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Jones, N., Mawson, S., Drummond, A. et al. (2026) The psychosocial impacts of having eating and drinking difficulties after stroke: a qualitative evidence synthesis. *Disability and Rehabilitation*. pp. 1-18. ISSN: 0963-8288

<https://doi.org/10.1080/09638288.2026.2669997>

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To cite this article: Natalie Jones, Susan Mawson, Avril Drummond, Kathryn Dugmore & Alicia O'Cathain (07 Jul 2026): The psychosocial impacts of having eating and drinking difficulties after stroke: a qualitative evidence synthesis, *Disability and Rehabilitation*, DOI: 10.1080/09638288.2026.2669997

To link to this article: <https://doi.org/10.1080/09638288.2026.2669997>



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RESEARCH ARTICLE



The psychosocial impacts of having eating and drinking difficulties after stroke: a qualitative evidence synthesis

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ABSTRACT

Purpose: Eating and drinking difficulties after stroke extend beyond physical impairment, affecting emotional well-being and social participation. This review explored the psychosocial impacts of these difficulties from the perspectives of stroke survivors, informal carers, and healthcare professionals.

Material and Methods: Following PRISMA guidelines and informed by the ENTREQ framework, a systematic search of eight databases (1990–2025) was conducted. A thematic synthesis was used to examine psychosocial experiences.

Results: A total of 1,419 records were identified. After screening and critical appraisal, 22 studies involving 645 informants were included. Two overarching domains were identified: psychological and social impacts. Psychologically, eating and drinking difficulties were experienced as a profound loss, not only of physical function but also of identity, routine, and sensory enjoyment. Survivors described intense fear and panic, especially around choking and aspiration. These were compounded by embarrassment, shame, and humiliation, particularly in social settings. Socially, participants reported self-imposed isolation, avoiding meals due to discomfort or fear of judgement. Nonetheless, many expressed a strong desire to re-engage in social dining and restore normality.

Conclusions: Eating and drinking difficulties after stroke affect psychological well-being and social identity. Recovery must go beyond physical rehabilitation to address emotional and relational dimensions, supporting meaningful participation.

ARTICLE HISTORY

Received 1 September 2025

Revised 1 May 2026

Accepted 2 May 2026

KEYWORDS

Stroke; psychosocial; eating; drinking; lived experience; qualitative evidence synthesis; life after stroke

► IMPLICATIONS FOR REHABILITATION

- Eating and drinking rehabilitation after stroke should adopt a biopsychosocial approach that addresses emotional, social, and identity-related impacts alongside physical swallowing impairments.
- Supported social dining opportunities during rehabilitation may help reduce isolation, rebuild confidence, and promote psychosocial recovery.
- Rehabilitation interventions should be personalised to reflect individual preferences, cultural context, and emotional needs to support autonomy, dignity, and meaningful participation.
- Informal carers play a key role in supporting eating and drinking recovery and should be included in rehabilitation planning and provided with appropriate guidance and support.

Introduction

Stroke can result in a wide range of disabilities, affecting cognition, vision, motor function, sensation, emotions, and communication. Among these, motor impairment is the most widely recognised, with approximately 80% of stroke patients experiencing it in the acute phase and around 40% continuing to face

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 Supplemental data for this article can be accessed online at <https://doi.org/10.1080/09638288.2026.2669997>.

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challenges in the chronic phase [1]. Loss of arm function is particularly common, initially affecting around 70% of survivors, and persisting in 40% of stroke survivors [2]. These impairments can significantly impact the ability to eat and drink independently, complicating even the most routine aspects of daily life [3].

In addition to motor impairments, swallowing difficulties (dysphagia) are a prevalent and serious complication of stroke, affecting between 37% and 78% of individuals [4,5]. Dysphagia may result from damage to the brain areas responsible for coordinating the muscles used in swallowing, and its effects can be exacerbated by co-occurring impairments in cognition, sensation, or communication. As a result, post-stroke eating and drinking difficulties are often multifactorial, involving physical, neurological, and behavioural elements.

There is growing recognition of the serious consequences these difficulties can pose for health, well-being, and quality of life [6–8] malnutrition [9], dehydration [10], reduced muscle strength [1], low mood [11], pneumonia [12], and pressure ulcers [13], are all commonly reported complications. These, in turn, are associated with higher mortality rates and prolonged hospital stays [14,15]. Despite the substantial body of research documenting these clinical and physical consequences, the psychological and social impacts of post-stroke eating and drinking difficulties have received comparatively less attention [16,17].

Klinke et al. [18] conducted a concept analysis to clarify the multidimensional nature of eating difficulties following stroke. Their analysis identified eating difficulties as a complex construct encompassing functional, meaning-related, and contextual dimensions. This included not only physical impairments such as swallowing and motor deficits, but also psychosocial consequences such as embarrassment, altered identity, social isolation, and reduced participation in social eating. They proposed a conceptual model demonstrating how eating difficulties affect emotional well-being, social relationships, and quality of life [18]. However, their work aimed to clarify the concept and develop a theoretical framework, rather than synthesise qualitative evidence specifically examining psychosocial experiences. Therefore, a systematic review focusing explicitly on qualitative studies exploring the psychosocial aspects of eating and drinking after stroke is needed to provide a more in-depth and contemporary understanding of these experiences and inform person-centred rehabilitation.

Recent qualitative studies have begun to explore the lived experiences of stroke survivors, caregivers, and healthcare professionals, shedding light on the emotional and social burden of these impairments. Stroke survivors often describe feelings of shame [19], humiliation [13], despair [20], and bewilderment [21] along with a loss of pleasure in eating and a withdrawal from previously valued social eating experiences [16,22]. These psychological and social consequences are critical to understand, not only for improving holistic stroke care but also for supporting long-term recovery and quality of life.

This review aims to systematically identify and synthesise existing qualitative research exploring the views, perceptions, and lived experiences of individuals who experience or support those with post-stroke eating and drinking difficulties. By focusing exclusively on qualitative evidence, this review seeks to offer a nuanced, contextual understanding of the psychological and social consequences of these often-overlooked impairments.

Methods

Design

This study employed a qualitative evidence synthesis (QES) approach to systematically explore findings from published qualitative research and develop a deeper understanding of the perspectives of stroke survivors, as well as formal and informal caregivers, on the psychosocial impact of eating and drinking difficulties. QES has increasingly been used to synthesise qualitative research exploring stroke survivors' experiences and rehabilitation needs (Pohontsch et al. [23], Connor et al. [24]). For example, Connor and colleagues [24] conducted a QES examining experiences of early supported discharge after stroke, identifying themes related to care transitions, rehabilitation processes, and unmet support needs. Similarly, Pohontsch et al. [23] outlined a protocol for a QES focusing on the healthcare needs of individuals with post-stroke aphasia. While these syntheses provide valuable insights into stroke recovery and service experiences, they do not specifically examine the psychosocial experiences associated with eating and drinking difficulties after stroke. Therefore, a focused qualitative evidence synthesis addressing this area is needed to better understand these experiences and inform person-centred care.

This study was informed by the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) framework [25] and PRISMA Guidelines Moher et al. [26]. The protocol was registered on the International Prospective Register of systematic reviews (PROSPERO) registration number CRD42022332330.

Search strategy

Eight databases were searched, from 1990 to 2025, that were relevant to the topic of the review using a combination of search terms relevant to the aims and objectives: Cumulative Index to Nursing and Allied Health (CINAHL EBSCO), NHS Centre for Reviews and Dissemination, Medline (Ovid), PubMed, Psych INFO (ProQuest), Embase (Ovid), Scopus (Elsevier) and Web of Science. This review was guided by the Population, Concept, Context (PCC) framework [27,28] focusing on stroke survivors and their formal and informal carers (Population), the psychosocial impacts of eating and drinking difficulties (Concept), and experiences situated within community, rehabilitation, and healthcare settings across diverse cultural and geographic contexts. A list of search terms was confirmed with an experienced medical librarian to ensure they were comprehensive, and search terms were tested in preliminary searches to ensure relevant studies were identified. Examples of a database search can be found in the [supplementary information](#).

For the search, a building block approach was used [29] to add concepts together using the Boolean operators, e.g., AND/OR. Features such as truncation and Medical Subject Headings (MeSH) terms were used to broaden the scope of the search to similar words and concepts. Reference lists from relevant studies were screened, and iterative citation searching helped to locate bodies of literature on the relevant topic [30]. An extensive search of grey literature was undertaken using free text searches such as 'stroke, eating and or drinking and psychological or social' to search for additional studies.

Inclusion criteria

Studies were included if they involved adult stroke survivors (aged 18 or over) with confirmed eating and drinking difficulties. In addition, the review included studies that explored the views of informal carers and healthcare professionals concerning the psychological and social impacts of eating and drinking difficulties. These perspectives were only included when they were directly relevant to understanding the lived experience of stroke survivors with eating and drinking impairments. Studies were excluded if participants had acquired brain injuries not confirmed as stroke, to maintain relevance to the review aims.

Exclusion criteria

Studies were excluded if they predominantly focused on other neurological conditions or included mixed populations without clearly disaggregated data for stroke survivors. Reviews, opinion pieces, and non-empirical literature (e.g., blogs, magazines, or other grey literature) were also excluded, as were conference abstracts and non-peer-reviewed publications. Studies published in languages without available translations were excluded due to feasibility constraints. Research focused on the broader aspects of stroke recovery (e.g., general rehabilitation, communication, or physical activity) was excluded unless it specifically addressed the psychological or social impacts of eating and drinking difficulties. This was necessary to ensure the review remained conceptually focused on the targeted phenomenon of interest and did not dilute the findings with unrelated recovery domains.

Study screening and selection

For this review, a study was defined as a unique research project or dataset which could be reported across multiple publications. When it was unclear whether publications originated from the same study or when they presented substantially different analyses, they were treated as separate studies. In such cases, the shared origins were clarified to ensure transparency and prevent duplication. A total of 1,419 records were identified through searches of eight electronic databases and supplementary sources. All

records were imported into NVivo 12 for reference management, and 188 duplicates were removed, leaving 1,231 unique titles and abstracts for screening.

Stage one: title and abstract screening

One reviewer (NJ) screened all titles and abstracts, with 50% independently reviewed by a second reviewer (KD). Discrepancies were discussed between NJ and KD, and if agreement could not be reached, a third reviewer (SM, AO, or AD) was consulted.

Stage two: full-text screening

Full-text articles were retrieved for 135 studies and independently assessed by NJ and KD against the inclusion criteria. Disagreements were resolved through discussion with the wider review team (SM, AO, AD). Thirty-two studies were initially considered potentially relevant, of which ten were excluded for reasons including lack of focus on psychosocial aspects of eating and drinking, absence of primary empirical qualitative data, insufficient inclusion of stroke survivors, or ineligible publication type (e.g., literature reviews, editorial). This resulted in 22 studies being included in the final synthesis.

Supplementary searches, including citation tracking, free-text searching, and screening of relevant organisational databases, identified an additional 31 records; however, none met the inclusion criteria. The full study selection process is summarised in the PRISMA flow diagram ([Figure 1](#)).

Quality assessment

Cochrane Qualitative and Implementation Methods Group recommend the use of the Clinical Appraisal Skills Programme (CASP) tool for quality assessment in health-related qualitative evidence syntheses [31]. According to Flemming and Noyes [32], the CASP qualitative checklist is most commonly used in qualitative evidence synthesis (to assess quality and rigour and identify flaws and weaknesses in the individual studies) [33]. The lead author, NJ, applied the CASP to the twenty-two publications. For robustness, 50% of the publications were independently quality assessed by a second reviewer (KD), including one of the papers, which was co-authored by the lead researcher [34].

Data extraction

Data extraction followed a two-stage process [32]. First, study characteristics, including author, title, country, year, aims, methodology, participant details, key findings, and any interventions, were recorded by the first reviewer (NJ) using a piloted data collection form [35]. Reviewer two (KD) independently checked 50% of the extractions for accuracy and completeness. Where studies had multiple publications, data were consolidated under a single study entry. Data from twenty-two studies were analysed in NVivo 12.

Data synthesis

Thematic synthesis was guided by a three-step approach [36]. In step one, NJ coded findings from each study inductively to generate initial codes. Step two involved grouping these codes into descriptive themes, with patterns and relationships compared across studies. In step three, final analytical themes were refined through team (SM, AO, AD, KD) discussions to ensure interpretive rigour and consensus.

Findings

Study characteristics

This review synthesised findings from twenty-two qualitative studies exploring the psychosocial impacts of eating and drinking difficulties after stroke (see [Table 1](#) for study characteristics). There were 645

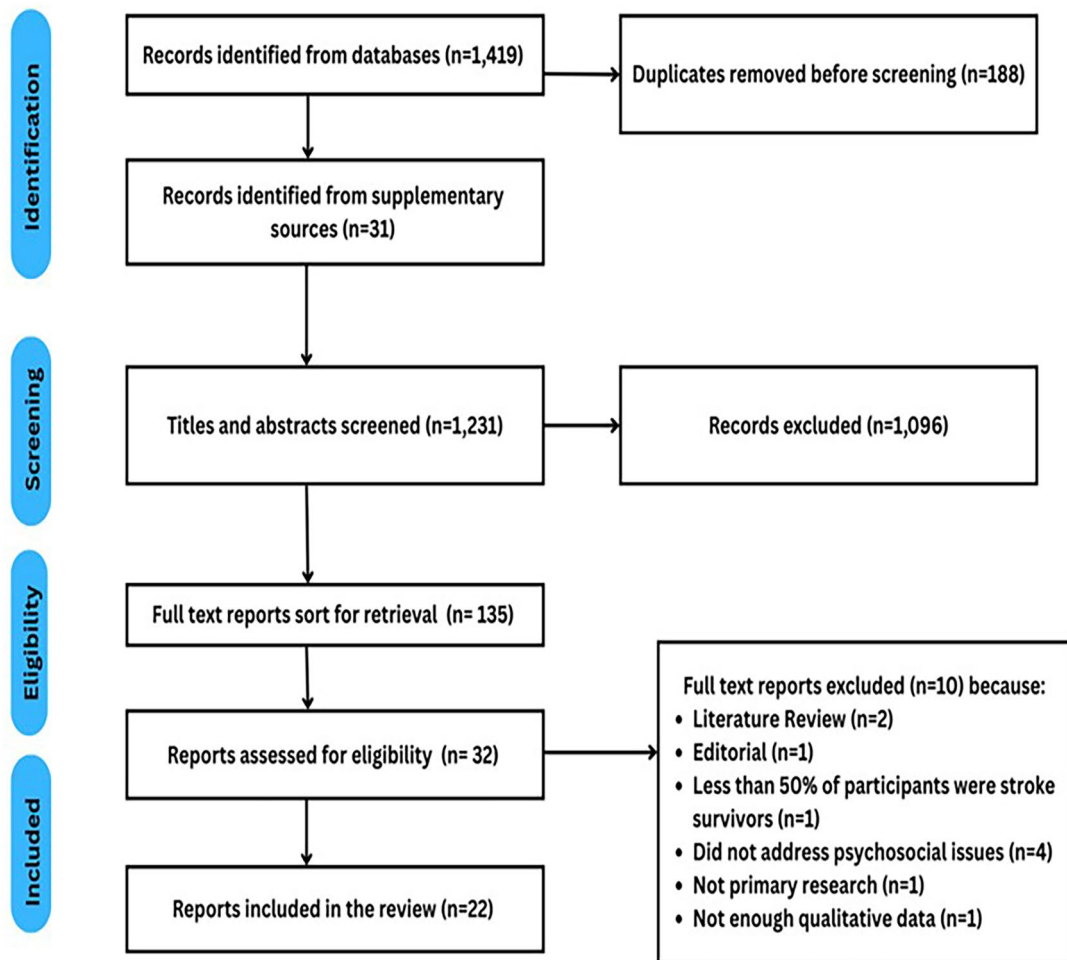


Figure 1. PRISMA Results of study screening and selection process.

informants, with 496 stroke survivors (234 male, 239 female), representing various stages of recovery from acute to long-term (ranging from 1 day to 17 years post-stroke). Sample sizes varied from 3 participants [37] to 91 [38]. Two of the included publications are based on the same dataset [21,39] but reported on distinct aspects of the study, so they were classified as two separate studies.

Six studies also included carers, either as the primary participant group [22,45] or supporting/interviewing alongside stroke survivors [21,34,40]. Three studies [34,38,48] additionally involved 143 health and care professionals.

A range of qualitative methods were employed, including interviews ($n=13$), interviews combined with non-participant observations ($n=5$), non-participant observations ($n=2$), focus groups ($n=1$), video, observation and interviews ($n=1$). Studies were conducted in eight countries, with the highest number from Sweden ($n=11$), followed by the United Kingdom ($n=6$), and from Ireland, Brazil, Denmark, Iceland and India ($n=1$ each). Study settings included community ($n=11$), hospital ($n=4$), combined hospital and home follow-up ($n=4$), and mixed settings such as day-care facilities, outpatient department ($n=2$) and care homes ($n=1$).

All studies reported on the psychosocial dimensions of eating and drinking difficulties, though the depth of focus varied. While some explored psychological impacts as a central theme, social impacts were addressed more peripherally. The term psychosocial was explicitly used in seven studies. However, authors often addressed psychological and social impacts separately, despite recognising their interrelated nature [16,34,47].

Quality assessment

The quality appraisal indicated that most studies met all ten criteria, reflecting a generally high level of methodological rigour (see Table 2). The majority received a 'Yes' on key items such as clarity of aims,

Table 1. Characteristics of the studies included.

Author (year)	Country	Study aim	Perspective	Study design	Sample size and gender	Setting
[38]	UK	To develop an in-depth understanding of support with eating and drinking for stroke survivors in hospital.	Stroke survivors, carers, healthcare professionals	Interviews and non-participant observations	Stroke survivors (M = 16, F = 15); carers (M = 3, F = 10); healthcare professionals (n = 47)	Hospital
[37]	Sweden	To explore long-term experiences of living with eating difficulties after stroke.	Stroke survivors	Interviews and non-participant observations	3 (M = 2, F = 1)	Community
[40]	UK	To explore experiences of swallowing difficulties following stroke from survivors and caregivers.	Stroke survivors and carers	Interviews	Stroke survivors (M = 2, F = 2); carers (F = 1)	Hospital and community
[41]	Sweden	To investigate experiences of living with dysphagia and its management after stroke.	Stroke survivors	Interviews and non-participant observations	5 (M = 5)	Hospital and community
[42]	Sweden	To describe a programme for assessment and nursing diagnoses for eating difficulties.	Stroke survivors	Interviews and non-participant observations	5 (M = 4, F = 1)	Hospital
[43]	Sweden	To describe the process and experiences of eating and oral function.	Stroke survivors	Interviews and non-participant observations	15 (M = 14, F = 1)	Hospital and community
[44]	Sweden	To describe eating experiences and oral function following stroke.	Stroke survivors	Interviews and non-participant observations	30 (M = 17, F = 13)	Hospital
[45]	Sweden	To explore relatives' experiences of family members' eating and swallowing disorders.	Carers	Interviews	9 (M = 1, F = 8)	Community
[34]	UK	To explore shared eating experiences and coping strategies following stroke.	Stroke survivors and carers	Focus group	Stroke survivors (M = 4, F = 2); carers (F = 1)	Community
[46]	India	To explore challenges in post-discharge stroke care, focusing on eating and drinking.	Healthcare professionals	Interviews	66 (M = 27, F = 39)	Community
[47]	Denmark	To explore perceptions of recovery following severe dysphagia after stroke.	Stroke survivors	Interviews	2 (M = 2)	Hospital and community
[16]	Iceland	To explore eating-related difficulties among stroke survivors living at home.	Stroke survivors	Interviews	7 (M = 5, F = 2)	Community / rehabilitation centre
[48]	Sweden	To explore eating, feeding and nutrition among stroke patients in nursing homes.	Healthcare professionals and stroke survivors	Interviews and observations	Healthcare professionals (n = 30); patients (M = 13, F = 27)	Care home
[49]	Ireland	To explore post-stroke swallowing experiences and acceptability of treatment.	Stroke survivors	Interviews	14 (M = 6, F = 8)	Community
[50]	Sweden	To explore experiences of eating difficulties six months post-stroke.	Stroke survivors	Interviews	13 (M = 7, F = 6)	Community
[51]	Sweden	To compare eating difficulties three months post-stroke.	Stroke survivors	Observations	36 (M = 15, F = 21)	Community
[39]	UK	To investigate eating-related experiences six months post-stroke.	Stroke survivors and carers	Interviews and observations	113 (M = 47, F = 67)	Community
[21]	UK	To explore survivors' perceptions of eating-related stroke consequences.	Stroke survivors	Interviews	Same cohort as Perry et al. (2003a)	Community
[7]	Brazil	To characterise quality of life in older adults with post-stroke swallowing difficulties.	Stroke survivors	Observational cross-sectional	35 (M = 16, F = 19)	Outpatient clinic
[22]	UK	To explore family members' experiences of living with post-stroke dysphagia.	Carers	Interviews	5 (M = 2, F = 3)	Community
[52]	Sweden	To describe mealtime preparation, fatigue, mood and nutritional status after stroke.	Stroke survivors	Interviews	89 (M = 45, F = 44)	Community
[53]	Sweden	To explore relationships between eating difficulties and nutritional status post-stroke.	Stroke survivors	Interviews and observations	24 (M = 14, F = 10)	Hospital and community

Table 2. Quality assessment of the papers included using the CASP checklist.

Study	Aims	Methodology	Design	Recruitment	Data Collection	Reflexivity	Ethics	Analysis	Findings	Value
[38]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[37]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[40]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[41]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[42]	Y	Y	Y	Y	Y	C	C	Y	Y	Y
[43]	Y	Y	Y	C	Y	N	C	Y	Y	Y
[44]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
[45]	Y	Y	Y	C	Y	C	Y	Y	Y	Y
[34]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[46]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[47]	Y	Y	Y	C	Y	Y	Y	Y	Y	Y
[16]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[48]	Y	Y	Y	C	Y	C	Y	Y	Y	Y
[49]	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
[50]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[51]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y
[39]	N	Y	Y	Y	Y	N	C	C	Y	Y
[21]	Y	Y	Y	Y	Y	Y	Y	C	Y	Y
[7]	Y	Y	Y	Y	Y	Y	C	Y	Y	Y
[22]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[52]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
[53]	Y	Y	Y	Y	Y	C	Y	Y	Y	Y

Note. CASP=critical appraisal skills programme checklist. Columns represent CASP qualitative domains: aims, methodology, design, recruitment, data collection, reflexivity, ethics, analysis, findings, and research value. Y=yes; N=No; C=cannot tell.

appropriate methodology, ethical consideration, and robust data analysis. Minor limitations were identified in a few studies, particularly where responses were marked as 'Can't tell' or 'No', most often due to unclear reporting of researcher-participant relationships or insufficient detail on ethical procedures. Despite these issues, the overall quality of the included studies was sufficient to support confidence in the review's findings.

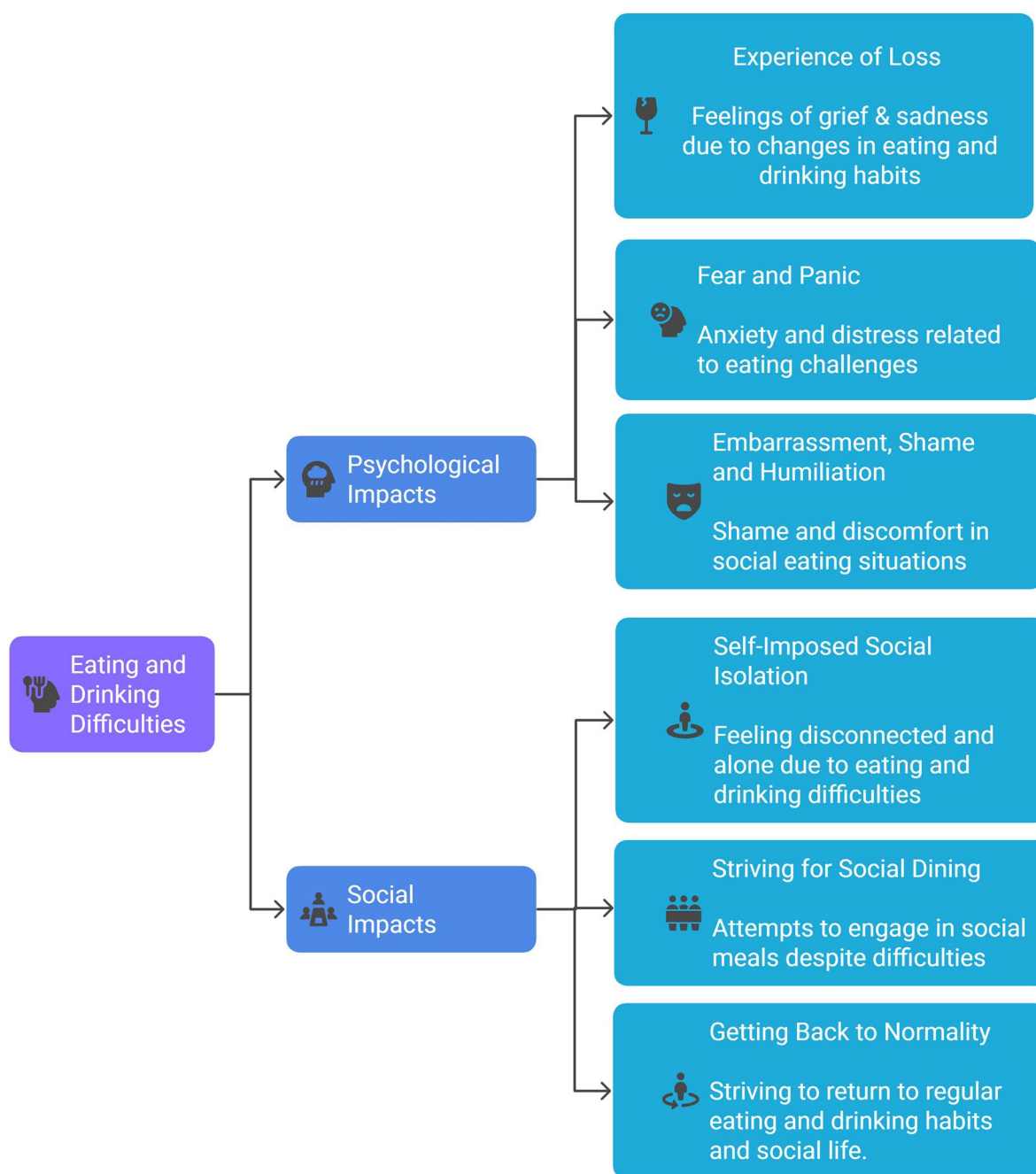
Overview of themes

Two overarching analytical themes were identified: psychological impacts and social impacts of eating and drinking difficulties following stroke, each with three subthemes (Figure 2). Psychological impacts included experiences of loss, fear and panic; and feelings of embarrassment, shame, and humiliation, often leading to emotional distress and withdrawal. Social impacts included: self-imposed isolation; efforts to maintain participation in social dining; and the journey towards a sense of normality. These themes highlight the complex and deeply personal consequences of post-stroke eating and drinking difficulties, shaping not only physical recovery but also emotional well-being and social identity.

Table 3 shows a visual summary of how each included study contributed to the analytical themes. This mapping helps demonstrate the breadth and consistency of evidence across the dataset, highlighting which studies addressed psychological and/or social dimensions of post-stroke eating and drinking difficulties. It offers a transparent overview of the distribution and relevance of studies within the thematic framework. Collectively, the papers offer an exploration of both psychological and social impacts, with most studies contributing to multiple themes, particularly fear, panic and social isolation. Notably, a few studies, such as Batt [38], Carlsson et al. [37], Klinker [16], and Medin et al. [50] addressed all six identified themes, highlighting their depth and breadth of insight into the topic under review. Social aspects, especially 'getting back to normality' and 'striving for social dining', were less consistently examined.

Psychological impact of eating and drinking difficulties

The psychological consequences of eating and drinking difficulties were evident across all twenty-two studies, with stroke survivors frequently reporting fear, panic, and emotional distress. Common experiences included frustration, humiliation, and a profound sense of loss, often linked to the erosion of independence and dignity during mealtimes.

Made with  Napkin**Figure 2.** A summary of themes.

The theme of feeling ‘child-like’ was reported in several studies [34,39], reflecting the psychological toll of needing assistance to eat or manage oral function. For example, Jones and Nasr [34] described participants struggling with messy eating, dribbling, and the need for others to cut their food experiences, which led to embarrassment and diminished self-worth. One participant commented: “You feel self-conscious... somebody has to cut your food up like a child” (*Stroke Survivor* [34]).

While some individuals attempted to reframe their dependence positively [16], most accounts highlighted the distress associated with the loss of autonomy, reinforcing findings from Kjaersgaard and Pallesen [47]. These emotional impacts extended beyond physical limitations, affecting identity, social participation, and mental well-being. Three interrelated subthemes captured this experience: (1) loss of ability and identity, (2) fear and panic around choking and loss of control, and (3) shame and embarrassment due to perceived loss of dignity. Together, these findings illustrate how the psychological

Table 3. Contribution of each paper to the themes.

Author (Year)	Loss	Fear & panic	Embarrassment, shame & humiliation	Social isolation	Striving for social dining	Getting back to normality
[38]	✓	✓	✓	✓	✓	✓
[37]	✓	✓	✓	✓	✓	✓
[40]	✓	✓	✓	✓	✓	✓
[41]	✓	✓	✓	✓	✓	✓
[42]	✓	✓	✓	✓	✓	x
[43]	✓	✓	x	✓	✓	x
[44]	✓	✓	✓	✓	✓	x
[45]	✓	✓	✓	x	x	✓
[34]	✓	✓	✓	✓	✓	✓
[46]	✓	x	✓	✓	x	x
[47]	✓	✓	✓	✓	✓	✓
[16]	✓	✓	✓	✓	✓	✓
[48]	✓	✓	✓	✓	x	x
[49]	✓	x	x	x	x	✓
[50]	✓	✓	✓	✓	✓	✓
[51]	✓	✓	✓	✓	x	x
[39]	✓	✓	✓	✓	✓	✓
[21]	✓	✓	✓	✓	✓	✓
[7]	✓	✓	x	✓	x	x
[22]	✓	x	x	✓	✓	✓
[52]	x	✓	✓	✓	x	✓
[53]	✓	x	x	✓	x	x

impact of eating and drinking difficulties is not only functional but deeply personal and socially embedded.

Experience of loss. Stroke survivors and informal carers described a multifaceted experience of loss. This included the loss of physical abilities, such as the capacity to eat and drink independently [37,38], as well as the loss of associated routines, including shopping, cooking, and gardening [42,50]. Other studies reported diminished pleasure in eating and drinking due to altered sensory perception, discomfort, or dysphagia [16,44].

Carers similarly reported a loss of intimacy for them during mealtimes, due to the practical and emotional burden of assisting with eating [45]. Stroke survivors frequently likened these experiences to a grieving process, marked by feelings of anger, abandonment, and depression [37,40]. Nevertheless, some stroke survivors demonstrated resilience, developing new coping strategies and embracing altered roles to re-establish autonomy [37,51].

Fear and panic

Fear was a pervasive and debilitating experience reported by stroke survivors in relation to eating and drinking. Many described intense anxiety around choking, aspirating, or suffocating, potentially leading to serious complications such as pneumonia or even death [21,40,44,48]. Excessive coughing, drooling, and difficulty managing food orally heightened this fear [16,45].

Fear extended beyond swallowing to the act of eating itself. Survivors expressed anxiety over hand-to-mouth coordination, clumsiness, spillage, and visible messiness, all of which threatened their sense of control and dignity [34,37,42]. These visible disruptions often led to the avoidance of social dining, particularly with unfamiliar people [41,54].

Jacobson and colleagues [43] outlined four domains of eating: handling, transporting, oral preparation, and swallowing; failures in any of which could undermine confidence and trigger panic. Survivors felt vulnerable during meals, requiring environments where they could feel safe and secure to ensure adequate nutrition [43,49].

Although strategies such as thickened fluids were not always welcomed, many participants accepted them as necessary precautions to reduce risk [40]. Participants and caregivers often expressed fear of serious health consequences, including pneumonia. For example, one caregiver described how the individual,

was expecting repercussions as a consequence of his dysphagia... he was convinced he was going to develop pneumonia. (Informal Caregiver, [40])

Similarly, Pontes and colleagues [7] observed that swallowing difficulties created a significant burden, reducing the desire to eat and contributing to fear of and prolonged mealtime. Overall, eating was no longer spontaneous but became a cautious and often stressful task, carefully managed to avoid danger [47,54].

Embarrassment, shame, and humiliation

Embarrassment, shame, and humiliation were commonly reported emotional responses to eating and drinking difficulties post-stroke, emerging in both early (1–3 months) and later (6+ months) stages of recovery [34,37,40,48,54]. These emotions were often linked to dependency on others for feeding, visible impairments like facial disfigurement or drooling, and socially disruptive symptoms such as coughing or spillage [44,48].

Survivors expressed concern about how others perceived their changed appearance or eating behaviours, leading to self-consciousness and efforts to conceal difficulties [16,39,47]. Avoidance of certain foods or social situations was a common strategy to mitigate embarrassment [16,54]. For example, one stroke survivor described deliberately selecting foods that were easier to manage in public settings:

I look at the menu and sort of thing, well, I can have soup; safe there. I won't have steak because I won't be able to cut it. I'll have curry because that's easy for me, I can use a spoon or fork for that. (Stroke Survivor, [21])

This illustrates how survivors adapted their food choices to conceal their difficulties and reduce the risk of embarrassment. One study also suggested that denial of difficulties, whether due to cognitive factors or self-preservation, was useful as a strategy to protect dignity [39]. Perceptions were shaped by personal values and past habits. While some were deeply embarrassed by changes in eating, others focused on overcoming difficulties and regaining control [50]. Ultimately, feelings of embarrassment and shame significantly constrained social engagement and undermined emotional well-being (see social theme later).

Social impact of eating and drinking difficulties

The social impact of eating and drinking difficulties after stroke was felt deeply by stroke survivors and informal carers. Stroke survivors described a marked reduction in social interaction, driven by anxiety, diminished self-confidence, and the practical challenges of eating in public. These difficulties often disrupted established social roles and routines, leading to withdrawal from communal settings and avoidance of meaningful social events such as weddings and funerals [41].

The loss experienced at an individual level frequently extended into the social domain, compounding feelings of disconnection and isolation. Several participants described regression to behaviours such as needing food cut up, messy eating, and dribbling, drawing uncomfortable parallels with childhood and contributing to feelings of infantilisation [21,34]. This loss of independence often led to embarrassment, self-consciousness, and withdrawal from social eating situations. For example, one stroke survivor described the emotional impact of relying on others for assistance during meals:

I can't use both hands to cut food up, whoever I go out with will usually do it for me but you know, you feel self-conscious, you know somebody has to cut your food up like a child. (Stroke Survivor, [34]).

This illustrates how reliance on others could evoke feelings of vulnerability and diminished autonomy, reinforcing social withdrawal and reduced self-worth. However, experiences were not universally negative; some individuals viewed receiving assistance more pragmatically as part of adapting to their condition and maintaining participation in daily life [16]. These contrasting responses highlight the complex interplay between loss of independence, emotional adjustment, and efforts to preserve dignity following stroke.

Three interrelated subthemes captured these experiences: social isolation, reflecting the withdrawal from social life; striving for social dining, highlighting the desire to re-engage in communal meals despite ongoing difficulties; and getting back to normality, expressing the aspiration to restore a sense of social identity and everyday routine.

Self-imposed social isolation. Self-imposed social isolation emerged as a common response to the emotional and practical challenges associated with eating and drinking difficulties after stroke. Anxiety, embarrassment, and frustration, particularly around slow or impaired eating, often led survivors to withdraw from social situations [42]. Many individuals choose to eat alone, perceiving mealtimes as stressful tasks to be managed privately rather than opportunities for social connection [37]. Contributing factors included the extended time required to eat [42,43] and diminished confidence in their ability to eat safely or without drawing attention [39,47].

Physical symptoms such as fatigue, reduced energy, and decreased alertness further limited participation in social life, compounding the tendency towards isolation [16,48,52]. Difficulties with concentration also made social dining more challenging [16]. Stroke survivors in Kjaersgaard & Pallesen's study [47] found that the pattern of withdrawal not only reduced social contact but also deepened emotional distress and hindered psychosocial recovery. Kumlien & Axelsson [48] also observed inconsistencies with patient reporting as some people hid and denied difficulties in an attempt to avoid changes in eating behaviours, which could further impact the desire to socialise while eating.

Striving for social dining. Despite the challenges posed by eating and drinking difficulties, some stroke survivors viewed shared meals as a powerful symbol of recovery, normality, and social reintegration [39]. Participation in social dining was not only a goal but also a deliberate act of resilience. Survivors employed a range of strategies to re-engage with communal eating, such as dining with trusted companions, selecting familiar and comfortable environments, and modifying food choices to reduce the risk of difficulty or embarrassment [34]. Participants described how determination and adaptation enabled continued engagement in valued activities:

To eat is a necessity, a desire and a pleasure. However, to prepare and cook can be a mighty challenge, but with a little planning, imagination and determination, and maybe a little help with improvised gadgets, it can be very rewarding. (Stroke Survivor, [34])

This highlights how survivors actively worked to overcome barriers, reframing eating not only as a functional necessity but also as an important source of pleasure, independence, and recovery. These adaptations often aimed to preserve independence and dignity, for example, by opting for food textures that were easier to manage without assistance [34,38]. However, as Batt [38] observed, these coping mechanisms could obscure underlying challenges, leading healthcare professionals to underestimate ongoing needs. Informal carers played a key enabling role, supporting social dining through discreet, personalised adjustments that aligned with survivors' preferences and evolving abilities [22].

Social interaction was observed to play a supportive role during mealtimes in a care home [48]. Five registered nurses highlighted the importance of creating a pleasant, social atmosphere, such as dining in communal areas or providing emotional support through touch and conversation during assisted feeding [48]. This was seen as particularly vital for stroke survivors in care homes, who risked being overlooked and missing out on meaningful human contact that typically occurs during shared meals.

Getting back to normality

The aspiration to regain a sense of normality, albeit often a "new normal," was a central concern for some stroke survivors. This process typically involved relearning eating skills, adjusting to altered roles, and re-establishing everyday routines [37,46]. Survivors frequently described "getting by" as a gradual and often challenging journey of adaptation, underpinned by hope and motivation for recovery [16,42].

Even small achievements were viewed as meaningful steps towards normalcy. However, this process was complicated by emotional and psychological hurdles. In some cases, this led to skipped meals or inadequate nutritional intake as individuals sought to avoid these uncomfortable experiences [34,38]. For others, the dining environment itself played a restorative role, offering familiarity, psychological comfort, and a tangible link to pre-stroke life [38].

The contribution of informal carers emerged as a key element within the sub-theme of getting back to normality. Across several studies, carers played a vital role in helping stroke survivors re-engage with eating and drinking as part of everyday social life. Their involvement extended beyond physical assistance, encompassing emotional support, encouragement, and the recreation of familiar mealtime

routines that contributed to a sense of normalcy. For example, Robinson et al. [22] and Eltringham et al. [40] illustrated how carers enabled survivors to participate in shared meals, adapt to new dietary needs, and rebuild confidence in social dining contexts. Johansson et al. [45] similarly highlighted how carers' support helped restore everyday rhythms, reinforcing survivors' identities and routines. However, the emotional burden and lack of structured guidance for carers were also noted, pointing to an often-overlooked area of need. These findings suggest that carers are not only facilitators of recovery but also co-participants in the eating and drinking rehabilitation journey, which is central to survivors' efforts to regain a sense of normal life after stroke.

Discussion

Eating and drinking difficulties after stroke extend beyond physical impairments to profoundly affect emotional well-being, identity, and social participation. These findings align with Klinke et al.'s [18] earlier concept analysis, which identified eating difficulties as a multidimensional experience encompassing physical, emotional, and social domains. As in that analysis, this review highlights how loss of identity, fear of choking, and social withdrawal shape survivors' experiences. However, the present review extends this work by providing a focused synthesis of qualitative evidence that more clearly illustrates the psychosocial mechanisms underlying these experiences. This review highlights the emotional consequences of feeling infantilised during meals and the ongoing tension between dependence and autonomy in public dining contexts. By incorporating perspectives from stroke survivors, informal carers, and health-care professionals, this synthesis provides a more holistic understanding of how eating and drinking difficulties affect both individual recovery and interpersonal relationships. These findings reinforce the need for rehabilitation approaches that address not only functional impairments but also the psychosocial complexities that accompany them.

A central theme across the included studies was the disruption of identity associated with eating and drinking impairments. Activities that were previously automatic became effortful and highly visible, threatening survivors' sense of competence and autonomy. These findings strongly reflect Charmaz' [55,56] concept of "loss of self," in which chronic illness disrupts taken-for-granted identities and social roles. Importantly, this loss was not solely related to functional impairment but to the symbolic and social meaning of eating. Mealtimes often represent independence, social belonging, and personal identity, and their disruption therefore had profound psychological consequences. However, consistent with Radley and colleagues [57] model of illness adjustment, survivors demonstrated diverse responses to these challenges, including acceptance, adaptation, and avoidance. Some developed compensatory strategies, such as modifying food choices or eating in safer environments, while others withdrew from shared meals to protect their dignity. These findings suggest that adjustment to eating and drinking difficulties is not a linear process but a dynamic negotiation between loss, adaptation, and identity reconstruction.

Emotional responses, particularly fear, shame, and embarrassment, were central to survivors' experiences. Fear was frequently associated with the perceived risk of choking or aspiration, contributing to anxiety and heightened vigilance during meals. While this fear has a physiological basis, it also reflects broader uncertainty and loss of bodily control, consistent with Lupton's [58] conceptualisation of risk as both an embodied and social experience. Embarrassment and shame were often linked to visible symptoms such as drooling, coughing, or requiring assistance, which disrupted social norms surrounding eating. Goffman's theory of stigma [56] provides a useful framework for understanding these experiences, as survivors frequently engaged in impression management strategies to avoid being perceived as vulnerable or dependent. This included avoiding social dining situations, concealing difficulties, or selecting foods that minimised the risk of visible impairment. These behaviours highlight the extent to which psychosocial concerns, rather than functional limitations alone, influenced participation in everyday life.

Despite these challenges, eating and drinking also represented an important opportunity for recovery, adaptation, and social reintegration. Many survivors actively worked to regain competence and participate in shared meals, viewing social dining as a marker of progress and normality. This aligns with Burgess and Watson's [59] 'Altered Eating Framework', which conceptualises eating as a relational and emotionally meaningful activity rather than simply a physiological function. Participation in social dining provided opportunities for connection, identity reconstruction, and emotional support, reinforcing

findings from other rehabilitation contexts that communal dining can enhance well-being and independence [60]. However, opportunities for meaningful social dining within stroke rehabilitation settings were often limited by institutional routines, risk-focused care models, and resource constraints. This suggests that current rehabilitation practices may insufficiently address the social and emotional dimensions of eating and drinking recovery.

At a systemic level, this review also highlights potential gaps in clinical interpretation of survivor behaviours. Adaptations such as avoiding certain foods or modifying eating environments may be interpreted by clinicians as indicators of successful adjustment, yet these behaviours often reflect unresolved anxiety, embarrassment, or loss. This aligns with Kitson's [61] argument that healthcare systems frequently prioritise physical safety and functional recovery while overlooking psychosocial well-being. Without explicitly addressing emotional and social concerns, rehabilitation may fail to support survivors in rebuilding identity and confidence. These findings emphasise the importance of person-centred care approaches that recognise eating and drinking as deeply meaningful, socially embedded activities rather than purely functional tasks.

Taken together, the findings of this review suggest a need to reconceptualise eating and drinking difficulties after stroke as complex psychosocial experiences that intersect with identity, social participation, and emotional well-being. Theoretical perspectives from Lupton [55] and Burges Watson [59] provide valuable frameworks for understanding these experiences and highlight the limitations of purely biomedical models of rehabilitation. Incorporating psychosocially informed interventions, such as supported social dining, peer support, and identity-sensitive rehabilitation approaches, may help bridge the gap between physical recovery and psychosocial reintegration. Addressing these broader dimensions of recovery is essential to supporting stroke survivors in regaining not only functional ability but also confidence, autonomy, and quality of life.

Strengths and limitations

While only seven of the twenty-two included studies explicitly used the term "psychosocial," all examined psychological and/or social effects, with psychological impacts reported more frequently and in greater depth. Social consequences, although present, were comparatively less emphasised and less extensively explored, highlighting an important area for future research.

The review was conducted using a rigorous and transparent methodological framework, adhering to PRISMA guidelines [26] and employing the CASP tool for critical appraisal [62] and followed the ENTREQ guidelines for reporting qualitative syntheses [25]. All included studies were independently appraised, with oversight provided by a team, enhancing the credibility and reliability of the findings.

The included studies encompassed a wide temporal range, from 2 weeks to 17 years post-stroke, capturing experiences across acute, subacute, and chronic recovery stages. This temporal and contextual diversity, spanning hospitals, homes, care facilities, and outpatient settings, strengthens the transferability of the results. Despite methodological heterogeneity, the psychological and social impacts reported were notably consistent across studies. Participant representation was broadly balanced by gender, closely reflecting global stroke incidence patterns (47% male, 53% female) [63].

Several limitations should be considered when interpreting the findings of this review. Most studies were conducted in high or middle-income countries, with limited inclusion of participants from low-income settings. This may affect the cultural and socioeconomic generalisability of the findings. In addition, the inclusion criteria required that at least 50% of study participants be stroke survivors, thereby excluding mixed-neurological condition studies, which may offer further insights. Finally, while most studies provided adequate demographic data, one required clarification [40], which was successfully obtained from the author.

Reflexivity

This review was conducted by a multidisciplinary team with both clinical and academic expertise. NJ and KD are healthcare professionals with experience in stroke care and research, bringing insider perspectives to the topic. The other team members (SM, AO, AD) contributed expertise in qualitative methodologies,

with AD also specialising in stroke research. The combination of clinical insight and academic rigour enhanced the depth and credibility of the analysis. The potential influence of prior experience and professional assumptions was managed through sustained reflexive practices. These included maintaining a reflexive journal, keeping a clear audit trail of analytic decisions, and engaging in regular team discussions throughout the screening, analysis, and interpretation processes. Collaborative decision-making helped ensure that no single perspective dominated the review, supporting a balanced and transparent synthesis.

Implications for research and practice

This review highlights the profound psychosocial impact of eating and drinking difficulties on stroke survivors, extending well beyond physical impairment to affect emotional well-being, social participation, and personal identity. Although eating and drinking rehabilitation is often approached from a physiological standpoint, the findings argue the need for more comprehensive, holistic interventions. A biopsychosocial approach described by Wade [64,65] is essential, one that considers survivors' previous habits, life experiences, emotional responses, and individual preferences.

Understanding the psychological and social dimensions of eating and drinking post-stroke can help clinicians deliver more personalised and meaningful care. This review suggests that interventions should aim not only to restore physical function but also to support emotional reintegration and social reconnection. For example, structured opportunities for social dining could help rebuild confidence, re-establish routines, and reduce the isolation that many survivors experience. Addressing emotional challenges such as fear and embarrassment is equally important, as these factors often contribute to social withdrawal and diminished quality of life.

Importantly, the role of informal carers must not be overlooked. Carers provide critical emotional, practical, and social support in the rehabilitation process. Studies by Robinson et al. [22], Eltringham et al. [40] and Johansson et al. [45] demonstrate the central role carers play in facilitating mealtime participation, managing dietary adaptations, and supporting psychosocial recovery. Their involvement not only helps survivors re-engage with food and shared meals but also plays a vital role in restoring daily rhythms and a sense of normality. However, carers themselves often face significant emotional and practical challenges. A deeper understanding of their experiences could inform more inclusive, person-centred rehabilitation models that recognise the interconnected needs of both survivors and those who support them.

Future research should investigate not only the effectiveness of such interventions but also the cultural, relational, and institutional factors that influence how they are implemented and experienced. Adopting this broader perspective is key to developing stroke rehabilitation approaches that are truly person-centred and socially responsive.

Conclusions

The psychosocial impacts of eating and drinking difficulties after stroke are profound, extending beyond physical impairment to affect emotional well-being, social participation, and personal identity. Stroke survivors often experience a deep sense of loss, not only of physical function but also of roles, routines, and the sensory and social pleasures of eating. Emotional responses such as fear, panic, and anxiety, particularly around choking, are common and may be intensified by embarrassment and public self-consciousness, leading to social withdrawal and isolation. Yet, some survivors express a strong desire to re-engage in social dining, viewing it as essential to restoring autonomy, dignity, and connection. To support meaningful recovery, rehabilitation must address both the psychosocial and physical dimensions of eating and drinking, integrating emotional support, stigma reduction, and opportunities for social reintegration.

These findings highlight important gaps in current rehabilitation approaches, which often prioritise physiological recovery and risk management while overlooking the emotional and social consequences of eating and drinking difficulties. Supporting recovery, therefore, requires a more holistic, person-centred

approach that recognises eating and drinking as meaningful, socially embedded activities. Interventions that promote social participation, address stigma, and support identity reconstruction, such as supported social dining and peer-based rehabilitation, may help facilitate both psychosocial and functional recovery. Recognising and addressing these broader psychosocial dimensions is essential to improving quality of life and supporting long-term reintegration after stroke.

Acknowledgements

The authors would like to thank Sheffield Teaching Hospitals FT, Rotherham Hospitals FT and Doncaster and Bassetlaw Teaching Hospitals FT. Professors O’Cathain and Drummond are NIHR Senior Investigators. The views expressed are those of the authors and do not necessarily reflect those of the NIHR, HEE, or the UK Department of Health and Social Care.

Consent to participate

Consent for publication, NIHR.

Author contributions

CRedit: **Natalie Jones**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Resources, Validation, Visualization, Writing – original draft, Writing – review & editing; **Susan Mawson**: Methodology, Supervision, Validation, Visualization, Writing – review & editing; **Avril Drummond**: Methodology, Supervision, Validation, Visualization, Writing – review & editing; **Kathryn Dugmore**: Conceptualization, Data curation, Formal analysis, Investigation, Methodology; **Alicia O’Cathain**: Methodology, Supervision, Visualization, Writing – review & editing.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This research is funded by Health Education National Institute for Health and Care Research (NIHR) through a Clinical Doctoral Research Fellowship awarded to Dr Natalie Jones (NIHR 300529).

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References

- [1] Hatem SM, Saussez G, Della Faille M, et al. Rehabilitation of motor function after stroke: a multiple systematic review focused on techniques to stimulate upper extremity recovery. *Front Hum Neurosci.* 2016;10:442. doi: [10.3389/fnhum.2016.00442](https://doi.org/10.3389/fnhum.2016.00442).
- [2] Intercollegiate Stroke Working Party. National Clinical guidelines for Stroke for the UK and Ireland. London: Intercollegiate Stroke Working Party; 2023. <https://www.strokeguideline.org/app/uploads/2023/04/National-Clinical-Guideline-for-Stroke-2023.pdf>.
- [3] Legg LA, Lewis SR, Schofield-Robinson OJ, et al. Occupational therapy for adults with problems in activities of daily living after stroke. *Cochrane Database Syst Rev.* 2017;7(7):CD003585. doi: [10.1002/14651858.CD003585.pub3](https://doi.org/10.1002/14651858.CD003585.pub3).
- [4] Martino R, Foley N, Bhogal S, et al. Dysphagia after stroke. *Stroke.* 2005;36(12):2756–2763. doi: [10.1161/01.STR.0000190056.76543.eb](https://doi.org/10.1161/01.STR.0000190056.76543.eb).
- [5] Song W, Wu M, Wang H, et al. Prevalence, risk factors, and outcomes of dysphagia after stroke: a systematic review and meta-analysis. *Front Neurol.* 2024;15:1403610. doi: [10.3389/fneur.2024.1403610](https://doi.org/10.3389/fneur.2024.1403610).

- [6] Chiba R, Tominaga S, Mikami K, et al. Factors Influencing Quality of Life in Stroke Patients: focus on Eating Habits. *J Stroke Cerebrovasc Dis.* 2019;28(6):1623–1628. doi: [10.1016/j.jstrokecerebrovasdis.2019.02.031](https://doi.org/10.1016/j.jstrokecerebrovasdis.2019.02.031).
- [7] Pontes ÉS, Amaral AK, de F. D, Rego F. D, et al. Quality of life in swallowing of the elderly patients affected by stroke. *Arq Gastroenterol.* 2017;54(1):27–32. doi: [10.1590/s0004-2803.2017v54n1-05](https://doi.org/10.1590/s0004-2803.2017v54n1-05).
- [8] Xiaoyu F, Yulan Z, Jingwen L, et al. Correlation between eating behaviour and swallowing quality of life with dysphagia after stroke. *Chin Res Nurse.* 2021;35:1151–1155.
- [9] Poels BJJ, Brinkman-Zijlker HG, Dijkstra PU, et al. Malnutrition, eating difficulties and feeding dependence in a stroke rehabilitation centre. *Disabil Rehabil.* 2006;28(10):637–643. doi: [10.1080/09638280500276612](https://doi.org/10.1080/09638280500276612).
- [10] Westergren A. Detection of eating difficulties after stroke: a systematic review. *Int Nurs Rev.* 2006;53(2):143–149. doi: [10.1111/j.1466-7657.2006.00460.x](https://doi.org/10.1111/j.1466-7657.2006.00460.x).
- [11] Torrisi M, De Cola MC, Buda A, et al. Self-efficacy, poststroke depression, and rehabilitation outcomes: is there a correlation? *J Stroke Cerebrovasc Dis.* 2018;27(11):3208–3211. doi: [10.1016/j.jstrokecerebrovasdis.2018.07.021](https://doi.org/10.1016/j.jstrokecerebrovasdis.2018.07.021).
- [12] Bath PM, Lee HS, Everton LF. Swallowing therapy for dysphagia in acute and subacute stroke. *Stroke.* 2019;50(3):E46–7. doi: [10.1161/STROKEAHA.118.024299](https://doi.org/10.1161/STROKEAHA.118.024299).
- [13] Westergren A, Karlsson S, Andersson P, et al. Eating difficulties, need for assisted eating, nutritional status and pressure ulcers in patients admitted for stroke rehabilitation. *J Clin Nurs.* 2001;10(2):257–269. doi: [10.1046/j.1365-2702.2001.00479.x](https://doi.org/10.1046/j.1365-2702.2001.00479.x).
- [14] Attrill S, White S, Murray J, et al. Impact of oropharyngeal dysphagia on healthcare cost and length of stay in hospital: a systematic review. *BMC Health Serv Res.* 2018;18(1):594. doi: [10.1186/s12913-018-3376-3](https://doi.org/10.1186/s12913-018-3376-3).
- [15] Eltringham SA, Kilner K, Gee M, et al. Impact of dysphagia assessment and management on risk of stroke-associated pneumonia: a systematic review. *Cerebrovasc Dis.* 2018;46(3-4):99–107. doi: [10.1159/000492730](https://doi.org/10.1159/000492730).
- [16] Klink ME, Hafsteinsdóttir TB, Thorsteinsson B, et al. Living at home with eating difficulties following stroke: a phenomenological study of younger people's experiences. *J Clin Nurs.* 2014;23(1-2):250–260. doi: [10.1111/jocn.12401](https://doi.org/10.1111/jocn.12401).
- [17] Cipriano-Crespo C, Rodríguez-Hernández M, Cantero-Garrito P, et al. Eating experiences of people with disabilities: a qualitative study in Spain. *Healthcare (Basel).* 2020;8(4):512. doi: [10.3390/healthcare8040512](https://doi.org/10.3390/healthcare8040512).
- [18] Klink ME, Wilson ME, Hafsteinsdóttir TB, et al. Recognizing new perspectives in eating difficulties following stroke: a concept analysis. *Disabil Rehabil.* 2013;35(17):1491–1500. doi: [10.3109/09638288.2012.736012](https://doi.org/10.3109/09638288.2012.736012).
- [19] Jones N, Mawson S, Drummond A, et al. The experiences of stroke survivors with eating and drinking difficulties, in acute stroke units: a qualitative inquiry. *Disabil Rehabil.* 2026;48(10):2975–2988. doi: [10.1080/09638288.2025.2563772](https://doi.org/10.1080/09638288.2025.2563772).
- [20] Wai Sze Mavis L, Lisa Pau Le L, Ka Yin Kayla W. Eating difficulties in newly-onset stroke patients: a qualitative inquiry of nurses' perceptions of the situation. *Int Arch Nurs Health Care.* 2018;4(1):1–8. doi: [10.23937/2469-5823/1510089](https://doi.org/10.23937/2469-5823/1510089).
- [21] Perry L, McLaren S. Eating difficulties after stroke. *J Adv Nurs.* 2003;43(4):360–369. [cited 2015 Jan 7]. doi: [10.1046/j.1365-2648.2003.02724.x](https://doi.org/10.1046/j.1365-2648.2003.02724.x).
- [22] Robinson A, Coxon K, McRae J, et al. Family carers' experiences of dysphagia after a stroke: an exploratory study of spouses living in a large metropolitan city. *Int J Lang Commun Disord.* 2022;57(5):924–936. doi: [10.1111/1460-6984.12724](https://doi.org/10.1111/1460-6984.12724).
- [23] Pohontsch NJ, Meyer T, Eisenmann Y, et al. Study protocol of a systematic review and qualitative evidence synthesis using two different approaches: healthcare related needs and desires of older people with post-stroke aphasia. *BMJ Open [Open].* 2021;11(4):e039348. doi: [10.1136/bmjopen-2020-039348](https://doi.org/10.1136/bmjopen-2020-039348).
- [24] Connor EO, Dolan E, Horgan F, et al. A qualitative evidence synthesis exploring people after stroke, family members, carers and healthcare professionals' experiences of early supported discharge (ESD) after stroke. *PLoS One [One].* 2023;18(2):e0281583 doi: [10.1371/journal.pone.0281583](https://doi.org/10.1371/journal.pone.0281583).
- [25] Tong A, Flemming K, McInnes E, et al. Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Med Res Methodol.* 2012;12(1):181. doi: [10.1186/1471-2288-12-181](https://doi.org/10.1186/1471-2288-12-181).
- [26] Moher D, Liberati A, Tetzlaff J, et al. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *J Clin Epidemiol.* 2009;62(10):1006–1012. doi: [10.1016/j.jclinepi.2009.06.005](https://doi.org/10.1016/j.jclinepi.2009.06.005).
- [27] Joanne Briggs Institute. The Joanna Briggs Institute Reviewers' Manual 2015: methodology for JBI scoping reviews. Adelaide: Joanne Briggs Institute; 2011. www.joannabriggs.org
- [28] Aromataris E, Lockwood C, Porritt K, et al., editors. JBI manual for evidence synthesis. JBI; 2024. <https://synthesismanual.jbi.global>.
- [29] Booth A. Unpacking your literature search toolbox: on search styles and tactics. *Health Info Libr J.* 2008;25(4):313–317. doi: [10.1111/j.1471-1842.2008.00825.x](https://doi.org/10.1111/j.1471-1842.2008.00825.x).
- [30] Hirt J, Nordhausen T, Fuerst T, et al. Guidance on terminology, application, and reporting of citation searching: the TARCIS statement. *BMJ.* 2024; 385:e078384. doi: [10.1136/bmj-2023-078384](https://doi.org/10.1136/bmj-2023-078384).
- [31] Long HA, French DP, Brooks JM. Optimising the value of the critical appraisal skills programme (CASP) tool for quality appraisal in qualitative evidence synthesis. *Research Methods in Medicine & Health Sciences.* 2020;1(1):31–42. doi: [10.1177/2632084320947559](https://doi.org/10.1177/2632084320947559).
- [32] Flemming K, Noyes J. Qualitative Evidence Synthesis: where Are We at? *Int J Qual Methods.* 2021;20:1–13. doi: [10.1177/1609406921993276](https://doi.org/10.1177/1609406921993276).

- [33] Cooke A, Smith D, Booth A. Beyond PICO: the SPIDER tool for qualitative evidence synthesis. *Qual Health Res*. 2012;22(10):1435–1443. doi: [10.1177/1049732312452938](https://doi.org/10.1177/1049732312452938).How.
- [34] Jones N, Nasr N. The experiences of stroke survivors with managing eating 6 months post stroke. *British Journal of Occupational Therapy*. 2018;81(2):106–115. doi: [10.1177/0308022617738487](https://doi.org/10.1177/0308022617738487).
- [35] Booth A, Papaioannou D, Sutton A. *Systematic approaches to a successful literature review*. 1st ed. London: Sages Publications Ltd; 2012.
- [36] Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Med Res Methodol*. 2008;8(1):45. doi: [10.1186/1471-2288-8-45](https://doi.org/10.1186/1471-2288-8-45).
- [37] Carlsson E, Ehrenberg A, Ehnfors M. Stroke and eating difficulties: long-term experiences. *J Clin Nurs*. 2004;13(7):825–834. doi: [10.1111/j.1365-2702.2004.01023.x](https://doi.org/10.1111/j.1365-2702.2004.01023.x).
- [38] Batt S. An in-depth inquiry into how stroke patients are supported with eating and drinking in stroke units. University of Leeds School of Medicine; 2023. <https://etheses.whiterose.ac.uk/id/eprint/30503/>.
- [39] Perry L, McLaren S. Coping and adaptation at six months after stroke: experiences with eating disabilities. *Int J Nurs Stud*. 2003;40(2):185–195. doi: [10.1016/S0020-7489\(02\)00060-3](https://doi.org/10.1016/S0020-7489(02)00060-3).
- [40] Eltringham SA, Pownall S, Bray B, et al. Experiences of dysphagia after stroke: an interview study of stroke survivors and their informal caregivers. *Geriatrics*. 2019;4(4):67. doi: [10.3390/geriatrics4040067](https://doi.org/10.3390/geriatrics4040067).
- [41] Helldén J, Bergström L, Karlsson S. Experiences of living with persisting post-stroke dysphagia and of dysphagia management – a qualitative study. *Int J Qual Stud Health Well-Being*. 2018;13(sup1):1522194 doi: [10.1080/17482631.2018.1522194](https://doi.org/10.1080/17482631.2018.1522194).
- [42] Jacobsson C, Axelsson K, Wenngren BI, et al. Eating despite severe difficulties: assessment of poststroke eating. *J Clin Nurs*. 1996;5(1):23–31. doi: [10.1111/j.1365-2702.1996.tb00223.x](https://doi.org/10.1111/j.1365-2702.1996.tb00223.x).
- [43] Jacobsson C, Axelsson K, Norberg A, et al. Outcomes of individualized interventions in patients with severe eating difficulties. *Clin Nurs Res*. 1997;6(1):25–44. doi: [10.1177/105477389700600104](https://doi.org/10.1177/105477389700600104).
- [44] Jacobsson C, Axelsson K, Osterlind PO, et al. How people with stroke and healthy older people experience the eating process. *J Clin Nurs*. 2000;9(2):255–264. doi: [10.1046/j.1365-2702.2000.00355.x](https://doi.org/10.1046/j.1365-2702.2000.00355.x).
- [45] Johansson AEM, Johansson U. Relatives' experiences of family members' eating difficulties. *Scand J Occup Ther*. 2009;16(1):25–32. doi: [10.1080/11038120802257195](https://doi.org/10.1080/11038120802257195).
- [46] Jones SP, Injety RJ, Pandian JD, et al. Healthcare professionals' perspectives of the provision of, and challenges for, eating, drinking and psychological support post stroke: findings from semistructured interviews across India. *BMJ Open*. 2023;13(10):e069150. doi: [10.1136/bmjopen-2022-069150](https://doi.org/10.1136/bmjopen-2022-069150).
- [47] Kjaersgaard A, Pallesen H. First-hand experience of severe dysphagia following brainstem stroke: two qualitative cases. *Geriatricstj*. 2020;5(1):15. doi: [10.3390/geriatrics5010015](https://doi.org/10.3390/geriatrics5010015).
- [48] Kumlien S, Axelsson K. Stroke patients in nursing homes: eating, feeding, nutrition and related care. *J Clin Nurs*. 2002;11(4):498–509. doi: [10.1046/j.1365-2702.2002.00636.x](https://doi.org/10.1046/j.1365-2702.2002.00636.x).
- [49] McCurtin A, Healy C, Kelly L, et al. Plugging the patient evidence gap: what patients with swallowing disorders post-stroke say about thickened liquids. *Int J Lang Commun Disord*. 2018;53(1):30–39. *. doi: [10.1111/1460-6984.12324](https://doi.org/10.1111/1460-6984.12324).
- [50] Medin J, Larson J, Von Arbin M, et al. Elderly persons' experience and management of eating situations 6 months after stroke. *Disabil Rehabil*. 2010;32(16):1346–1353. doi: [10.3109/09638280903514747](https://doi.org/10.3109/09638280903514747).
- [51] Medin J, Windahl J, von Arbin M, et al. Eating difficulties among patients 3 months after stroke in relation to the acute phase. *J Adv Nurs*. 2012;68(3):580–589. [cited 2015 Jan 7]. doi: [10.1111/j.1365-2648.2011.05759.x](https://doi.org/10.1111/j.1365-2648.2011.05759.x).
- [52] Westergren A. nutrition and its relation to mealtime preparation, eating, fatigue and mood among stroke survivors after discharge from hospital - a pilot study. *Open Nurs J*. 2008;2(1):15–20. doi: [10.2174/1874434600802010015](https://doi.org/10.2174/1874434600802010015).
- [53] Westergren A, Ohlsson O, Hallberg IR. Eating difficulties, complications and nursing interventions during a period of three months after a stroke. *J Adv Nurs*. 2001;35(3):416–426. doi: [10.1046/j.1365-2648.2001.01884.x](https://doi.org/10.1046/j.1365-2648.2001.01884.x).
- [54] Medin J, Larson J, von Arbin M, et al. Striving for control in eating situations after stroke. *Scand J Caring Sci*. 2010;24(4):772–780. [cited 2014 Oct 23]. doi: [10.1111/j.1471-6712.2010.00775.x](https://doi.org/10.1111/j.1471-6712.2010.00775.x).
- [55] Charmaz K. The body, identity, and self: adapting to impairment. *Sociol Q*. 1995;36(4):657–680. doi: [10.1111/j.1533-8525.1995.tb00459.x](https://doi.org/10.1111/j.1533-8525.1995.tb00459.x).
- [56] Charmaz K. Loss of self: a fundamental form of suffering in the chronically ill. *Sociol Health Illn*. 1983;5(2):168–195. doi: [10.1111/1467-9566.ep10491512](https://doi.org/10.1111/1467-9566.ep10491512).
- [57] Radley A, Green R. Illness as adjustment: a methodology and conceptual framework. *Sociol Health Illness*. 1987;9(2):179–207. <https://onlinelibrary.wiley.com/doi/pdfdirect/10.1111/1467-9566.ep11346972> doi: [10.1111/1467-9566.ep11346972](https://doi.org/10.1111/1467-9566.ep11346972).
- [58] Lupton D. *Risk*. 3rd ed. London: Routledge; 2023. doi: [10.4324/9781003316299](https://doi.org/10.4324/9781003316299).
- [59] Burges Watson DL, Lewis S, Bryant V, et al. Altered eating: a definition and framework for assessment and intervention. *BMC Nutr*. 2018;4(1):14. doi: [10.1186/s40795-018-0221-3](https://doi.org/10.1186/s40795-018-0221-3).
- [60] Hung L, Chaudhury H, Rust T. The effect of dining room physical environmental renovations on person-centered care practice and residents' dining experiences in long-term care facilities. *J Appl Gerontol*. 2016;35(12):1279–1301. doi: [10.1177/0733464815574094](https://doi.org/10.1177/0733464815574094).

- [61] Kitson AL, Muntlin Athlin Å. Development and preliminary testing of a framework to evaluate patients' experiences of the fundamentals of care: a secondary analysis of three stroke survivor narratives. *Nurs Res Pract*. 2013;2013:572437–12. doi: [10.1155/2013/572437](https://doi.org/10.1155/2013/572437).
- [62] CASP. Critical appraisal skills programme [Internet]. CASP Checklist for Qualitative Research; 2018. <https://casp-uk.net/>.
- [63] Feigin VL, Brainin M, Norrving B, et al. World Stroke Organization (WSO): global stroke fact sheet 2022. *Int J Stroke*. 2022;17(1):18–29. doi: [10.1177/17474930211065917](https://doi.org/10.1177/17474930211065917).
- [64] Wade D. Rehabilitation – a new approach. overview and part one: the problems. *Clin Rehabil*. 2015;29(11):1041–1050. doi: [10.1177/0269215515601174](https://doi.org/10.1177/0269215515601174).
- [65] Wade D. Rehabilitation – a new approach. Part two: the underlying theories. *Clin Rehabil*. 2015;29(12):1145–1154. doi: [10.1177/0269215515601175](https://doi.org/10.1177/0269215515601175).