection on the group's interest and responses to the topics during the interviews. A thematic network illustrates the themes and subthemes (figure 7). This is followed by an in-depth analysis of the main themes and subthemes constructed for this group. Definitions describe and delimit the scope of each main theme (Braun and Clarke, 2022). Details of subthemes are described to clarify the content.

An overarching theme of 'focus on the impact of mealtimes on individuals' covered four main themes:

- Personal cultures are important.
- Ward mealtimes are chaotic.
- Listening to patients' insights.
- Others' awareness of mealtime difficulties.

These themes included some similar content to the themes from the patient and staff groups discussed previously, the SLT perspectives are presented below, and the similarities and differences presented in the following Chapter 8 synthesis and discussion.

### 7.2 Participant characteristics

Interviews were completed with 12 participants, all of whom identified as female and worked in England. The majority (n=11) were white British and one other person was white European; ages ranged from mid-twenties to mid-fifties. Almost half (n=5) identified as Christian, and the remainder reported being of no religion. Experience as an SLT working with people who have mental illness ranged from 1 to 17 years.

No further breakdown of demographics is described to maintain anonymity. Almost all SLT participants described combined roles with duties covering other populations during the working week including older people services, forensic services, learning disability and acquired neurological conditions. The duration of the interview ranged between 33:51 minutes and 57:53 minutes with the total data time being 561:10 minutes. The interviews were completed between April and August 2022. Reference codes for each participant are given following each quote, in the format 'SLT number'.

The SLT participants described their role in attending mental health wards as being primarily to respond to referral requests for clinical evaluation of swallowing, advice to patients and staff on swallowing difficulties, and the provision of mealtime recommendations. Advice would be given regarding adaptation of food and/or fluid textures and recommendations for any mealtime assistance (e.g. prompts or supervision or other supports needed for food and drink). The main focus of the contact would be on an individual patient and their swallowing difficulties, even though this might involve being in a dining room with other patients present. SLTs typically attended the wards intermittently rather than being embedded within the regular staff team, visiting for a relatively short time, and usually only for one meal (typically midday meal) or snack per visit. It is recognised that the SLT perspectives discussed reflect this context and this is acknowledged in the interpretation of the SLT interviews.

### **7.2.1 Reflection**

SLT participants engaged readily with the interview process commenting on their keen interest and motivation to contribute to research into SLT practice in mental health settings. Participants reflected that the wider mealtime issues discussed (e.g. mealtime cultural practices, the nature of patients' mealtimes at home) were not usually raised in their clinical practice but they felt these were important to mention in the research. They reflected on the differences observed in the patients' mealtime experiences and also compared mealtimes on the mental health wards to those for adults with other health conditions on other hospital wards.

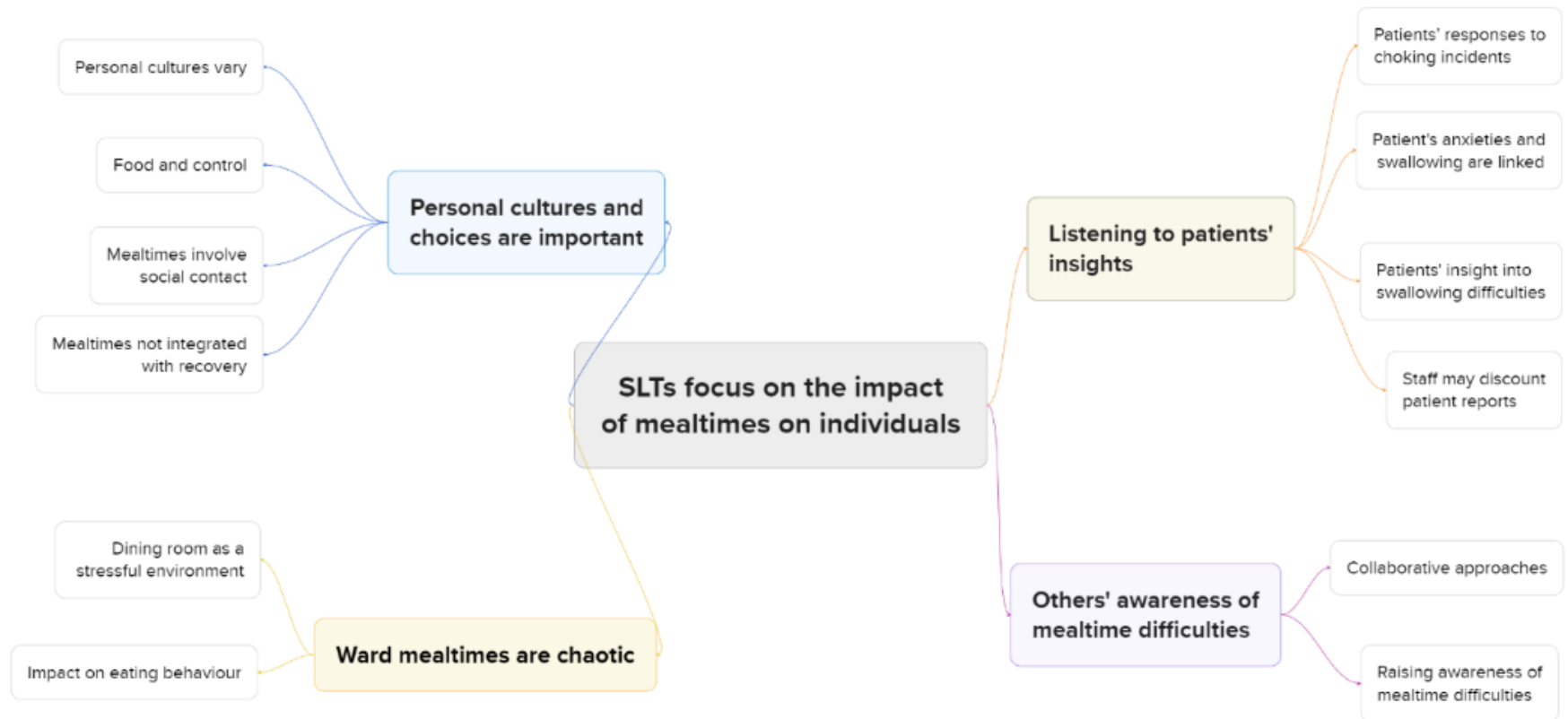


Figure 7 SLT group thematic network



### **7.2.2 Overarching theme: SLTs' focus on the impact of mealtimes on individuals**

The overarching theme expressed by this group of participants concerned the attention to the impact of the inpatient mealtime experiences on the individual patients. There were repeated comments relating to the chaotic nature of the mealtimes (characterised by heightened noise levels and crowding), and the adverse effects of this on the patients. SLTs described varied levels of understanding and responses from staff to patients' attempts to raise concerns. SLTs described the focus of staff's attention as managing the dining room as a whole with little recognition of the individual or personal aspects for each patient having a meal.

### **7.3 Theme: patients' personal cultures are important**

Definition: SLTs considered that the personal mealtime customs and cultures of the patients are important and varied but not usually considered by hospital staff. They highlighted the importance of individual variations in terms of mealtime needs and preferences. Home mealtimes were important opportunities for maintaining individual customs and for making choices associated with relationships and promoting wellbeing. In contrast, on the wards, patients' preferences were either not identified or neglected. The SLTs observed little social interaction occurring during the mealtime. The mealtime experience was thus viewed as being negative and stressful affecting the patients' wider wellbeing and recovery.

SLTs were asked to consider and provide their own views on the mealtime experiences of the patients living on inpatient wards. They reflected on the patients' perspectives and the potential value of background information about patients' mealtime experiences:

"That's food for thought for me [i.e. considering the relevance of information about patients' home mealtimes] ... I doubt that anybody ever says to a patient 'What are your mealtimes like at home' or 'what do you ...?' you know, because some people, lots of people, don't sit around a dining room table, do they? ... I bet they're not asked." SLT 10

The SLTs acknowledged that patients' personal cultures and home customs for food and drink were not generally known or sought either by SLTs or other staff. Some SLTs outlined what they viewed as possible challenges for patients coping with ward dining room environments, particularly with using table and chairs for every meal which might not be common practice for a patient prior to hospital admission. The SLTs viewed that ward mealtime routines set an "expectation" (SLT 12) that patients will "conform" (SLT 10) to the customs of the ward and also be able to cope with a room full of other patients and staff. Participants described a blanket approach of "everybody has the same" (SLT 04) that they saw provided on the wards with no reference to individual needs or preferences.

SLT participants acknowledged the importance of understanding individuals' backgrounds in terms of routines and how understanding patient cultures and norms would support current mental wellbeing and recovery in the future. This included any history of difficulties associated with mealtimes and relationships at home. Anxiety, mealtime cultures and social issues were described as potentially influencing engagement with mealtimes on the ward. Mealtime schedules on the wards imposed situations potentially unfamiliar to some:

"I think it's trying to understand what is normal for that person, talking to the families and for example, like in the hospitals especially, we tend to give bigger meals at lunchtimes. And that doesn't work for some people at all actually." SLT 06

The ward mealtimes were often perceived to be at odds with personal routines at home or in the community. SLTs reflected on different cultures and customs for mealtime routines such as their belief that working adults would normally have smaller meals at midday; the ward routine of having three substantial meals every day was considered atypical for most adults. Participants also described how the ward mealtime setting differed from the customary places to eat chosen by patients prior to admission. These included personal habits (pre-admission) such as eating whilst walking or on the street, eating while watching TV, and social patterns of eating alone or with partners and family. Individual patient eating styles were highlighted by some in light of culturally diverse eating customs:

“... eating with cutlery is a big one. We had a gentleman who would be eating with his hands and that was part of his culture. But it was felt that that was a deterioration for him, and we should be supporting him to use cutlery ... and maybe not being prepared on how to support that rather than wanting to change that.” SLT 02

This showed how SLTs perceived staff's attitude to mealtime customs, adhering to own personal styles rather than understanding a patient's cultural norms. Some SLTs thought that staff saw mealtime behaviours as a reflection of the patients' physical ability – for example staff suspected difficulties with using cutlery - rather than evidence of a different cultural tradition.

Lack of awareness in relation to patients' personal mealtime customs extended to understanding the variations in cultures for mealtime routines and food choices associated with different ages:

“I think these people have not had a smoothie their entire life. Why would they? Now they're in their 90s with psychosis. Why would they suddenly want a banana smoothie? I don't know.” SLT 10

Clearly the SLTs considered that the ward mealtime options did not link with patient lifestyles outside the ward. This was seen as confusing for some patients and actively difficult for others. Another important aspect of mealtime experience was adherence to personal social choices and how compatible these were with ward settings. For some patients, eating alone (or with a partner) was their normal experience, so that the crowded dining room on the ward was difficult to tolerate or aversive. It was interesting to hear that staff's preconceptions about mealtimes became an issue for some:

“We meet quite a lot of resistance when we put recommendations in place because of staff's own beliefs around what we are recommending our patients versus what they think they should be.” SLT 07

SLT accounts built a picture of unconsidered approaches to ward mealtimes, of ward staff offering their own cultural norms without being aware of the patients' own customs and home lifestyles.

### 7.3.1 Food and control

Participants described issues around control over access to food and how this affected the mealtime for patients and staff. Patients sought ways to control food choices. For some this was achieved through buying snacks, takeaways or accessing self-catering but such access was often restricted:

“A lot of it's about them having their own ... access to snacks, ... it is a way that people can demonstrate using choice and demonstrate their free will while they're living in a really restricted setting.” SLT 03

Having control over access to food was seen as linking to life outside the ward and sustaining connections with home or community. In a setting with many restrictions, this was perceived as having a “massive massive impact” (SLT 07). Other participants gave examples of how patients had used food refusal in a ward setting where there was little individual autonomy - in order to “feel like they have some level of control of their life” (SLT 07). SLTs described how maintaining personal food choices as part of individual customs and routines was difficult for patients to achieve and for staff to support in the institutional setting.

An underlying influence on the patients' mealtime experience was the degree of choice and control over timing of meals. SLTs described having choice and flexibility as an important aspect of their own mealtime routines:

“I've got a routine, I guess, but .... You know, if I don't feel like eating, I won't feel like eating. Or if I don't feel like eating what I had planned, I'll eat something else. Or, you know, I'll just eat when it suits me and when it feels right.” SLT 10

This contrasted with the experience of patients on the ward. The lack of choice, control and flexibility in the routines contributed to feelings of “institutionalisation” (SLT 08). For some patients the food was chosen by them individually, others described ‘blanket’ choices where the staff chose food for the entire group:

“We think most people will like the chicken, so we'll order more of that kind of thing.” SLT 01

There were descriptions of bland menus and shortages of supply. Choosing food options a day or more ahead was seen as difficult, inflexible, and unrepresentative

of normal life. The food ordered often did not materialise, the resulting sense of frustration and disappointment for patients was clear:

“I think kind of turning up to a mealtime and genuinely not knowing what your options are gonna be ... it isn't a very nice thing.” SLT 12

The descriptions suggested many patients had become resigned to the ward routines. There was a loss of autonomy as patients were told what time they could attend the meal, then directed where to sit and what to eat. Passivity in the patients' mealtime experience was repeatedly captured in comments such as “They're so used to the routine ... you do what you're told sort of thing” (SLT 07). Patients were described as becoming distressed by this. SLTs suggested this could be due to the waiting, the failure to get the choice ordered, frustration, and uncertainty:

“Definitely frustration. A kind of a bit of a distrust, I think, of staff as well that, ... that kind of ‘what's the point in asking for it, they're not going to give it to me’ kind of thing ... doesn't feel very caring, I don't think.” SLT 08

Food was linked to “caring” activities in life outside the ward, in contrast to the perceived lack of individualised care in the ward mealtime routines. The SLTs described how the mealtime routines related to risk management and extended to controlled seating arrangements:

“So that's [i.e. seating plan] organized for them on some wards ... due to safeguarding concerns, other risks, whether there's been ongoing issues on the wards ... might have an impact and people's seats get moved around at times.” SLT 07

SLTs described staff control and the lack of patients' autonomy over the mealtime routines including seating plans, and restrictions relating to the implementation of guidance around food preparation and delivery. Patients felt “belittled” (SLT 02) by the experience of needing support at mealtimes:

“he felt like a child having someone cut up his meal. And you could see in his body that ... just really upset that it had come to this, and someone was cutting his food up for him. And that's been a feature for a lot of his incidents where someone else is controlling the situation for him.” SLT 02

This loss of control over the meal was perceived by some as triggering deeply felt resentment and distress which could then escalate into anger and frustration. Another example showed how staff's mealtime practices could be an issue for patients needing support for pacing their eating style:

"They would yank the plate away from him to try and slow him down. And I was like, that's the worst thing. And then he would get really angry, really frustrated. And then that would make his behaviour more heightened." SLT 06

There was a general feeling that patients would most often "minimize the difficulties that they have" (SLT 12) and this meant that it was challenging for SLTs to understand and assess the patient's difficulties. This also impacted on identifying and discussing any need for mealtime adaptations. Guidance and risk mitigation measures brought added stress to the mealtime and could be counterproductive if these led to potential further compromise of safety as stress levels escalated. Routines and time restrictions became a reason for patients seeking to avoid the meal entirely.

### **7.3.2 Mealtimes involve social contact**

SLTs described positive experiences and emotional associations with their own mealtimes. They felt that customs of eating together underpinned family events and strengthened relationships. They described positive experiences and emotional associations with their own mealtimes:

"Like it's a social thing, isn't it? It's ... enjoyment ... celebrations. You know, you go out for a meal ... or you invite people around, have a dinner party, that kind of thing. It's a big part of a lot of people's culture." SLT 08

They emphasised the enjoyment and importance of shared mealtimes with family and/or friends. Participants explained how they saw mealtimes as a key part of building and maintaining relationships bringing comfort and emotional benefits. They reflected that this might not be the case for patients on the ward:

“They just sit very randomly apart from each other. So, nobody sitting with somebody else. So, mealtimes are not about sharing ... conversation when you're having a meal ... it's very, very removed from what mealtime tends to be for people who are not ... you know, on a ward.” SLT 09

In a busy shared dining room, patients were generally perceived to avoid conversation during the meal. SLTs gave examples of patients being seated with other patients who were possibly unwelcome company, and recognized the difficulties for patients sharing a ward with others who were struggling with mental illness:

“The people on our wards aren't choosing to live there and live with the people that they're on a ward with. So sometimes they can be put on tables with people that they, you know, might have fallen out with ... you know, we wouldn't want to sit at a table with people that we don't like and eat our dinner. So why would our patients be any different?” SLT 07

Patients in the dining rooms were sitting with other patients with whom they had no connection or relationship, who were not compatible, or who were actively aggressive. SLTs considered how previous incidents might influence the patient's engagement with the mealtime:

“It might be something that's hung over from that morning with another patient, that can be kind of altercations and rumbling arguments, I guess between patients and that kind of thing. So those can kind of spill over into a lunchtime.” SLT 12

SLTs also raised concerns about patients who had previous trauma. They reflected on how this related to mealtime experiences on the ward particularly in relation to the social aspects of the meal. Examples included patients moving from prison, life in care, homelessness, or settings where food supply was short, and they felt vulnerable to losing their food to others. Comments highlighted how previous difficulties could be influencing ward mealtime experiences:

“During a meal, somebody might ... you know, ask a question or just make a comment and the response of the staff member maybe isn't what they wanted

or has triggered a trauma for them and has meant that they've become very agitated and then the whole mealtime has been derailed." SLT 08

There were many descriptions of patient anxiety related to these social aspects of mealtimes. The result was for the patient to rush their food, ("cramming" was reported as a frequent issue) seen as a response to perceived threats from others.

A sense of conflict affected some patients' engagement with mealtimes, and this had the potential to influence wider recovery. The difficulties of living with others who had mental illness came to a head during the meal as "a time that we quite often have sort of flashpoints of violence and aggression" (SLT 01). Disagreements or personality clashes between patients could also be an influence in avoiding the dining room entirely. The accounts described the frequency of arguments between patients, and triggers from previous events. This could extend to difficulties coping with queuing, increased tension during the meal and had the potential to impact on others in the dining room.

Additional SLTs' concerns highlighted how an individual's mannerisms and customs could affect others sitting nearby. Describing "animosity" in the dining room (SLT 07) one participant presented the experience of a patient who was perceived as unacceptable by others around him. Enjoyment and comfort of a meal could be hampered when sitting close to others who had a different style of eating and appeared "messy" (SLT 10); "dribbling" (SLT 07) or "unpleasant" (SLT 05). Patients needed staff awareness and support to understand how to tolerate other patients.

During mealtimes staff were present on the ward but they were perceived as seldom engaging with patients during the mealtimes: instead, the staff presence was described as "policing" (SLT 08) and potentially inhibiting for patients. The set routine and physical environment meant at mealtimes it was not possible to avoid close proximity with other patients and staff if the person wanted their meal. SLTs reflected that this was an aspect of mealtimes that was not regularly considered by staff:

"Do they ever reflect on that? No, never comes up in conversation. Be great if it did." SLT 07



This comment also suggested that SLTs did not raise this issue with the staff or seek to address these concerns. SLTs as visitors could perceive how the stresses of the restricted dining room settings affected the emotional aspects of the mealtimes and how the lasting “detrimental effect” (SLT 09) potentially affected wider mental wellbeing. However, despite participants’ appearing conscious of the social issues and stresses at mealtimes their responses did not describe whether they sought to review these with the staff on the wards.

### **7.3.3 Mealtimes not integrated with recovery aims**

The interviews concluded with questions around how mealtimes supported individual recovery and links to life outside the ward environment:

Researcher: “Would you say that mealtimes are seen by the [multidisciplinary team] as part of the recovery process?” Participant: “I would say ‘no’, but that's based on not being fully integrated in the teams.” SLT 06

SLTs felt that their interest in mealtime experience was not shared by ward staff. The impact of being a visitor rather than fully embedded in terms of presence on the ward was acknowledged. The SLTs suggested that this lack of integration meant that there was little opportunity to remind other staff about the mealtime concerns. As a result, the mealtime continued to be overlooked in terms of significance for improving patient wellbeing both for time on the ward and for promoting future mental health. Many repeated their perception that the staff and patients saw the mealtime as a task to be completed that was detached from the wider recovery planning process:

[mealtimes are] “very much just a means to an end. It doesn't seem to be much recovery ... at the moment doesn't feel like it is ... any emphasis on that recovery part of it ... it's just your breakfast, your dinner, your tea.” SLT 07

Many saw this as “an opportunity that is being missed” (SLT 09), and reflected that mealtimes could offer a better experience in terms of enjoyment, promoting wellbeing and building skills for maintaining future healthy living:

“it's not seen as part of a therapeutic environment and a pleasant experience and an opportunity for socialization and all of those sorts of things.” SLT 10

This negativity was described as potentially countering the aim of achieving a nutritional task: patients were observed leaving the meal as the options available and/or the environment were not appropriate or acceptable. The personal version of mealtimes, the “what people go home to” (SLT 01), was not generally considered as part of planning for future recovery. The lack of involvement in cooking or setting tables ensured patients remained passive throughout the process in contrast with mealtimes away from the ward.

Many participants were keen to see patients having more independence with the option to cook for themselves:

“I think people tend to be a bit calmer, so don't rush as much ... So having that control over it, I think it means that people tend to eat a bit slower and tend to just be in a better place mentally to have the meal.” SLT 08

Increased choice, flexibility, and control through self-catering and then sharing this food with others was presented as a means of developing skills and self-confidence. There was a sense of a reciprocal process: improved access to choice and independence at mealtimes would benefit recovery and also, as recovery progressed, the mealtime experience would improve becoming more comfortable and enjoyable.

Participants acknowledged that staff faced many barriers to making mealtimes more therapeutic. Staff were responsible for maintaining safety procedures which included the supervision of behaviours, and this reduced the enjoyment of the meal. In addition to limited access to cutlery, having to wait for checking, and a ban on leaving the room during the mealtime, patients also experienced restrictions through being supervised. SLTs showed empathy describing how this impacted on patients at the meal:

“you've got about three or four members of staff, sitting, or standing watching them with their arms folded against the wall. If I was, I might be like shoving down my food, as quickly as I could as well, just to get out of that situation.

So, it's not an enjoyable experience where you wanna stay, you wanna chat, you wanna have these enjoyable mealtimes.” SLT 07

The discussions returned to the SLTs' views of wider therapeutic benefits of mealtimes which included opportunities for socialisation. As mealtimes became more sociable and enjoyable there was potential for a beneficial effect of increased peer support. Patients became more aware of each other when the meal offered an opportunity for chat rather than being purely task focused:

“People talking to each other that probably wouldn't have done before ... I've seen really lovely conversations about supporting each other's mental health journey. You know people saying like, 'oh, you had a shave today. I can see you're feeling better' “. SLT 08

Mealtimes offered a time to connect which was different from interactions at other times of day. Having staff sitting at a shared table for a meal was described as beneficial for all. There was a strong sense of the mealtimes' potential – that sitting and eating together could offer a more relaxed contact between staff and patients and enhance relationships generally. SLTs appeared keen for the mealtimes to be incorporated into recovery planning, to use the mealtimes to reintroduce social contact between patients and suggested this would develop the skills needed for future wellbeing on discharge. The reality of whether this was achieved in practice was unclear.

#### **7.4 Theme: ward mealtimes are chaotic**

Definition: Participants described how the crowded and noisy dining rooms were difficult for patients to tolerate. The frantic overwhelming nature of the environment impacted on patients' wellbeing. The staff were perceived to feel pressured in supporting each patient whilst covering their duties to provide nutrition for the group as a whole. Routines and institutional aspects of the mealtimes were perceived as restrictive and potentially in conflict with promoting safety and patient recovery.

Participants presented many aspects of ward mealtimes that were counter to patients' personal preferences and customs described above. There was variation in how the atmosphere appeared to patients:

"[dining rooms] really can vary from peaceful, enjoyable environments that I would happily sit and eat a meal in ... to routine, noisy, distractible, unpleasant sometimes, unpredictable. That range really, from one extreme to the other."  
SLT 12

There was often a sense of frantic activity with crowding and disorderly systems highlighted. The word "chaotic" (SLT 09) was often repeated with descriptions of patients and staff in close proximity. There were multiple pressures from the sense of crowding, from people waiting to come in when a space became free, issues with queuing and the need to "hurry" (SLT 12) influenced by complex emotions:

"I think to a certain extent, the whole feel around it is ... get past that part of the day. Then you're near the afternoon, then you're nearer another day gone, and then you're nearer leaving the ward." SLT 10

The pressures on staff were clearly described with accounts of how the staff were "stretched" (SLT 06) or "in a mad rush" (SLT 07). SLTs perceived the dining room as "a very challenging environment" (SLT 09) presenting an overwhelming and stressful experience for both staff and patients.

#### **7.4.1 Dining room as a stressful environment**

The impact of the austere, uncongenial surroundings influenced how the patients experienced the mealtime emotionally. Vocabulary such as "institutional" and "plain" (SLT 04) was used presenting a sense of austerity and bleak surroundings:

"[there is a need for] making it a valued, pleasant environment, relaxed environment ... that doesn't look like a medical ward, really, or doesn't look like a prison ... some of those dining rooms are very stark with that grey plastic heavy furniture that you can't move. And feel sort of a bit punitive, really... and bleak." SLT 10

There was a sense of repression, inhibition and restriction derived from the physical environment including the heavy institutional furniture, the bare walls of the dining rooms, and the table settings with no tablecloth or decoration permitted. SLT accounts described how environmental factors impacted on the mealtime experience and successful eating and drinking:

“For those patients who are struggling and do have swallowing difficulties, even those who are just unwell, it’s very overwhelming and difficult to concentrate.” SLT 05

In addition to concerns about the room itself there were frustrations around erratic timekeeping and queuing. Waiting at a hatch to receive an unpredictable meal, standing next to other patients who were equally stressed and experiencing the “squeeze” (SLT 12) of crowded tables and chairs were repeatedly described. Participants used vocabulary such as “volatile” and “pressurized” (SLT 01) describing the impact of a lack of personal space. The noise levels were a particular source of concern affecting the mealtime experience for patients:

“It’s more around people shouting and screaming and that ... you know, that makes environment very noisy and a bit, you know, distracting for the rest, you know, for whoever is not shouting and screaming. So yes, the noise, the actual setup.” SLT 09

This was seen to be a deterrent for patients. SLTs described how noise levels escalated and became more stressful. The descriptions included “shouting and arguing” (SLT 12) and others added a sense of “fear” (SLT 08) in a room that was crowded with people with heightened emotions.

The participants described how the raised emotions were exacerbated by being “really starving, hungry” (SLT 04). SLTs described the importance of understanding the patients’ personal circumstances and triggers:

“[at mealtimes] either people are very agitated and distressed or they’re anxious and distressed ... but they’re on an inpatient ward because they’re very unwell and they’re acutely unwell. And so, I think we see people at their

least ... able to cope with all aspects of everyday life and including some physiological processes.” SLT 10

The concentration of numbers at meals presented issues not experienced at other times of day when patients would have access to their own space in their bedrooms or opportunity to find quieter areas on the wards.

#### **7.4.2 Impact on eating behaviour**

SLT participants reflected on the consequences of the busy mealtime environment for the patients. They frequently described their concerns regarding the stressful environment and how this led to the patients’ “rapid, rapid eating speed” (SLT 10). Participants felt it was important to consider how the swallow efficacy could be affected by anxiety and distractions, their comments suggested links between heightened emotions, the distracting environment and swallow function:

“People ... just wanting to get the job done as quickly as possible, I think is quite classic and that is going to involve people, maybe not chewing as much and all of those things and just people being constantly vigilant in their surroundings. I mean, what a horrible way to have to eat your meal, you know?” SLT 01

The “physiological processes” (SLT 10) considered by several participants included how effectively the person was able to control food and drink during the mealtime and how these skills could deteriorate when a patient was distracted and stressed. SLTs described how they had observed patients walking around, shouting, or talking with food in the mouth so that their risk of choking was increased. In addition, there were observations of stress leading to fast paced eating styles with patients bolting and/or cramming food:

“When they’re a bit more distracted, they then start having more difficulties. They’re distracted themselves, overfilling their mouth, they’re cramming, they’re coughing more. So, I think it definitely does have an impact on some of our patients, kind of what’s going on around them.” SLT 11

There were concerns specific to those patients who were struggling with the hectic dining room and seeking to leave the mealtime as fast as possible. This led to fast eating, impaired oral processing, and associated risks to effective and safe swallowing:

“So, it can make eating very quick, and they want to eat and be gone ... definitely fast pace of eating, which when movements are impacted and slower, that can mean chewing’s not as efficient and food’s just kind of thrown into the back of their mouth.” SLT 02

SLTs were clear that the negative mealtime experience, when associated with distraction and stress, could foster specific difficulties in swallowing and raise the potential for choking. Heightened anxiety was associated with wider physiological aspects affecting the experience further and limiting eating and/or swallowing skills:

“Maybe feeling of nausea and ... anxiety if that’s what it is, and so some people will feel like in their throat, won’t they, and some people will feel it in their stomachs. And I guess both of those things will impact on how easy someone finds it to be able to kind of get food down and then keep it down. And all of that kind of thing, and appetite I suppose, just thinking about dry mouth.” SLT 12

Faster pace of eating and overfilling the mouth were most frequently described - influenced by the desire to leave the disturbing environment. Generally, SLTs showed empathy for the patients’ perspectives as they reflected on how aspects of the eating, drinking and swallowing process might be affected by the stressors present in the chaotic environments.

## **7.5 Theme: listening to patients’ insights**

Definition: Patient self-awareness was perceived as important but variable. With support, the patients’ self-report could be encouraged and offer useful details about their experiences of mealtimes and swallowing difficulty. Some SLTs were cautious about self-reports, describing patients whose concerns related to more general anxiety levels. Other patients were unable to self-report or self-monitor, and this led to concerns in determining recommendations for mealtime support. Staff’s attitudes

to patient self-reports were varied but could be dismissive relating to 'overshadowing' by co-existing conditions.

SLTs described their particular interest regarding the level of patient insight into swallowing skills or dysphagia and the wider impact of this on mealtime experience. Participants reported that direct self-reports from patients experiencing dysphagia were rare:

“We get the odd few who report like it feels like something's getting stuck in their throat. But more often than not, it's kind of what staff have witnessed.”

SLT 11

but conversely there were also occasions when patients might report a problem of which the staff were unaware:

“They [staff] say they've haven't noticed anything but however a certain patient is reporting that food is getting stuck or they're having trouble swallowing certain food items.” SLT 11

Levels of patient insight varied so that the severity or extent of the difficulty might not be fully reported by the patient. For some the “vague” (SLT 08) level of the patients' reporting warranted further investigation. SLTs reported patients giving general descriptions such as “it feels dry”, and “it's getting stuck” (SLT 11). Others described more detailed reports of symptoms and concerns from patients:

“We get some patients that are complaining about tension and coordination and tiredness and ... around kind of effortful swallow ... which feeds into that anxiety and tension”. SLT 05

Occasionally patients with more detailed insights could offer explanations and solutions. Examples included patients who demonstrated awareness of how their mental illness affected their swallowing and general mealtime skills:

“He said, “I know I eat really quickly and put lots in my mouth, but I can't stop myself, and that's something with schizophrenia”. And he had that awareness that it was part of his illness.” SLT 08



SLTs reported how they tailored their assessment and guidance based on the patient's report and the extent of the patients' awareness into the swallowing difficulties. Engaging the patient in discussion about swallowing increased understanding of the patient's perspective, informed the level of support and guidance needed and gave opportunity to identify any confusions or limitations in the patient's understanding.

### **7.5.1 Patients' responses to choking incidents**

SLTs gave several examples of listening to patients who reported their experience of choking incidents:

"If they've had a choking incident, they quite often are aware. Well, there are times when it has happened, the person has been able to describe what happened, say what they think caused it on that occasion, give a bit of an insight." SLT 03

However, SLTs described wide variation in individual patients' insights and understanding of the incident. Some patients clearly retained their experience of choking and how it felt. Others appeared to dismiss choking as "unlucky" (SLT 12) and have little awareness of the implications and future mealtime risks. There was widespread concern amongst the participants regarding how to support patients' understanding and awareness of choking. They described how some patients appeared unaware of the issues observed by SLTs:

"a lot of the cases where people are saying, 'Oh no, there's nothing wrong... There's not a problem', even if they've just coughed in front of you ... for five minutes." SLT 01

whereas others reported patients who described choking incidents that staff suggested were unsubstantiated. SLTs reflected that some patients were greatly concerned about choking at mealtimes and this differed from the staff's perspectives:

"I've had some patients say 'oh, I was choking. It was really, really serious. This has happened and staff had to get involved.' But when you have that conversation with staff then staff said, 'Oh no, he coughed once on it but was able to ... like we didn't need to intervene.' And then we've had the opposite

where patients have said, 'Oh no, I've had nothing wrong whatsoever' and staff are like 'no, it was quite a serious one. We've had to intervene with kind of backslaps and abdominal thrust'. But the patient just didn't see that at all."

SLT 11

The ability of patients to understand and report their experience of choking was raised as SLTs reflected on how they had supported patients to articulate their concerns. Some participants reflected that the report of choking had only been triggered by the SLT's visit to the ward and that more usually reports came via staff who supported the patient to describe their difficulties.

### **7.5.2 Patients' insight into swallowing difficulties**

SLTs outlined in some detail their views on patients' insights into swallowing skills and dysphagia, and the wider ramifications of patients lacking insight which impacted on their mealtime safety. SLTs described their approaches to offering support and developing the patient's awareness around mealtime difficulties. For the patients with greater insight there were many descriptions of how the patients themselves had designed self-help strategies around their swallowing difficulties. With time and support these could be discussed, and the relevance confirmed:

"She said, 'so I think if I just had food that was a little bit easier to chew, I'd be OK'. I was like, yeah, yeah, absolutely logical." SLT 06

Offering reassurance led to greater engagement in discussions around mealtime experience. Determining strategies for improving mealtimes could be designed acknowledging the patient's perspectives:

"I think it's important that we listen to her and reassure and give her, you know, just the simplest strategies that ... like listening to her essentially, believing her and saying, you know, it sounds like the things that you're doing, staying up, sitting up upright, taking your time, having a drink with meals, those kind of things ... are working at the moment and those are sensible strategies to keep on doing." SLT 03

Understanding a patient's insight and ability to self-monitor during the meal brought opportunity to pre-empt difficulties or deterioration. There were repeated descriptions of the need to take extra time for listening and supporting the patient to describe their swallowing concerns. For some patients, the difficulty was in finding the words to communicate their perspective. For others, the issue was due to acute mental illness and associated loss of self-awareness. SLTs gave examples of patients experiencing fluctuations and many anxieties associated with a mental illness which meant that a conversation to elicit any concern about experience of swallowing difficulties could be challenging:

"It's very interesting because if you have the conversations with people, ... they always in the end, most times they [say], oh, you know, 'I have been avoiding steak recently' and then when you really get to it, it's because they're finding it difficult to swallow. So, we should be listening to them more ... but obviously, I get that it can be difficult if they are mentally unwell." SLT 06

However, SLT participants also gave examples of when patients' mental illness had deteriorated impacting on their ability to understand how to maintain safe eating and appropriate mealtime behaviour:

"a lady I see who is very high risk, she's cramming ... but just has such low awareness and not much chewing in between so ... it's just that total lack of awareness that if you don't sit and watch every mouthful ... and it's also the fact that she grabs food from the trolley, she grabs all the people's food." SLT 04

For some patients, the level of insight could be fluctuating. Where insight varied participants reflected on the need to find a time when the patient was more settled and could then offer their perspective on how the swallowing difficulty affected them at mealtimes.

### **7.5.3 Patients' anxieties and swallowing are linked**

SLTs commented that patients who were more affected by persisting anxiety needed greater support and reassurance in relation to exploring any mealtime difficulties. Participants described variation with some patients being "very traumatized" (SLT

07) after experiencing choking and others appearing unscathed or complacent. Participants described drawing on their combined SLT skills in understanding dysphagia and in supporting communication to tailor individualised support after a choking experience. The emotional impacts of choking were described most often in terms of fear:

“They are scared. But they're scared of eating certain things because they know they may choke.” SLT 09

This included fear around types of foods, fear around food getting stuck, and descriptions of heightened anxiety at mealtimes. This was sometimes exacerbated by stress from other events on the ward:

“a lot of people report that when they are stressed that, well, something's come up - like a CPA [meeting] or a tribunal's coming up, they report difficulties eating around those times ... patients say, ‘it feels like when I'm eating, it feels like something's getting stuck in there’. So, I suppose probably being really anxious, you're tensing up completely. ... the whole body, and that's probably where they're feeling that tense as well in their throat when they're swallowing.” SLT 11

For others, swallowing difficulties and anxiety around mealtimes were linked closely to the mental illness itself. Participants described how improvements in mental wellbeing could lead to improvements in mealtime experience:

“They self-report difficulty swallowing when their mental health is really poor ... but then as their mental health starts to stabilize, actually it resolves spontaneously. And you do think, is that anxiety that's playing a part there? ... It would seem plausible to me that anxiety would ... if you think about like the ‘lump in your throat’ kind of feeling as well, muscle tensing, are your muscles tensing, in your throat as well? It would all seem to make sense.” SLT 08

There were many such reflections on the relationship between physical and mental wellbeing and the experience of mealtimes. One SLT gave an example of a patient using relaxation self-help strategies before the mealtime, another described patients

struggling to cope with the consequences of stress such as dry mouth or a feeling of tightness restricting the swallow function. Throughout, SLTs highlighted that engaging the patient and understanding their perspective was seen as key to effective support and planning.

#### **7.5.4 Staff may discount patients' reports**

SLTs discussed their experiences of working with some ward staff who had less awareness of both dysphagia and of the heightened risks of choking associated with patients with mental illness. Their accounts of patient self-reports of mealtime difficulties reflected barriers to understanding the patients' experience and the need for "asking the right questions" (SLT 05). The need to offer time to listen and encouragement to communicate was raised as a challenge for staff on a busy ward:

"They [staff member] said 'oh [patient's name]'s refused [her meal]' and I said, 'have you spoken to her?' ... I'd asked her [the patient] about foods she found difficult ... she said 'oh I can't manage dry food' ... [but] staff weren't aware of any of that. That's another example of patients who won't necessarily initiate sharing the information." SLT 05

There were also comments that mealtime difficulties were not regularly discussed and were not part of staff monitoring processes on the wards. Some gave examples of how patients had tried to communicate their concerns, but this was described as unsuccessful:

"What he said to me was, 'well, I've said this over and over again to the doctors and nobody's looking at it'. ... and so, unless a nurse or somebody on the ward sees that somebody is struggling, self-reports, in my opinion, don't seem to be taken that seriously." SLT 09

SLTs observed that if the ward staff had prior experience or specific training in the signs of dysphagia this improved their understanding of the patient self-reports. However, many highlighted that patients needed to be assertive and consistent in their reporting so that ward staff would be more likely to listen and respond to their concerns. The patient perspective was sometimes lost as a result of institutionalised ward routines and procedures:

“It's easy for us as professionals as well to get institutionalised ... I think sometimes we miss how unusual either that kind of behaviour is or indeed any other kind of behaviour that's going on as well.” SLT 01

The degree of staff's awareness affected how they responded to the patients' concerns. For some patients, the concerns were dismissed by staff as part of their delusions or general anxiety associated with their overall mental illness:

“Some of them [the patients] have such wonderful insight, but I think they're just 'poo-pooed' almost because they've got a mental health condition.” SLT 06

Others described “dismissive” responses denying the self-report. SLT 10 reported being approached by staff “to prove that it's all in their [i.e. the patients'] mind” and asked to “rule out dysphagia” (SLT 10) with an assumption that the mental health condition was the only issue. Further examples presented how SLT assessment and recommendations for mealtime difficulties were seen as counterproductive to mental health:

“I've had a consultant say, 'well, unless there's any actual evidence of dysphagia, I'm reluctant to ... I don't want to like feed into this' and ...' so I'm reluctant to have any specific dysphagia recommendations in place'.” SLT 03

Participants gave examples of staff mistrusting self-reports and described their general misgivings around how patients expressed their perspectives about mealtimes, particularly for those patients with multiple anxieties. SLTs were concerned that there were occasions when the patient's mental health diagnosis was seen to be overshadowing other issues including possible physical health concerns.

Other concerns were raised when the ward staff response to the self-reports was dismissive due to overshadowing by behavioural concerns:

“There's a lot of comments around things being behavioural ... 'doing something for attention'. And so, I had somebody that ... had had several choking incidents and he was already on one to one observations and the staff member said, 'well, he's just choking for attention'.” SLT 08

There were repeated observations suggesting staff may dismiss patients' reports of concerns as unsubstantiated "attention seeking" (SLT03) and staff becoming unresponsive to repeated self-reports. Some SLTs sounded frustrated and concerned that the accuracy of the patient reports was being questioned.

Overall, SLTs appreciated the value and importance of patients' individual insights about mealtimes. The descriptions covered patient experiences of both swallowing difficulties and choking incidents. However, there were SLT concerns that the ward staff may not encourage or support patients to voice their experiences, stresses, or concerns around mealtimes. For those patients who did express concerns there was a tendency by overstretched staff to frame these as part of the patient's overarching mental illness or 'behaviours' rather than exploring the potential for an underlying physical health concern.

## **7.6 Others' awareness of mealtime difficulties**

Definition: SLTs contrasted their insights and their role in supporting mealtime difficulties with that of the ward staff. SLTs described different perspectives of the need to consider safety and the issues involved in introducing support for mealtime difficulties. Staff's attention focussed predominantly on mealtime safety, but their awareness varied.

### **7.6.1 Raising awareness of mealtime difficulties**

SLTs described how their role focussed on understanding the patients' mealtime experiences and concerns but to become involved they relied on staff to support patients to identify and report any signs of difficulty, and then to request SLT involvement. SLTs wanted to raise awareness and enable staff to understand patients' mealtime difficulties:

"I will often insist that someone comes and sits with me and sometimes I'll say to them 'did you hear that? or did you notice that? or what was that? So, I kind of forced some training upon them, but often they're oblivious to what I'm doing.'" SLT 10

Training was therefore perceived as a “huge investment” (SLT 04) bringing potential to raise awareness of the patients’ mealtime experience. Given the limited self-reporting described above, and the lack of SLT presence on the wards, the patients were unlikely to access SLT directly. Staff attention to (and understanding of) the patients’ experience of difficulties was crucial in ensuring SLT referral was completed. This necessitated attention to how the patient was coping physically at the mealtime, but staff awareness was limited:

“I think fatigue’s a big thing [for patients] and I think people [staff] don’t reflect on that enough ... especially in quite a stimulating busy ward. Are they like as aware ... they [patients] could be ... quite tired by that evening time. So, I think that’s just something people aren’t always aware of.” SLT 06

SLTs described advocating for patients’ needs at the mealtime and providing “reassurance” (SLT 12) to staff in supporting the patient with mealtime recommendations. There was a wide range in how SLTs reported staff perceptions of the patients’ swallowing difficulty:

“[staff have] ... a strange contradiction of fear and complete obliviousness, because you know you can have someone who’s choked several times and they’ve not done an incident report. They’ve not done anything about it.” SLT 10

Professional roles and responsibilities were emphasised regarding responses to choking risk, but patients’ viewpoints were less prominent. SLTs focussed on reducing risk of choking and managing dysphagia. They described how the ward staff were often seen to have become habituated in how they managed mealtimes, resulting in “people just not really looking out for stuff” (SLT 01) and descriptions of staff not seeing choking “as a priority” (SLT 09). Participants questioned whether some staff would have sufficient awareness or motivation to action a referral to SLT:

“Sometimes somebody will be coughing really regularly or showing lots of different signs that they’re struggling, and it becomes completely normalized and nobody notices it until they choke.” SLT 08



However, in contrast, SLTs also acknowledged that they did receive referrals from the staff requesting dysphagia assessment and guidance implying some staff did have awareness of signs of dysphagia and/or choking. There were concerns that the referrals were not “pre-emptive” but rather “reactive” (SLT 09). Many commented on how seldom choking was recognized. They described their perception that only “more obvious, more visible things” (SLT 12) were reported. In contrast, those staff that had bystander experience of choking incidents and follow up SLT involvement, were reported to be more pro-active in observing for signs of dysphagia and making referrals, “referrals breed referrals” (SLT 01). Direct experience of choking sharpened staff’s attention to patients’ mealtime skills and experience heightening their awareness of how patients were coping.

### **7.6.2 Collaborative approaches**

SLTs reported supporting ward staff to consider the patients’ mealtime experience as an important aspect of their role. Fluctuating mental health with concomitant distractibility and anxiety could reduce patient insight and retention of information so that the ward staff were then key to providing the patient with consistent reminders and support.

However, ward staff could also be faced with patient frustration and resistance to SLT recommendations for safety (e.g. following advice on adapting mealtimes or avoiding certain items). SLTs highlighted the importance of making time to listen to the patients’ concerns and choices. SLTs described the need for support and patience, so that patients could express their concerns and preferences for mealtimes and collaborate in decisions about mealtime adaptations and safety measures. Finding ways to cope with different textures whilst maintaining their preferred mealtime customs was important:

“You don't want to sort of patronize somebody. You want to check with them first, but it feels like ... Staff worry about, you know, affecting somebody's independence, but you can have a chat about these things and work it out, and it might be they're more than happy for some help.” SLT 04

SLTs recognised the importance of understanding how each patient felt about different options for food and drink and the wider mealtime environment. They made attempts to ensure ward staff were also aware of these elements to support an informed and person-centred approach to mealtime support. Presenting the patients' concerns was a priority in reaching decisions about mitigating risk of choking. However, SLTs also reflected on "tricky" (SLT 03) experiences in working collaboratively with patients and staff describing issues with supporting patients in decision making:

"There's a lot of things that we do to try and ensure that the patient is also involved in their care ... We wanna manage risk, but we also want the patients to have their say and be involved in their own care as well as much as possible." SLT 11

Overall, SLTs acknowledged that mealtime experience and food choices were an important part of the patients' wellbeing. This included understanding of patient and staff awareness of risks and the impact of adaptations to mealtime experience.

## **7.7 Summary of SLT findings**

The SLTs described their unique role on the wards and their focus on the individual patients' mealtime skills. Observations of ward mealtimes as chaotic and uncomfortable contrasted with participants' own more positive mealtime experiences. The missed opportunity for mealtimes to contribute to wellbeing and sustained recovery was highlighted but ward mealtimes remained chiefly task focused. SLTs' skills supported understanding of patients' choices, customs, and concerns. The impact of environmental and social stresses on how patients experienced their meals was a source of concern with descriptions of fast paced eating as a result. They also described working with ward staff enabling them to understand and report signs of swallowing difficulty in the patients.

The following chapter presents a synthesis of themes from the three participant groups.

## Chapter 8 Synthesis of study themes

### 8.1 Introduction

This chapter presents a synthesis of the themes derived from the three study groups. Firstly, the overarching themes of the three groups are compared and contrasted to highlight both commonality and variation. This is to present the “conceptual reintegration of diverse findings” (Thorne 2016 p.273) described earlier in chapter 3. Secondly, the main themes of the patient group findings are similarly presented discussing how each links to similar themes from the staff and SLT group interviews. Thirdly, the remaining themes raised by the staff and SLT groups but not prominent for the patient group, are considered in terms of relevance to the patients’ perspectives. Finally, the findings from the literature reviews are compared and integrated highlighting the different perspectives and themes.

The patients’ perspectives are the primary focus of this research study - the other groups’ findings are therefore mapped to the main themes of the patient group considering these as the priorities for understanding the patients’ experiences at mealtimes. A reflection is included to present the researcher’s experience during the study analysis and to clarify the personal standpoint.

### 8.2 Reflection

Conducting the interviews and data analysis was continually challenging and distracting as a clinician with experience of working on the wards. I have had a long career working with people who have swallowing difficulties which has entailed observing patients with and without swallowing difficulties and how they are supported by staff. The desire to understand and inform practice was a constant pull towards data around swallowing difficulty, mealtime guidance and clinical utility. I needed to return constantly to the research question, pulling my focus back towards understanding the complexities of patients’ personal mealtime experiences. Swallowing difficulties were described by all participants with strong emotions around the experiences of these. However, other aspects of mealtime experience were of equal or greater interest to patients and staff. I

needed to balance all the concerns voiced and using thematic analysis was helpful to represent the interwoven and complex issues discussed.

### **8.3 Overarching themes: commonalities and differences**

The patient group's overarching theme concerned the heightened emotions associated with mealtimes. Anxiety and stress were foremost in the patients' reflections, triggered by their wide ranging mealtime difficulties. For some these extended beyond the mealtime into wider ward experience and had the effect of diminishing mental health. The impact of swallowing difficulty and experience of choking affected the emotions for some but for others these issues were dismissed as infrequent and ascribed to bad luck. The patients' accounts emphasised the importance of comfort, control, achieving independence, connections, and social aspects in mealtimes. The interaction between mealtimes and mental health was prominent and reiterated by all the groups. The potential for mealtimes to bring joy and comfort was an aspiration for all but this was countered by the negative aspects of inpatient mealtimes which brought stress and conflict for many patients whilst on the ward. The importance attributed to individual patients' choices and flexibility was clearly expressed and strongly linked to emotions by participants in all the groups. Considering the routines, choices, and customs of home in contrast to the inpatient settings appeared to be key to understanding the range and nature of positive and negative emotions associated with mealtimes. The mental health recovery process sought during admission appeared to be compromised by the mealtime stresses and anxiety. Rather than promoting recovery, mental wellbeing was frequently diminished by patients' mealtime experiences on the ward.

The staff's overarching theme also reflected the underlying emotionally loaded nature of the ward mealtimes, but staff interpreted this as driven by the pressures of working within organisational constraints so that individual patient choices were difficult to support. The staff showed concern around understanding the patients' strengths and needs around mealtimes however, this interest was often shelved due to the pressures of managing the meal as another difficult task in a day of multiple demands. The meal was presented by staff as a nutritional

necessity with the social and personal aspects having to be sidelined due to other duties.

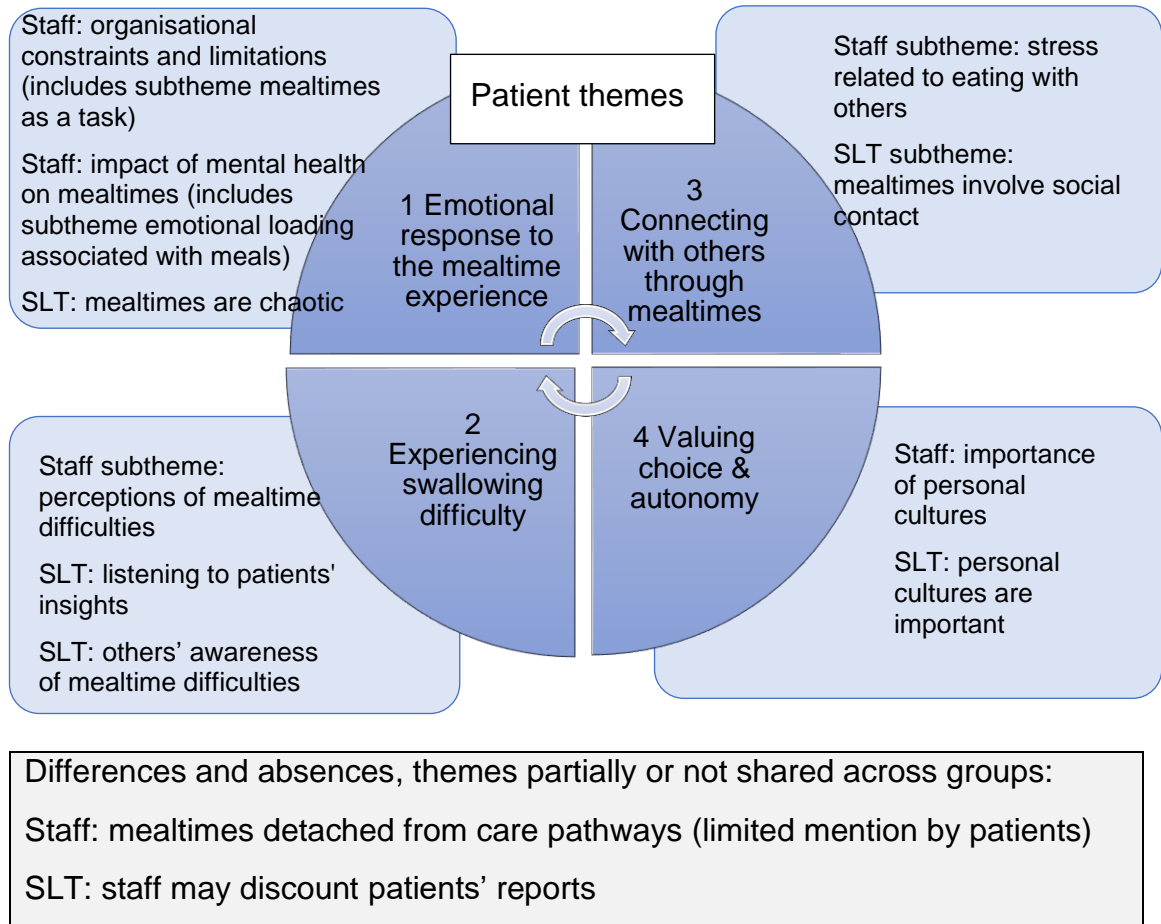
Specific swallowing difficulties were a source of anxiety for some staff, but these issues were not prominent in the staff group. Staff focussed more on their role in supervising and monitoring safety describing behavioural challenges and managing conflict. Participants from all the groups were aware of developing tensions between patients (and sometimes between patients and staff) which might come to a head at the meal. The majority were conscious that the mealtime was the only time in the day that patients and staff would be compelled to meet together. At other times patients had the option to withdraw either to their own room or (for some) to access other areas or time in the community. The crowded mealtime environment was a concern for patients and staff alike due to the impact on emotions and mental wellbeing. This linked to patients' comments about difficulties in connecting with others and maintaining relationships through mealtimes.

The SLT interviews returned the focus to the needs and choices of the individual but also highlighted the environmental issues and staff pressures. The themes of the SLT group captured the emotional impact of the hectic and difficult atmosphere of the dining experience, how this could affect mental wellbeing and how this linked to physical ability to eat and drink in the inpatient setting. The heightened emotions of stress and anxiety experienced by the individual at the mealtimes was evident to SLTs who observed consequent fast paced and thus riskier styles of eating (cramming and bolting). There was concern around how much the patients could voice their concerns, express their emotions, and receive staff support. SLTs reflected at length on how patients' insights could be informative and focussed or vague and distracted. They gave concerning descriptions of how the ward staff responded to self-reports: many SLTs described dismissive attitudes and lack of understanding around the potential swallowing risks and patients' need for support around these.

### **8.3.1 Main themes: synthesis**

The main themes determined for each group showed similarity in the majority of concerns and interests raised. Figure 8 below presents the patient themes as central mapped against the other groups' themes where these align either fully

or partially. These will be discussed for each section below in terms of how closely the themes from staff and SLT groups compare or contrast with the patients' themes.



**Figure 8 Commonalities, differences, and absences in main themes**

### 8.3.2 Theme: emotional response to the mealtime experience

The mealtimes on inpatient wards were presented as difficult emotionally for both patients and staff. Anxiety, differences in personal mealtime cultures, and social difficulties were described by all participants as potentially influencing patient ability, engagement, and enjoyment with mealtimes on the ward. All participants described how mealtimes could trigger emotions, escalate anxiety, and become a flashpoint in the day when previous altercations came to a head in the crowded dining room setting.

Participants concluded that inpatient mealtime experiences were significant but often neglected influences on levels of patient wellbeing and future recovery. The descriptions repeatedly highlighted the importance of mealtimes for promoting patients' mental wellbeing. However, many participants expressed concerns that emotional aspects and individual needs were overlooked in the fast paced and institutional routines associated with providing food at prescribed times of day in institutional environments. Participants reported concerning consequences of stress at mealtimes including agitation and rushed eating with associated risks to individual patients' physical safety and mental wellbeing. Adding SLT guidance or staff implementation of additional restrictions could escalate stress and frustration exacerbating the emotional strain of the experience. This included SLTs advice on modifying food consistencies or providing heightened supervision levels. Patients sought to leave the dining room and ate faster to achieve this, thus adding further to the risk of choking.

Patients' concerns included varying perspectives on the experience of swallowing difficulties and the emotional and psychological impact of choking. Whilst not a frequent occurrence, the potential risk of choking triggered anxiety in patients further affecting the process of eating and swallowing. Occasionally, staff raised the negative emotions they felt themselves regarding choking but more often they reflected on mealtimes generally. The concerns and difficulties of completing the nutritional task for the whole group dominated the staff's interviews. The pressures felt were complex and stressful as they strove to complete the routines in line with safety procedures, manage behaviours and observe everyone in the crowded room for signs of difficulty or deterioration whether mental or physical.

Patients discussed how their mental health related to mealtimes. In contrast to the positive and comforting role of home mealtimes, the ward mealtimes brought anxiety and stress. Many participants described a reciprocal process between mealtimes and recovery: the underlying mental health issues were described as influencing mealtime skills and the avoidance of others, but social mealtimes were described as an important part of rebuilding relationships and recovery in mental health. The influence of medication on mental wellbeing, attention, and physical swallowing skills was rarely mentioned by patients. Rather recovery was linked to relationships, freedom, and control. Loss of personal customs and cultures meant patients felt further detachment from home life and previous

relationships and mealtimes brought this to the forefront of their attention. In building an individualised recovery pathway the potential for immediate and wider benefits of mealtimes appeared to be overlooked by staff and SLTs.

The mealtime environment had a strong influence on all the participants' emotional experiences of the meals. Patients reflected that as they recovered their mental health so they could tolerate the mealtime better in terms of setting and social aspects. Staff also had insights about the effect of the crowded and bleak, institutional dining rooms. There was a desire expressed by staff to have greater flexibility to be able to respond to patients who needed quieter space for eating and for options to adapt timing of meal to suit individuals better. Overall, the established rules of the organisation appeared at odds with the need for flexibility required by patients at different stages of their recovery. Staff aspired to offer a more personalised and sensitive approach to mealtimes but felt restricted by the organisation and their workload pressures. SLTs presented the mealtimes as very negative. As visitors, they typically had overview of more than one ward, and they described chaotic, unpleasant mealtimes with blanket approaches and volatile emotions. However, there was again an interest to seek more adaptability and personalised approaches to connect patients with each other and to links with a wider community and previous home life.

Overall, the heightened emotions affected everyone in the dining room, escalating anxiety and becoming a reason to avoid the mealtime. There was a shared sense of regret and loss as most participants could describe happier mealtimes associated with home life that they could not access or replicate on the ward.

### **8.3.3 Theme: experiencing swallowing difficulty**

Patients recalled previous experiences of choking with great clarity and could reflect on the emotional impact of their experiences. Descriptions of choking by patients themselves were insightful and expressed in terms of fear and shock. They could describe their choking sensations and were aware of the potential for harm. There was limited discussion of future risk and potential for recurrence but some residual anxiety after choking affecting mealtimes was occasionally reported by patients worrying about recurrence of difficulties. Patients also focused on their experience of mealtime difficulties associated with declining



mental health: a lack of interest in eating and the difficulty in maintaining nutritional intake was described.

All participants were aware that anxiety and stress at mealtimes often resulted in patterns of fast eating and cramming food. Observation of this and the resulting impact on risk of choking were described by patients and SLTs but less frequently by staff. It was apparent that SLTs reported relying on staff for identifying patients at risk of choking and were keen to elicit patients' self-reports, yet they conceded that staff and patient awareness was variable. SLTs reported how some patients had designed coping strategies to promote safer swallowing but their self-reports and personal needs were not often recognised or supported by staff. This linked to the themes concerning patients' wishes for greater autonomy and reports of feeling powerless. It was disturbing to hear how patients' attempts to voice their difficulties were sometimes dismissed or misinterpreted as behavioural.

From the staff interviews there appeared to be an assumption that patients would assert their needs whether cultural or physical, without staff support or prompting. This was a concern as a patient's ability to be assertive may be reduced due to mental illness, lack of confidence or limited cognitive and/or communication skills. SLTs gave examples of their experience of patient self-reports being neglected or discounted by staff and reported that patient assertiveness was seen by staff as disruptive. SLTs highlighted the need for patients to be supported to communicate their concerns and anxieties. Issues of capacity and consent to advice and recommendations from the SLT were raised as concerns. These were frequently described as a balancing act between respecting patients' personal choices and customs against mitigating increased risks associated with certain foods and eating styles.

The comments showed variation in how the staff perceived the patients' difficulties with the meal and their understanding of individuals' needs. For those who had direct experience there was clearly trauma and continuing anxiety affecting the mealtime experience. The staff's attitudes towards risk of choking and swallowing difficulties varied between fear and complacency, whereas SLTs consistently highlighted the lack of staff awareness and staff's difficulties in both recognising and supporting patients' mealtime needs.

#### **8.3.4 Theme: connecting with others through mealtimes**

Socialising at mealtimes was described as minimal between patients and for patients with staff by all participants. Patients' preference to sit alone in the dining room or to seek isolation was connected to their level of mental illness and difficulties tolerating others on the wards. The declining skills for coping with other people generally, and loss of connections with patients' own cultures, were concerns for achieving future wellbeing and sustaining the return to a community life. The mealtime experience as a measure of, and a support for mental wellbeing was repeated by all the groups. Staff suggested that increasing social opportunities at mealtimes was helpful for improving patients' mental welfare and this also allowed staff to monitor for signs of recovery or deterioration. Some staff and SLT participants also described how targeted interventions at mealtimes could support recovery if needed by supporting individual patients to address issues such as behavioural or swallowing difficulties and to promote social skills but this had limited attention.

The patient participants were keen to describe their home mealtimes and how past family experiences had shaped their customs and choices for meals and food and drink generally. The warmth of emotion present as they reflected on previous environments in happier times was in contrast to the anxiety associated with the descriptions of inpatient mealtime experiences. Participants in all three groups described the enjoyment of sharing a meal with friends and/or family, and how their relationships were initiated and sustained during mealtimes spent together. However, the staff's and SLTs' discussion of relationships on the wards were more focussed on managing difficulties in behaviours and swallowing respectively and these included concerns about conflict and lack of tolerance between patients who were mentally ill. Both staff and SLT participants reflected that they did not routinely explore these topics or seek history of previous mealtime customs to understand social aspects and preferences.

Those participants who were able to cook for others cited this as an important and positive activity for sustaining a caring relationship and bringing mutual benefit. Patients shared their past experiences of cooking for families or partners at home; staff and SLTs warmly described cooking at home. There were examples from staff on how self-catering sessions appeared to replicate this

effect to varying degrees. Staff reported improvements in self-esteem and social contact on the wards when patients shared out food they had made either to other patients or to staff. The positive effect lasted beyond the mealtime itself and strongly promoted mental wellbeing.

A few participants in each group made reference to more negative aspects of home mealtimes prior to admission. Influences from traumatic events had been a significant part of past life for some and for others deterioration in mental illness had brought a negative impact on mealtime experiences. Whilst eating disorders were outside the scope of this study, some patients and staff described difficulties associated with eating disorders as part of a complex mental illness diagnosis. These difficulties affected relationships in the past and present and were a measure of general wellbeing: when mental health improved, staff and patients described an associated improvement in connecting with others at a mealtime. Likewise, more positive mealtime experiences were seen to promote relationships. Sharing a meal or merely having a drink with another person were seen as important activities to improve and sustain mental wellbeing.

Connecting with staff at mealtimes was a topic of interest for all the groups. Patients reported on the distance they experienced between staff and patients during mealtimes, fostered by the sense of being supervised and managed. Staff reflected that they would welcome the opportunity to sit and eat with patients, but they felt constrained or distracted by their duties and organisational processes. The staff accounts clearly suggested that the act of sharing a meal brought a more relaxed and positive approach and contributed to better relationships between staff and patients. Staff also felt that informal mealtime conversations would be beneficial to understanding the patients' strengths and needs leading to better informed recovery planning and support. However, they conveyed a sense of barriers and pressures preventing this mealtime opportunity for connection.

SLTs presented their own positive experiences of mealtimes as an important part of home life and acknowledged the importance of sharing meals to build and maintain relationships. However, they did not describe connecting with patients during meals in the same way as ward staff. They emphasised their role as

visitors and appeared detached from the ward – their role required observation of mealtimes as part of swallowing assessment, and this brought a sense of supervision and authority. SLTs considered briefly the emotional role of the mealtime and the impact on relationships suggesting that the mental illness affecting patients on the wards affected understanding between patients of each other's needs and reduced their tolerance levels. The main concern of the SLTs was the noise and distraction present in the crowded dining environment and the effect of this on the patients' eating, drinking, and swallowing skills and safety.

### **8.3.5 Theme: valuing choice and autonomy**

Patients presented many frustrations and anxieties centred on loss of control and autonomy as an inpatient. There was a strong sense of institutional approaches to mealtimes restricting choices which was reiterated by all participant groups. The loss of personal mealtime customs and freedoms at mealtimes were deeply felt and contributed to deterioration in wellbeing. Sharing meals with other patients on the wards was stressful due to the unpredictable nature of not only the people present but also the institutional systems which were described as either rigid, erratic or uncertain. The crowding and queuing were particularly difficult to tolerate, and the staff supervision added to the sense of dependency, pressure, and constraint. The unpleasant and random nature of the food itself resulted in patients avoiding the meal entirely when possible. Some patients appeared to feel more hopeless than frustrated and described a passive approach to meals as a task to be endured.

Cooking for self or others was an integral part of how patients perceived regaining their independence enhancing choice, flexibility, and autonomy. The option to cook and share food with others was important for many patients bringing self-esteem and pride in achievement. Staff also mentioned cooking as a valuable part of a person's caring role consequently promoting self-worth. Staff were sometimes aware of the loss of personal choices and routines for patients within the institutional setting, but others imposed their own mealtime customs as a 'norm' without question or understanding the issues around ethnicity and diversity. SLTs' primary concern was risk of choking and finding strategies for mitigation through restrictions of food types and textures. This could be in conflict with patients' wishes and affect their mental wellbeing by diminishing quality of life. Some SLTs acknowledged that patients may have developed appropriate

coping strategies and outlined a more inclusive approach to decision making around risk mitigation for swallowing difficulties.

Staff and SLT participants needed to be prompted during the interviews to consider diversity of mealtime customs and cultures. They reflected that information on the patients' personal mealtime needs and preferences was not a regular part of case history taking with patients, nor of discussions on the ward. Staff and SLTs did feel that this topic was relevant for supporting patient wellbeing and important for improving practice generally. Participants compared their own personal customs, mealtime routines and choices with those available to the patients on the wards. Enjoyment and independence linked with choosing food was associated with wider wellbeing at home. Consideration of social norms and customs around eating of the patients' previous lives at home, was lost in the busy routines on the ward. Adherence to religious and dietary requirements was described as intermittent with menu orders often not appearing at the hatch as requested. Alternatives were described as unappealing and thus declined. Staff participants reflected on the fact that patients may not be comfortable with the timing of the meals and felt that this too was restrictive; this lack of personal choice and control contributed to make mealtimes into negative experiences. Conversations about the nature of the food and lack of choice were reported to take place between patients and staff, however choices around psychosocial aspects were not readily voiced by patients with anxieties so that staff could be unaware of how the dining room was affecting them.

Staff and SLTs commented on restrictions in opportunity to offer greater choices in place to eat, choice of food and self-catering. These were seen as valid concerns but difficult to address due to environmental and organisational pressures. The many demands of managing the group of patients on a ward resulted in blanket approaches with a loss of attention to individual patient's perspectives.

#### **8.4 Differences and absences**

Presenting the patients' voices describing their perspectives was the primary concern for this study but it was useful to compare the perspectives of the other two groups considering others' perceptions of patient mealtime experiences on

the wards and to understand how a patient's recovery might be compromised or supported. Themes raised by staff and SLT groups relating to patient mealtime experience, but with limited comment from patient participants, are presented below.

#### **8.4.1 Mealtimes not part of recovery**

Mental wellbeing was a common concern but recovery from mental illness was not at the forefront in patient interviews. The primary foci of mealtimes for patients were comfort and access to choice. This included not just choice of food but also choice of timing and environment with particular preference for cooking own food and eating in a quieter setting. Reflections on home mealtimes were powerfully conveyed and contrasted sharply with the inpatient experience. The staff's main focus was entirely different. They felt obliged to complete the meal as a nutritional task whilst managing safety, behaviours, and other risks through supervision. The potential benefits of mealtimes for wider mental health recovery were discussed during the interviews with staff recognising the value of mealtimes in promoting wellbeing as a missed opportunity.

The nutritional aspects of the mealtime task were emphasised by staff as the core purpose of the mealtime, but all participants acknowledged that the mealtime as a nutritional task was not successfully completed in many cases. Examples were given of patients avoiding the dining room through dislike of the environmental and/or social aspects, those others that queued for a meal were described as not engaging in or finishing their meal if their menu choice was either not available or not appealing. All participants reflected that takeaway food and snacks were often acquired to replace meals and satiate hunger but that nutritionally, these were of varied benefit.

The patients' recognition of how mealtimes could contribute to their overall recovery was limited or absent. The accounts suggested a lack of hope, dependency and passivity in the dining room environment – most gave examples of how they would avoid the inpatient catered meal and find alternative options (snacks and takeaways) to eat alone in their bedrooms. Staff and SLTs had more understanding of the potential therapeutic effect of a positive mealtime. However, they highlighted that personal customs and cultures were only partially

understood if at all, with harmful consequences for the patients' self-esteem, maintaining relationships and community presence.

The organisational policies and protocols for mealtimes were unclear in the participants' accounts. For example, patients eating alone in a bedroom appeared to be a common occurrence and the risks associated with this had little attention from patients and staff. SLTs were aware of choking risks and described the recommendations for patients to be supervised when eating but nurses and other staff had limited recognition of this concern. Other rules governing whether staff were allowed to share tables and eat with patients at mealtimes were also unclear, but staff appeared generally to reject this as an option for them to eat either catered food or their own meal. Some staff did report sitting at tables in the dining room, but this was separate from patients' tables and these staff appeared to be busy with administrative tasks such as checking off menu choices rather than eating. However, staff were consistent in their comments that sharing a meal with patients would be mutually beneficial and showed interest in how this could develop and support patients' recovery.

#### **8.4.2 SLT views on others' awareness**

Staffs' awareness of choking was considered limited by SLTs when describing staff practice and knowledge on the wards. Training and support around swallowing difficulties was discussed for staff but patient involvement in this was not mentioned. In staff and SLT accounts there were minimal descriptions of inclusion in discussing physical swallowing difficulties, rather the accounts of care planning around swallowing difficulty described 'doing to' rather than a collaborative approach. Mealtime difficulties and swallowing problems are by their nature often reliant on subjective reports initially, referral for specialist assessment and advice relies on the person identifying an issue and describing how it feels. This appeared to be a concern for staff and SLTs who were aware of conflicting and fluctuating reports from patients and described challenges when trying to distinguish between mental and physical health symptoms.

SLTs considered patient insights and self-monitoring skills as important but neglected by staff. Shared decision making as a topic was also scarce in the interview discussions. Individual patients' difficulties with mealtime routines and

staffs' offers of support were generally presented as impairment focussed with a lack of comments about linking with patient choices and cultures. The impact of mealtime difficulties on sustained recovery (i.e. for when the patient was discharged from the ward) was also not considered. SLTs offered more descriptions of patients' levels of capacity and insight than the other participants – they suggested that staff might not have time to listen to patients' concerns and suggestions regarding mealtimes.

### **8.5 Findings of literature review**

The themes from the literature review related primarily to medical perspectives; the papers reviewed described clinical impairment at mealtimes from the perspective of clinicians. The issues and concerns regarding the wider mealtime experience described above by the three groups of participants have little attention in current research. The literature review identified an absence of accounts of patient insight and the impact of mealtime difficulties. This area of neglect was highlighted in the SLTs' reports of patient insights being overlooked or dismissed. Although choking was described as an infrequent occurrence, the patients in the interviews were able to give clear accounts of their experience of mealtime difficulty and/or choking. These valuable insights contribute to assessment and intervention and highlight how their mealtime experiences impact on overall mental and physical wellbeing. This is not recognised in existing literature which presents medical factors and physical symptoms almost exclusively. Wider literature exploring mental health recovery also refers to the medical model and the focus on impairment rather than holistic approaches (McAllister and Moyle, 2008, Swords and Houston, 2021).

There was limited acknowledgement in the literature review of behavioural aspects affecting mealtime skills – with few examples of how fast paced eating may be an issue affecting safe swallowing. This was reiterated and expanded upon by the interview participants with all groups describing the impact of stress leading to faster eating and associating this with an increased risk of choking. Patients were very aware of the consequences of rushing the meal but emphasised that the environment and social aspects of the mealtime influenced their pace of eating. SLTs reiterated the risks associated with bolting and cramming styles of eating and some staff also were aware that individual patients,



particularly those with heightened anxiety levels, would benefit from addressing the adverse environmental and social aspects of the mealtime.

Patient inclusion in decision making around assessment and intervention for dysphagia and risk of choking is scarce in the literature for adults with mental illness. The use of instrumental swallowing assessment promoted in the literature neglects consideration of the impact of the mealtime setting on the efficacy of the swallow and on the wider comfort and safety of the patient. The interviews in this study have emphasised the importance of psychosocial aspects of the meal – but these are not highlighted in current research for this population. Access to the patients' self-reports of how mealtimes are experienced and their insights into the risks are not presented in the literature and are overlooked by staff on the wards on a regular basis. The individual aspects of mealtime culture and choice have important relevance for adults with mental illness, the interviews for this study confirmed that these are frequently neglected in current mealtime practice to the detriment of patients' wellbeing and recovery.

## **8.6 Summary of synthesis**

There was a recognition in all study groups that the topic of mealtimes was not generally raised for discussion, assessment, or review apart from conversations about specific menu choices or food and drink requests. However, during the interviews there was a consensus that it was an important and highly relevant topic - important for current wellbeing and relevant for future recovery and successful return to community living. Patients' difficulties in swallowing had varied attention and their reports of concerns were overlooked by staff during the pressured ward routines. It was concerning that SLTs reported dismissive responses from staff when patients reported their mealtime concerns and difficulties, not least regarding the risk of choking which was a source of anxiety to many. Awareness and knowledge of dysphagia and risk of choking were described as limited amongst patients and staff.

The maintenance of personal customs, spiritual needs and cultural norms was often neglected or lost entirely during time on the wards. This affected links with past, current and future life outside the ward environment and participants reflected that this contributed to deterioration in mental wellbeing. Inpatient mealtimes frequently were described as stressful and anxiety-provoking leading

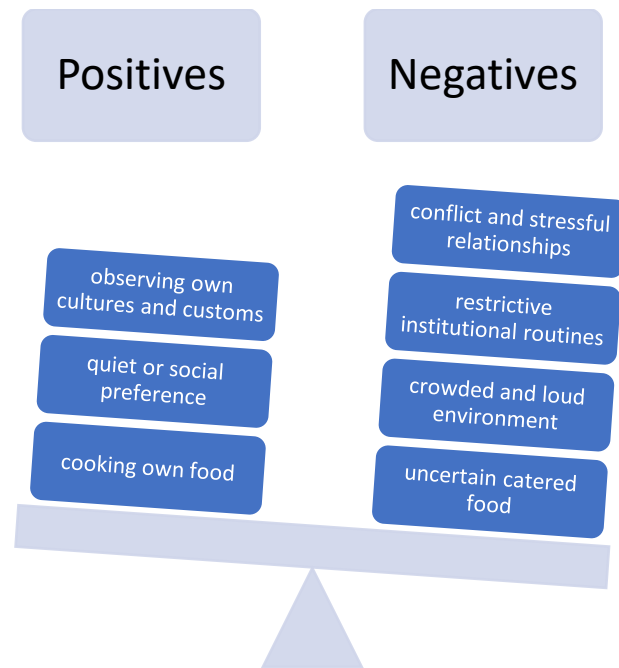
to deterioration in wellbeing. However, the positive effect of a mealtime in the right environment (i.e. choosing between social or quiet, catered or self-cooked, and following the person's individual preference) appeared to have a beneficial and therapeutic effect on wellbeing and self-esteem. The mealtime on the wards brought specific pressures to bear on both patients and staff. The crowded dining rooms triggering raised emotions and conflict, were actively disliked by the majority. However, offering more flexible mealtimes with tables shared by staff and patients were welcomed by many participants who saw this as a more informal and sociable opportunity which would support relationships between patients and staff.

### **8.7 Overview of thesis**

The experience of inpatient mealtimes for adults with mental illness is a topic that has been neglected with a paucity of qualitative research in existence. The background to this was raised in chapter 1 and the literature review in chapter 2 confirmed the limited evidence in this area. Methodology and method were presented in chapters 3 and 4 offering transparency with auditable processes and clarifying the decision making. Patient and caregiver involvement was achieved throughout with discussions with HEER and SUN groups to gain feedback, review themes and prompt further researcher reflection. Adopting a pragmatic approach with an interpretive description perspective supported the clinical-academic standpoint of the researcher throughout the analysis of the findings in chapters 5, 6 and 7. This ensured that the research aims stated in chapter 1 were grounded in exploring clinical practice and centred on patient perspectives. The findings from the three participant groups were synthesised in chapter 8 (above) and from this the implications for practice are discussed below.

### **8.8 Discussion**

Figure 9 below presents the balance of positive and negative aspects present at mealtimes derived from the synthesis of themes across the three participant groups. In clinical practice the balance between these may be adapted to improve the overall mealtime experience for patients, staff and SLTs and promote recovery and mental wellbeing. Details of recommendations for clinical practice are described below.



**Figure 9 Positives and negatives at mealtimes**

In this study mealtime practices on inpatient wards appeared at odds with and detached from the aims of recovery and personalised care. The constraints of organisational processes, staff pressures and crowded dining rooms override personal comfort, choices and customs bringing anxiety and stress to many patients and staff. Inpatient mealtimes are often not considered as part of the recovery process, yet they can have intense emotional triggers for patients impacting on mealtime safety and mental wellbeing. The findings of this study highlight the individuality associated with mealtimes so rather than providing a generalised rule book, the recommendation must be to prompt respect and attention to individual variation. Understanding of risks and patients' individual concerns should be a collaborative process through supported conversations to promote shared decision making and empowerment. Acknowledgment of the importance of individual cultures and customs around mealtimes and the impact of this on mental wellbeing and recovery is essential.

Information about personal preferences and routines was acknowledged as important for clinical decision making and support for the individual patient but staff and SLTs generally did not seek out or consider such information about individual patients' mealtime norms prior to their admission to the ward. The positive aspects of mealtimes from patients' home life are not incorporated into

ward routines so that individual cultures, choices, and preferences are often neglected. The importance of mealtimes or other shared food and drink activities in creating and sustaining relationships and social skills are not understood or implemented on the wards. Patients and staff appeared accepting of the institutionalised routines and did not report any challenges to these. However, the participants described the importance of flexibility and autonomy in mealtimes. This was not just around choices in place, time and food but included having flexibility to change and adapt rules and routines for multiple reasons at different times. This personal level of control was difficult to reconcile with ward and system processes. Recent guidance has highlighted the need to understand the wider benefits of food and drink into healthcare (Corben et al., 2022, Shelley et al., 2020) but this was not in evidence in the participants' accounts in this PhD study.

SLTs as visitors may recommend adaptations to meals that do not take account of these personal preferences and cultures. It appears that a medicalised, impairment focussed approach for mealtimes is upheld by staff and SLTs seeing these as a nutritional task rather than an opportunity for building wider skills and promoting recovery of mental health (Leslie and Crawford, 2017). This prompts patients to consider inpatient mealtimes with the same functional approach.

Awareness of patients' psychosocial and physical mealtime needs is limited – the patient voice is often not sought, patients do not identify their concerns spontaneously, and when self-report is offered it can be dismissed by staff on the ward. The information expressed by the patient may be interpreted as part of the mental illness rather than a valuable description of specific difficulty or anxiety. Awareness of risk of choking and swallowing difficulties varied in the participants with concerns from staff and SLTs that patients' insights can be inconsistent or fluctuating. Equally, it was apparent that patients and SLTs considered that staff insights can be variable (Swords and Houston, 2021).

The importance of person centred care is highlighted by UK guidance (Greenhalgh et al., 2014). Rehabilitation psychiatry is defined as:

"a whole systems approach to recovery from mental illness that maximises an individual's quality of life and social inclusion by encouraging their skills, promoting independence and autonomy in order to give them hope for the

future and leading to successful community living through appropriate support" (Killaspy, 2023 p.51).

Mealtime experience is integral to this. Sharing a meal fosters "quality of life and social inclusion". Experiencing "independence and autonomy" in preparing and consuming meals has a far reaching effect on self-esteem and mental wellbeing, particularly if sharing food with others. The importance of food, drink and mealtimes in personal cultures (i.e. "successful community living") has been highlighted in the general population (Leslie and Broll, 2022, Ratcliffe et al., 2019) and warrants greater recognition in recovery planning for inpatients with mental illness. Mealtimes on wards for adults with mental illness have been recognised as times when safety incidents and aggression can escalate (Duxbury and Whittington, 2005,). The influences described as present in noisy crowded dining rooms are known antecedents for aggressive incidents (Papadopoulos et al., 2012). Familiarity, consistency, and awareness of staff has been shown to be effective both in addressing quality of life concerns and in reducing risks at mealtimes (Guthrie and Stansfield, 2017). Time on an inpatient ward offers an opportunity for developing skills whilst offering support for individual patients from the staff team and SLT (Dickinson et al., 2008).

Understanding an individual's needs, hopes and identity has been placed as central to structuring a sustained recovery pathway (Leamy et al., 2016, McAllister and Moyle, 2008). The concepts included in mental health recovery also include attention to connectedness and empowerment – mealtimes offer an opportunity to support recovery in these areas. Indeed, other activities or isolation that occur at other times of day may be more individually focussed, whereas mealtimes offer a social opportunity where support can still be tailored to the individuals' needs. This study has highlighted concerns that current practice on the wards around mealtimes works against these concepts of recovery and may impair rather than improve mental wellbeing. Recovery planning does not generally include consideration of mealtimes within its scope losing an important and influential opportunity for wellbeing both for on the ward and in future life.

The lack of autonomy and inclusion in recovery processes has been highlighted by the participants in this study. The findings and synthesis of this study illustrate the individuality underpinning every person's mealtime preferences. At present this is overridden by organisational concerns and processes on the wards to the

detriment of patients' and staff's mental wellbeing. There is a clear need to understand personal choices to inform and support recovery pathways and improve practice and conditions on the wards around mealtimes.

The issues around mealtimes and the consequent impact on recovery have been described for the general population (Leslie and Broll, 2022, Leslie and Crawford, 2017) and also considered in relation to specific patient populations such as older people's services (Dickinson et al., 2008) and eating disorders (Rankin et al., 2023). Interestingly, the latter study also found a predominant medical perspective with a focus on nutrition and physiology that neglected psychological aspects of the mealtime difficulties. Studies of interventions for inpatient wards supporting patients with dementia have begun to evaluate how integrating mealtimes with recovery has the potential to address wider concerns (Faraday et al., 2021, Liu et al., 2023, Shune and Barewal, 2022). Moving beyond a purely nutritional focus in these studies has suggested wider benefits for recovery in people with dementia – there is a clear need to explore this in working age adults with mental illness.

### **8.8.1 Implications for patients**

The interviews raised serious concerns regarding the patients' self-awareness and their skills in identifying and then reporting anxieties about mealtime difficulties. Mental illness is a priority on admission to hospital and may override attention to other physical health concerns, patients may also be so habituated to long term swallowing difficulties so that they do not draw attention to these initially. The combined effect of the stressful mealtime environment and adverse social experiences may lead to a deterioration in physical mealtime skills. Reporting concerns and seeking help for mealtime difficulties requires cognitive insights, communication skills, and assertiveness but these may be impaired. The interconnecting influences of mental illness and mealtime difficulties are multiple and complex and compounded by lack of awareness in staff on the wards. Information and training for patients is indicated to develop skills in recognising and coping with mealtime difficulties following a co-designed and collaborative approach.

### **8.8.2 Implications for SLT practice**

Understanding swallowing difficulties and appropriate assessment of patients' needs are enhanced when the multiple influences present at mealtimes are considered. These include:

- Physiological aspects such as dry mouth, feeling of discomfort, problems with oral, pharyngeal, and sequencing movement. These may be affected by emotional as well as iatrogenic factors.
- Psychosocial influences should be considered as integral to swallowing and wider mealtime skills. The impact of negative or positive emotions will contribute to the physiological aspects above.
- Behavioural styles of eating will also be influenced by both aspects listed above. Faster eating and cramming into the oral cavity were widely reported deriving from anxiety and stress originating from multiple complex responses to the mealtime.
- Flexibility and autonomy of choice were highlighted by participants as essential to mealtime wellbeing and quality of life. SLTs recommending changes to food and drink options need to have full understanding of how this will relate to the patients' quality of life, their personal customs, and cultural needs.

It was clear that SLT participants were typically visitors to the wards following referrals requesting specialist assessment and guidance. This implied a distance from the ward and patients and a reliance on staff raising referrals before swallowing concerns could be supported. The SLT role would benefit from being embedded into multidisciplinary teams bringing closer collaboration with patients and staff. More subtle signs of dysphagia and risk of choking would be identified earlier, and wider awareness of mealtime difficulties raised with patients and staff.

### **8.8.3 Implications for practice on the wards**

The emotional aspects of mealtimes have been presented in this study: staff and patients need to work collaboratively to find ways to address negative aspects of the mealtimes and to benefit from the opportunities offered by mealtimes for supporting recovery. Despite organisational pressures, staff and patients need to find ways to improve environmental and social concerns and put the patient's

individual needs at the centre of the mealtime. The benefits for patient recovery have been made clear but the benefits for staff practice and morale also have the potential to be enhanced by positive mealtimes.

The nutritional aspects of mealtimes were highlighted as a priority by participants, but the accounts described patients either avoiding mealtimes, rushing through the meal or leaving food on the plate. The nutritional task is thus compromised by the adverse influences experienced on the wards. Mealtimes are a particular area of cultural need, interviews raised concerns that individual identity is not recognised or respected in terms of ethnicity and diversity. The individual patient's personal, cultural, and spiritual needs relating to food and drink should be understood and supported throughout the time on the ward to enhance and sustain recovery. It is clear that individuals may not be able to express and then assert their needs and staff should support each patient to ensure this information is voiced from the outset. The previous lifestyle and choices of the patient may or may not be an aspiration for the future (Swords and Houston, 2021). Discussion raising awareness of the benefits and disadvantages of mealtime behaviours and cultures will also support recovery planning. Mealtime routines may be a positive anchor in the day bringing useful structure and consistency. However routines should not be at the expense of autonomy and empowerment (Smith et al., 2023).

Environmental aspects of mealtimes were highlighted as a source of dislike, stress, and sensory overload through raised noise levels and crowding. The institutional experience related to the physical setting and to the staff supervisory roles which were difficult for patients to tolerate. Despite the organisational limitations, staff and patients may be able to find ways to adapt the mealtime experience to address some of these concerns. Recognising individual patients' personal norms and choices is important in this, rather than implementing a routine that imposes staff norms or a blanket approach.

#### **8.8.4 Implications for policy**

Participants described a sense of pressure implicit in the systems and practices of ward mealtimes. Organisations should collaborate with staff and patients to understand the issues and open debate on how to offer more flexible approaches to mealtimes respecting the individual's cultural and personal needs. Habitualisation of staff and patients to institutional routines can be challenged



and environmental and social aspects adapted to contribute to patient recovery. Rotas and assumptions around mealtime routines can be reviewed in patient and staff meetings to capitalise on interests and skills available. Involvement of patients in preparing mealtimes is essential in promoting wellbeing, self-esteem, and rehabilitation. Levels of risk and security can be discussed and carefully evaluated to determine feasible solutions.

Policy should be clear in how staff can support individual patients' preferences for place, time and social choices when eating. Where patients opt for eating in their bedrooms there is a need to consider risk of choking or other support needs. Flexibility should be supported to allow for day to day variation in wellbeing and preference. This needs to include options for quieter environments as well as more social opportunities. Participants showed an interest in shared mealtimes with staff and patients sitting together working on social and behavioural mealtime skills, organisational structures should support this in recognition of the benefits for patient recovery and staff morale.

#### **8.8.5 Implications for future research**

The synthesis of this exploratory study raises issues and concerns suggesting the need for future research with a more explanatory focus (Fryer, 2022). It has been highlighted that rehabilitation in psychiatry lacks evidence base (Edwards et al., 2023) and that research should consider exploration of life skills and psychosocial interventions as important aspects of recovery (Davidson, 2005, Wright, 2018). Of fundamental importance is the need to incorporate collaboration with patients, caregivers and staff on the wards to determine the focus and format of investigations into making mealtimes more person centred and understanding the impact on recovery more fully (Swords and Houston, 2021). Addressing the themes raised in this study will improve understanding of the emotional and social stressors present at mealtimes. The benefits of individualised mealtime support should be investigated to understand better the options for integrating mealtimes with wider mental health recovery. Sustained and positive relationships necessary for individual recovery can be supported and developed through shared food and drink. These relationships need to be considered for time on the ward (between staff and patients and also between

individual patients) and for moving on in recovery to community provision and living at home.

Future research should be fully collaborative involving patients and staff in participatory action research to direct the focus towards improving individual mealtime experience. This will address psychosocial and environmental influences present at mealtimes and the impact on mental and physical wellbeing. Further research is also indicated to understand the specific impact of stress and emotional effects on the physiological swallow function at mealtimes on the wards. This should include understanding of inclusive assessment and intervention for reducing risks and promoting wellbeing in people with dysphagia.

### **8.9 Strengths and limitations**

This study has brought an in-depth evaluation of mealtimes as an important aspect of mental healthcare which is currently overlooked. A strength of this study is its originality in exploring the patient experience and highlighting the stressful nature of inpatient mealtimes and mealtime difficulties with a focus on the individual with mental illness and presenting individual patient experiences. This has not been a feature of previous research and yet the importance and the wide ranging implications of mealtime difficulties on recovery and mental wellbeing have been clearly highlighted in this research. This study has followed the direction of those with lived experience through consultation with the HEER and SUN patient and caregiver groups. The patient and caregiver groups and the study participants confirmed the importance of addressing inpatient mealtimes as an area of interest and priority. A further strength has been the in-depth nature of the interviews supporting participants to reflect and reconsider current practice and assumptions around mealtime difficulties, routines, and concerns. Describing the impact of negative, stressful mealtime experiences has raised questions regarding nutrition, risk of choking, mental wellbeing, and the consequences for wider recovery. It has raised important questions about supporting individual patient's customs and cultural needs on the wards and whether current practice on the wards sufficiently considers equality and diversity around mealtimes.

Methodological strengths include the use of interpretive description to orientate the study towards individualised and person centred healthcare. The study findings have been synthesised and related to practical aspects of clinical

practice with details of the implications for patients, clinicians, and organisations. The silences identified in adults with mental illness regarding the mealtime experience have been clearly voiced and this will continue through shared dissemination processes (Serrant-Green, 2011). Reflexive thematic analysis is conducted by a single researcher and values the ‘insider’ clinician-researcher insights of the researcher. Transparency of methods has been presented in this thesis. The use of the EQUATOR checklists has brought transparency and an auditable structure to this research, the COREQ was used to map the study to the relevant domains. Quality has been further enhanced by regular review by supervisors and feedback from patient groups. The patient and caregiver groups offered review and feedback on the concepts, study design and draft themes prompting further reflection by the researcher to achieve greater depth of analysis.

Limitations include the nature of the sample interviewed. A single site of investigation with 25 interviews presents examples of patient and staff mealtime experience in one city in the north of England. However, generalisation of the findings was not an aim for this study. Using thematic analysis and including reflexivity, will allow the reader to understand the issues explored in this study and reach their own conclusions regarding transferability. The SLT participants contributed information based on their role as visiting clinicians to wards in hospitals across the UK. Thus, these SLTs’ observations and insights derive only from a partial view of ward routines and practices. Their role is to respond to referrals for patients with obvious signs of mealtime difficulty and their accounts highlighted the lack of staff awareness of the more subtle signs of dysphagia and risk of choking. As a result, SLT insights are based on the more severe levels of mealtime difficulties and the limited number of mealtimes that they observed.

The participants volunteering for the interviews may present with a particular interest and motivation to discuss this topic – the patients, staff and SLTs who did not volunteer remain unknown in terms of mealtime experiences and concerns. Capacity and consent needed careful support from staff for patients expressing interest in the study – those who were unwell at the time of the study and who were unable to give consent were not interviewed. These patients may have different concerns and insights. The advice and direction of the patient and caregiver groups were helpful in considering wider patient experiences and in

reflecting on findings. Recruitment for SLT participants was advertised across the wider UK but participants only responded from England, there were no participants recruited from the other devolved nations. Provision of SLT in mental health settings across the UK is known to be limited and the response rate reflects the fact that SLT services in mental health settings are predominantly situated in England (Guthrie and Leslie, 2023).

The researcher as a member of staff and having perceived authority may have influenced the participants (particularly the patients) in how they responded to the interview questions and prompts. This was partly mitigated by excluding participants on the researcher's current caseload. However, patients may have felt the need to offer 'correct' responses and have been hesitant due to anxiety about the researcher's connection to the ward staff. The purpose of the research interview and the maintenance of anonymity were reiterated for all participants to clarify the role of the researcher each time. The use of pictures, accessible information and reassurance during the interviews helped to encourage participants to contribute their insights and concerns. Staff and SLTs were also reassured and the need for research in this area was reiterated to encourage them to contribute.

Quality checking in this study was hampered by the restrictions of COVID-19 and the difficulty in returning to participants more than once. To address quality in the study there was repeated review by supervisors to check transcriptions, interview process and analysis. Triangulation was considered during thematic analysis: themes were confirmed as participants in each group offered similar insights and concerns around the interview topics. The synthesis drew together the similarities in themes across the groups and identified differences, absences, and outliers between the groups. As described above, the patient and caregiver groups were invited to discuss the themes and they confirmed that these reflected their lived experiences of mealtimes on the wards.

### **8.10 Dissemination**

The clinical academic role of the researcher will be instrumental in applying the findings into practice locally and nationally through work with NHS organisations and professional bodies such as RCSLT and Royal College of Psychiatrists. The groundbreaking nature of this research and the use of interpretive description to

support the patient voice have been supported throughout by local NHS services and it is hoped this support will continue with further research and interest in embedding of results into practice.

The dissemination of findings of this study will include multiple formats, events and settings to ensure inclusive and accessible information is offered to participants, patients, caregivers, staff, SLTs and organisations. The patient and caregiver groups will be involved in determining format and direction of dissemination and will be supported to contribute to presentations and write up. Findings will be written up and submitted to peer reviewed journals including keywords to enhance searches (mental illness, mealtime, dysphagia, choking, inpatient treatment, lived experience, qualitative). Participants, patients, caregivers, and staff will be offered an easy read accessible summary with links to relevant self-help websites for dysphagia and mealtime support needs. Infographics and 'bite-sized' information on findings will be displayed on wards and presented at multidisciplinary staff meetings across the organisation. Oral and poster presentations will include conferences and special interest groups for relevant disciplines including SLTs, psychiatry, mental health nursing, occupational therapy and third sector organisations for people with mental illness. Social media will be used to circulate information on these (e.g. Researchgate and Twitter/X).

### **8.11 Conclusion**

This final chapter has synthesised the themes across the three participant groups considering commonalities, differences, and absences. These have highlighted that mealtime experiences and concerns are shaped by individual patients' views, their access to choice, and the maintenance of autonomy. Patients' difficulties at mealtimes have an impact on their wider recovery, and on staff working practices. The organisational processes impose pressures on patients and staff at mealtimes but there was interest from participants in addressing institutional routines and constraints to improve mealtimes for all with potentially wide ranging effect on recovery and morale.

This thesis has demonstrated the relevance and importance of including patient voice in recovery from the outset. This includes understanding the patient's past life and influences and respecting personal customs and preferences. There is

work to do to raise awareness of the issues highlighted around mealtime practice and central to this is supporting patients to express their insights and concerns as individuals. Change and improvement of practice on the wards will be underpinned by recognising the individuality of recovery and finding ways to achieve holistic outcomes that are feasible and sustainable for patients and their care networks. Recovery should include attention to the quality of individual mealtimes as a vital element for living both inside and outside the walls of the hospital and incorporating planning for future health and wellbeing. To conclude this PhD and to summarise the conclusions the focus will return to the patient's voice:

"It's just the mood, ... normally when you're at [home] ... you feel proper young ... places like this one [inpatient ward] makes you feel a bit um ... not old just a bit more ... it's not good thing ... it's less sociable ... let me think ... places where you can't live your life." Patient 01

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## Appendix A Concepts for literature search

Concept 1 <b>Mental disorders (Mesh)</b>	Concept 2 <b>Dysphagia or Deglutition</b>	Concept 3 <b>Experience of mealtimes</b>
<b>Mesh terms:</b> Psycholog* or psychiatr*  Mental disorders capturing:- Anxiety disorders Bipolar and related disorders Disruptive, impulse control and conduct disorders, Dissociative disorders, Mood disorders, Motor disorders, Neurocognitive disorders, Neurodevelopmental disorders, Neurotic disorders, Personality disorders,	<b>Mesh terms:</b> Dysphagia Deglutition Aspiration pneumonia Asphyxi* <i>includes Obstructive asphyxia</i> Airway obstruction  <b>Other keywords:</b> Dysphagia – to include oropharyngeal and oesophageal dysphagia or OD Odynophagia Swallow* or eat* or feed* or swallow* adj4 diffic*/problem*/disorder*	<b>Mesh terms:</b> Quality of life  <b>Keywords</b> Health-related quality of life OR HRQoL Quality of life OR QoL  Mealtimes– behaviours /interventions/assistance Eat* habits/difficult* Feed* difficult* Mealtime or feeding assistance Mealtime or dining experience

<p>Schizophrenia spectrum and other psychotic disorders</p> <p>(Schizophrenia, Schizo-affective disorder, Bipolar affective disorder (BPAD)),</p> <p>Somatoform disorders,</p> <p>Substance related disorders .</p> <p>Ment* III*</p> <p>Mental Health, mental wellbeing, mental health diagnosis.</p> <p>Severe OR serious OR persistent mental illness</p> <p>Intellectual disabilit*</p> <p>Developmental*dis*; Cognitiv* impair*; Cognitive deficit*;</p> <p>Developmental dis*; Mental* handicap*; mental retardation, learning disabilit*</p>	<p>Cough* or Chok* or gag*) adj6 (eat* or feed* or swallow*</p> <p>“Café coronary”</p> <p>Food adj3 sticking</p> <p>Cramming/bolting food</p>	
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**Appendix B Example search strategy – Ovid Medline database**

Search number	Search term
1.	"mental disorders".ti,ab,kw.
2.	(psycholog* or psychiatr*).ti,ab,kw.
3.	exp mental disorders/ or exp anxiety disorders/ or exp "bipolar and related disorders"/ or exp "disruptive, impulse control, and conduct disorders"/ or exp dissociative disorders/ or exp "feeding and eating disorders"/ or exp mood disorders/ or exp motor disorders/ or exp neurocognitive disorders/ or exp neurodevelopmental disorders/ or exp neurotic disorders/ or exp personality disorders/ or exp "schizophrenia spectrum and other psychotic disorders"/ or exp somatoform disorders/ or exp substance-related disorders/ or exp "trauma and stressor related disorders"/ or exp behavioral sciences/ or exp mental health services/
4.	((Mental or psychiatry* or psychologic*) adj2 (health or illness* or disorder* or disease* or problem* or issue or issues or well being)).ti,ab,kw.
5.	(intellectual disabilit* or mental* handicap* or mental* retard* or learning disabilit*).ti,ab,kw.
6.	("Developmental* dis*" or "Cognitiv* impair*" or "Cognitive deficit*" or "Developmental dis*").ti,ab,kw.
7.	((anxiety or bipolar or conduct or dissociative or mood or motor) adj3 (disorder* or problem* or diagnosis)).ti,ab,kw.
8.	((neurocognitive or neurodevelopmental or neurotic or personality) adj3 (disorder or diagnosis or impairment)).ti,ab,kw.
9.	((Schizophreni* or affective) adj3 (disorder or diagnosis)).ti,ab,kw.
10.	("somatoform disorder" or "substance-related dis*" or (trauma adj3 disorder)).ti,ab,kw.
11.	((severe or persistent or serious) adj3 (mental* ill* or mental* dis*)).ti,ab,kw.
12.	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13.	exp Deglutition Disorders/ci, co, cn, et, pa, pc, rh, th [Chemically Induced, Complications, Congenital, Diet Therapy, Etiology,

	Mortality, Nursing, Pathology, Physiology, Prevention and Control, Psychology, Rehabilitation, Therapy]
14.	(aspiration pneumonia* or asphyxia* or "airway obstruction").ti,ab,kw.
15.	(dysphagia or odynophagia).ti,ab,kw.
16.	(deglutition adj3 disorder*).ti,ab,kw.
17.	((Swallow* or eat* or feed* or drink*) adj4 (diffic*or problem* or disorder*)).ti,ab,kw.
18.	((cough* or chok* or gag*) adj6 (eat* or feed* or diet* or swallow* or meal*)).ti,ab,kw.
19.	("cafe coronary" or "food adj3 sticking" or "cramming food" or "bolting food").ti,ab,kw.
20.	((mealtime* or feeding or dining) and (behaviour* or assistan* or experience)).ti,ab,kw.
21.	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
22.	12 and 21
23.	("quality of life" or qol).ti,ab,kw.
24.	("health related quality of life" or hrqol).ti,ab,kw.
25.	23 or 24
26.	22 and 25
27.	limit 26 to English language
28.	limit 27 to humans

### Appendix C Worksheet for service user discussions



What was your best meal ever?

Please could you write or draw something to describe your best meal – think about where it was, who was there, what you were eating and drinking. What made it so good?

Write or draw your ideas here.....



What is it like having dinner or tea on an inpatient ward?

What is dinner or tea like for you normally – when you're not in hospital?

Where do you eat most often?

What kind of meal do you usually have for dinner .....

.....and for tea?

Designing the mealtime research:



Where should we look to find out more about mealtimes for service users with mental illness in Leeds?



Names of places we should investigate?



Who should we talk to?



What time of day or which mealtimes?

What questions should we ask?

Thankyou for this information. It will help me to design a study into mealtimes for inpatients in Leeds. No personal details will be shared.



The results will be discussed with a future HEER meeting.

If you have any difficulty with eating, drinking or swallowing you should ask your doctor for advice or ask for referral to speech and language therapy.

## Appendix D HRA letter



Professor John Baker

Professor of Mental Health Nursing

Email: [approvals@hra.nhs.uk](mailto:approvals@hra.nhs.uk)

[HCRW.approvals@wales.nhs.uk](mailto:HCRW.approvals@wales.nhs.uk)

University of Leeds

Room 3.13, Baines Wing

Woodhouse Lane

Leeds

LS2 9JTN/A

03 April 2021

Dear Professor Baker

### **HRA and Health and Care**

<b>Study title:</b>	<b>The mealtime experiences of adults with mental health conditions on inpatient wards: a qualitative exploratory study.</b>
<b>IRAS project ID:</b>	<b>270116</b>
<b>Protocol number:</b>	<b>N/A</b>
<b>REC reference:</b>	<b>21/YH/0038</b>
<b>Sponsor</b>	<b>University of Leeds</b>

I am pleased to confirm that [\*\*HRA and Health and Care Research Wales \(HCRW\) Approval\*\*](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the “Information to support study set up” section towards the end of this letter.

### **How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?**

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

### **How should I work with participating non-NHS organisations?**

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

### **What are my notification responsibilities during the study?**

The standard conditions document “[After Ethical Review – guidance for sponsors and investigators](#)”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

### **Who should I contact for further information?**

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **270116**. Please quote this on all correspondence.

Yours sincerely,

Helen Poole

Approvals Specialist

Email: [approvals@hra.nhs.uk](mailto:approvals@hra.nhs.uk)

Copy to: Ms Jean Uniacke

### List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [LYPFT letter of support]	0.1	02 November 2020
Copies of materials calling attention of potential participants to the research [Poster]	v1	19 November 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)	v1	01 October 2020
Interview schedules or topic guides for participants [Interview topic guide]	1	06 November 2020
IRAS Application Form [IRAS_Form_25012021]		25 January 2021
Non-NHS/HSC Site Assessment Form [Risk assessment]	v1	13 November 2020
Organisation Information Document [OID LYPFT Me at mealtimes]	v1	18 January 2021
Other [Researcher risk ax]	v1	13 November 2020
Other [Data management plan v2]	2	01 March 2021
Other [Protocol signature v2]	2	01 March 2021
Other [Protocol]	2	01 March 2021
Other [Response to REC]	v1	01 March 2021
Other [Managing distress policy]	v1	06 November 2020
Other [Public and employers indemnity]	v1	26 August 2020
Other [signature page study protocol JB]	v1	20 November 2020
Participant consent form [Consent form]	2	01 March 2021
Participant information sheet (PIS) [Patient info leaflet]	2	01 March 2021
Response to Additional Conditions Met		01 March 2021
Schedule of Events or SoECAT [SoE Me at mealtimes v1]	v1	20 January 2021
Summary CV for Chief Investigator (CI) [Baker J short CV]	0.1	05 November 2020
Summary CV for student [CV S Guthrie]	0.1	05 November 2020

## Appendix E SHREC letter

### HREC 21-008 - Study Approval Confirmation

Medicine and Health Univ Ethics Review

To: Susan Guthrie

Wed 30/03/2022 11:40

Dear Susan

**HREC 21-008 The experience of mealtimes for adults with mental health conditions on inpatient wards**

***NB: All approvals/comments are subject to compliance with current University of Leeds and UK Government advice regarding the Covid-19 pandemic.***

I am pleased to inform you that the above research ethics application has been reviewed by the School of Healthcare Committee and on behalf of the Chair, I can confirm a favourable ethical opinion based on the documentation received at date of this email.

***Please retain this email as evidence of approval in your study file.***

Please notify the committee if you intend to make any amendments to the original research as submitted and approved to date. This includes recruitment methodology; all changes must receive ethical approval prior to implementation. Please see <https://ris.leeds.ac.uk/research-ethics-and-integrity/applying-for-an-amendment/> or contact the Research Ethics Administrator for further information ([FMHUniEthics@leeds.ac.uk](mailto:FMHUniEthics@leeds.ac.uk)) if required.

Ethics approval does not infer you have the right of access to any member of staff or student or documents and the premises of the University of Leeds. Nor does it imply any right of access to the premises of any other organisation, including clinical areas. The committee takes no responsibility for you gaining access to staff, students and/or premises prior to, during or following your research activities.

*Please note:* You are expected to keep a record of all your approved documentation, as well as documents such as sample consent forms, risk assessments and other documents relating to the study. This should be kept in your study file, which should be readily available for audit purposes. You will be given a two week notice period if your project is to be audited.



It is our policy to remind everyone that it is your responsibility to comply with Health and Safety, Data Protection and any other legal and/or professional guidelines there may be.

I hope the study goes well.

Best wishes

Sou

***On behalf of Professor John Baker, Chair, SHREC***

~~~~~

**Sou Sit Chung, Research Ethics Administrator, The Secretariat, University of Leeds, LS2 9NL, [s.chung@leeds.ac.uk](mailto:s.chung@leeds.ac.uk)**

## Appendix F Consent form

Study Title: Mealtime experiences of adults with mental health conditions

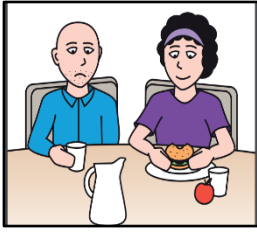
|                                                                                                                                                                                                                                                                                                                                                                                                                      |  |
|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| I confirm that I have read and understood the participant information sheet (version 2, dated 01/03/2021) explaining the above research study. I have had the opportunity to consider the information, ask questions and discuss this study. I have received satisfactory answers to all of my questions.                                                                                                            |  |
| I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without there being any negative consequences. If I withdraw, all identifiable data obtained from me, may be withdrawn if I wish. I understand that if the data has already been anonymised and is no longer identifiable as mine, that it cannot be removed and will be used. |  |
| I understand that my consent and my interview will be audio-recorded. The recordings will be destroyed after they have been transcribed.                                                                                                                                                                                                                                                                             |  |
| I understand that any information I provide, including personal details, will be kept confidential, stored securely and only accessed by those carrying out the study.<br><br>I am aware that if I were to disclose abuse, potential harm to others or malpractice among health professionals, this would need to be followed up by Susan Guthrie, who would discuss                                                 |  |
| I understand that any information I give, including direct quotations from me, may be included in published documents but all information will be anonymised.                                                                                                                                                                                                                                                        |  |
| I understand that data collected during the study may be looked at for audit or inspection by individuals from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this study. I give permission for these individuals to have access to my data.                                                                                                                                |  |
| I understand that I have the option of receiving a summary of the study findings by post or email and that I may provide feedback on the findings if I wish.                                                                                                                                                                                                                                                         |  |
| I agree to take part in this study.                                                                                                                                                                                                                                                                                                                                                                                  |  |
| I understand that anonymised interview transcripts may be archived at the University of Leeds Research Data Repository (Research Data Leeds) so they may be shared and reused for a minimum of 10 years. I do/do not agree to my data being archived in the repository.                                                                                                                                              |  |
| Name of participant                                                                                                                                                                                                                                                                                                                                                                                                  |  |
| Date                                                                                                                                                                                                                                                                                                                                                                                                                 |  |
| Name of researcher                                                                                                                                                                                                                                                                                                                                                                                                   |  |
| Date*                                                                                                                                                                                                                                                                                                                                                                                                                |  |

*This form will be read out to the participant, the information will also be presented on paper to allow reading. The participant will be asked to consent verbally, this will be audio-recorded and the audio file saved into a password protected M drive folder on University of Leeds secure server*

| Project title                | Document type | Version # | Date       |
|------------------------------|---------------|-----------|------------|
| Study ID number: IRAS 270116 | Consent Form  | 2         | 01/03/2021 |

**Thank you for agreeing to take part in this study**

## Appendix G Patient information sheet



### Research study:

**Me at Mealtimes, the mealtime experience in hospital for people with Mental Health conditions.**

Contact Susan Guthrie, Advanced Practitioner

email: [hcs@leeds.ac.uk](mailto:hcs@leeds.ac.uk)

Hello.

We are trying to find out more about mealtimes in the mental health inpatient wards in Leeds and York. We want to talk to patients and also to staff.



We would like to invite you to take part in an interview. Would you like to talk to me about what it's like in the dining rooms and how patients manage with food and drink in hospital?

Before you accept, please read the information below and feel free to ask any questions to help you decide.

If you're a patient - please talk to ward staff to find out more.

If you're staff - then please contact me by email.

### What is the purpose of this research?

This is part of a research study to understand what's important for in-patients on the wards at mealtimes. We want to find out what works well or not so well. Some people may enjoy eating and drinking, other people may find it difficult or even choke.



We would like to hear from patients and staff in your ward or unit about their experience of mealtimes. In this research study we will use information from your interview, just the information that we need for the research study. We will let very few people know your name or contact details, and only if they really need it for this study.

The results of the interviews will be written up and the information used to improve our understanding of patient and staff views of mealtimes on the wards. No names or identities will be shared, all the information you give will be kept anonymous.

At the end of the study, we will save some of the data in case we need to check it and for future research. We will make sure no-one can work out who you are from the reports we write.

The information below tells you more about this.

The ideas for this came from discussions with the Service Users Network in Leeds (SUN) and the HEER members. NHS ethical approval has been given. This study is part of my PhD study and will be checked by supervisors and examiners at University of Leeds.

#### What will happen in the research interview?



If you are an inpatient and would like to take part, please talk to staff, and ask them to contact me. They will check that you are fully informed and ok to take part. Staff will email me your contact details and then we can arrange a date and time for interview.

If you are LYPFT staff and you would like to take part, then please contact me directly.

I will come and visit the ward and we will talk in a quiet room. Alternatively, we can talk on the phone or have a video call. You can choose which option, but it may depend on COVID 19 restrictions.

Before the interview starts, I will remind you about this information and ask you to give your verbal consent to interview. If you want to stop at any time that's fine and you can leave when you choose. The interview will take about an hour. This will be just one meeting and it won't affect anyone's treatment and care.



The interview will be like a conversation, you will be able to talk about mealtimes on the wards and give your thoughts and ideas about this topic. I will use a digital recorder to record our talk, this will then be written out for analysis.



**Do I have to take part?** No, you don't have to take part. It's entirely voluntary and if you're a patient this won't affect your treatment and care. If you don't want to be interviewed, then this won't matter.

It will be fine with ward managers, doctors and nurses too.

### What are the benefits and disadvantages of agreeing to interview?



We hope you will enjoy talking about your experiences and opinions of mealtimes on the wards. You will get a certificate for participating and a £10 shopping voucher.

This research will provide useful information which we hope will lead to improved mealtimes on the wards. You can have a copy of the results summary if you wish.



We will be talking about eating, drinking and swallowing. If you need to take a break, please let me know. You may become worried about the risks at mealtimes, or you may find part of the conversation upsetting. If this happens, we will stop the interview and I will help patients find support from ward staff.

For staff, support is available from Occupational Health.

### Sharing the research



My PhD supervisors will check my research. I will write up the study for my thesis.

I will send my work for publication in a journal and talk about the research at conferences.

I will make sure that service users, nurses, therapists and doctors hear about the research too. No names or identifiable information will be shared.

### Confidentiality – data management.

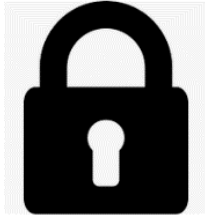


I will make sure your name is kept anonymous. The personal information that you give me will be kept confidential and stored safely on secure University computers until the study is finished.

Your personal information will include your name and contact details. I will use this information to do the research and to check and make sure that the research is being done properly.

People will not be able to see your name or contact details unless they need to for checking the research. Your data will have a code number instead.

We will keep all information about you safe and secure.



I will also ask you about whether you would give additional consent to save the anonymous information from your interview on a longer-term storage system – called the Leeds research data repository. This is completely optional. Information can be saved in the repository for a minimum of ten years to help further research about this topic. Your information and personal details would not be identifiable.

### Important information



If you tell me about something that sounds risky or worrying, then I may have to talk to ward staff or managers – for example if you have seen someone choking or having a severe difficulty at a mealtime. This is to keep them safe and ensure that they get the help they need. Your name will be kept anonymous.

[Data management – more details.](#) [Please ask if you would like more explanation.](#)



The University of Leeds is the sponsor for this study. This means that the university is responsible for looking after your information and using it properly. We will use information from you in order to undertake this study and the university will act as the data controller for this study.

The University of Leeds will keep identifiable information about you until the end of the study.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. All information that is collected about you for this research will be kept strictly confidential in accordance with the Data Protection Act (2018) and General Data Protection Regulation (2018).

### Personal details:

We will always collect the minimum amount of personal data required to carry out our research. We will never share this information with anyone outside the research team. If you decide to take part in the study you will be asked to provide us with a name and means of contacting you, e.g. an email address or telephone number. We assign each interviewee a code (using letters and numbers e.g. MPt15date) and we use this code to label the interview data file (see below). Your contact details and participant code will be kept confidential. All participants' personal details will be stored on a spreadsheet which

will be password protected and stored on University of Leeds secure servers. Only the researcher carrying out interviews has access to this file (unless it is requested for audit by the University of Leeds). The spreadsheet will be securely deleted at the end of the study. The deletion of this file breaks the link with the transcripts which are then completely anonymous.

If you would like to be sent a summary of the study results you will be asked to provide an email address when you complete the consent form. This email address will be stored securely in a password-protected mailing list spreadsheet on University of Leeds secure files and not linked to any data.

#### Interview data:

With your agreement at the start we will take an audio recording of your consent and then audio record the interview. We label these audio files with the code we assign to each participant (see above). All digital recordings will be encrypted and stored in a folder on a secure University of Leeds server that only the research team can access. The recordings will be transcribed for analysis by a company that is an approved supplier of the University of Leeds and is bound by a confidentiality agreement. To do this we upload recordings to the transcription company secure server and download the completed transcript from the same place when it is ready. Once the researcher has received the transcript she will delete the original recording. At this point the transcript will be edited to make the text anonymous, this means the researcher will delete any references to names or places or specific events that might make it possible to identify you.

We will use this anonymised transcript to carry out the analysis of the interviews. We will use direct quotations from some interviews in our research report and other publications but these will never be attributed to a specific individual, we use a description instead, e.g. 'Interviewee 3: male patient'. Anonymised transcripts will be stored on the University of Leeds secure servers up to the end of the study before being securely deleted. If you change your mind about having taken part you can withdraw your data from the study for up to two weeks after your interview (contact the researcher Susan Guthrie by email at [hcsg@leeds.ac.uk](mailto:hcsg@leeds.ac.uk)).

To read more about how data is used in research please see the University of Leeds Research Privacy Notice that can be found here <https://dataprotection.leeds.ac.uk/research-participant-privacy-notice/> or on request from the research team.

If you have any further queries about how we use your information please contact the Chief Investigator, Professor John Baker at [J.Baker@leeds.ac.uk](mailto:J.Baker@leeds.ac.uk) or 0113 343 1271, or the University of Leeds Data Protection Officer on [dpo@leeds.ac.uk](mailto:dpo@leeds.ac.uk) or 0113 343 7641.

### Any concerns?

If you have a concern about any aspect of this study you should contact the Chief Investigator, Professor John Baker who will do his best to answer your questions (contact details above). If he is unable to resolve your concerns, or you wish to make a complaint regarding the study, please contact the University of Leeds, Faculty of Medicine, Head of Research Integrity and Governance on 0113 343 4897 or by email to [C.E.Skinner@leeds.ac.uk](mailto:C.E.Skinner@leeds.ac.uk).

This study has been reviewed and given favourable opinion by the University of Leeds, School of Healthcare and an NHS Local Ethics Committee (Reference number: xxx). The research project is also approved by Leeds and York Partnership NHS Foundation Trust. The sponsor is University of Leeds.

You can find out more about how we use your information at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/). The link to the HRA generic patient data and research leaflet which the HRA recommend is available to all patients involved in research is, [https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2020/08/My\\_data\\_and\\_research.pdf](https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2020/08/My_data_and_research.pdf).

### Contact details - for more information and if you want to volunteer for interview

If you are a patient please talk to your ward staff and ask them to contact me. This is to make sure you have full understanding of the study and have considered it carefully. They will also make sure you are well enough to take part.

LYPFT staff should contact me directly if they wish to take part.

My name is Susan Guthrie, email is [hcsq@leeds.ac.uk](mailto:hcsq@leeds.ac.uk)

**Many thanks for reading this information.**



**Me at Mealtimes study – aiming to understand and improve inpatient mealtimes.**



## Appendix H Example of coding using NVivo

|    |                                                       |    |     |
|----|-------------------------------------------------------|----|-----|
| —○ | patient response to restriction                       | 9  | 28  |
| —○ | patients coping with environment                      | 29 | 71  |
| —○ | noisy environment for meal                            | 15 | 28  |
| —○ | patient perceived to benefit from quieter room        | 10 | 20  |
| —○ | patient struggle with distractions at meal            | 9  | 20  |
| —○ | patients avoiding dining rooms                        | 28 | 55  |
| —○ | patients have positive dining experience              | 17 | 34  |
| —○ | patients leave dining room early                      | 4  | 7   |
| —○ | patients rushing through meal wanting to leave        | 17 | 28  |
| —○ | patients mealtime experience affected by prior events | 13 | 32  |
| —○ | patients positive social at mealtimes                 | 26 | 60  |
| —○ | peers offering support                                | 8  | 10  |
| —○ | patients requesting help at meal                      | 2  | 3   |
| —○ | patients struggle with peers in dining room           | 34 | 107 |
| —○ | patients' unpleasant experience at mealtime           | 28 | 79  |