#### RESEARCH REPORT



### The impact of acquired communication impairments on sexuality and intimacy: A scoping review

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#### **Abstract**

Background: Communication is critical to sexuality and sexual health. It is therefore reasonable to assume that acquired communication impairments would impact sexuality, but research is sparse. The research that does discuss these impacts can be difficult to find, as studies are spread across a wide variety of literature bases, and sexual topics are often combined with other concerns. Coupled with clinicians' discomfort in addressing sexual issues, this leads to a lack of clinical support for patients' sexual concerns.

**Aims:** This scoping review aimed to map and summarize the existing literature on sexuality and acquired communication impairments.

Methods & Procedures: Six databases were searched: CINAHL, PubMed, MEDLINE, PsycINFO, Web of Science and Scopus. To find studies from the literature on acquired communication impairments and their aetiologies that addressed sexuality and communication, a combination of sexuality and communication impairment terms was used. A total of 97 articles met inclusion criteria.

Main Contribution: Across actiologies and literature bases, acquired communication impairments have been found to negatively affect sexuality. However, researchers rarely evaluate the nature of the communication impairment or its effects on sexuality directly. People with communication impairments are more often systematically excluded from acquired disability research on sexuality. Using the reviewed literature, we present recommendations for including sexuality-related topics in communication disorder research and including people with communication impairments in sexuality-related research. We also present recommendations for speech-language pathologists to begin incorporating sexuality-related topics in their clinical practice.

Conclusions & Implications: The effects of communication impairments on sexuality are insufficiently researched. The literature that does exist points to substantial impacts. This area of research deserves more concerted attention so

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that clinicians may have guidance and support in addressing the issue with their clients.

#### KEYWORDS

aphasia, brain injury, communication disorders, sexual health, sexuality, stroke

#### WHAT THIS PAPER ADDS

What is already known on the subject

 Though researchers have long posited reasons why acquired communication impairments would logically affect sexuality and intimacy, the literature on the topic has been difficult to find. Such research is spread across disorder areas. Sexuality effects are often hidden amid multiple quality-of-life indicators, or communication impairment impacts are described as one of many independent variables.

What this paper adds to the existing knowledge

This scoping review is the first of its kind to provide an overview of the research
into communication impairments' effects on sexuality. It describes the effects
that communication impairments can have on sexuality.

What are the potential or actual clinical implications of this work?

• This scoping review will help clinicians to find relevant research for their clients' needs and help researchers conduct more thorough research in this area. It also provides clinical recommendations for helping clients with communication impairments access this important part of life.

### **INTRODUCTION**

For most individuals, sexuality is an important part of well-being, self-concept and romantic relationships (Christopher & Sprecher, 2000; Glowacka et al., 2017, 2019; Nery-Hurwit et al., 2022; Sakaluk et al., 2020). The World Health Organization (WHO) (2006) describes sexuality as:

a central aspect of being human throughout life that encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. It is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviour, practices, roles and relationships.

The ability to express and experience sexuality is a crucial component of sexual health. Sexual health, in turn, is 'fundamental to the overall health and well-being of individuals, couples, and families' and is dependent on access to comprehensive sex education, access to sexual health

care and being in environments that affirm sexual health (WHO, n.d.).

### Communication is vital to sexuality

Communication is a crucial part of sexuality. Communication ability has been linked to individuals' ability to participate in consent-related discussions (Giampieri, 2012; Willis & Jozkowski, 2019), sexual health and safety (Lindgren et al., 2009), sexual self-esteem and self-efficacy (Impett & Tolman, 2006), sexual satisfaction (Byers & Demmons, 1999; Litzinger & Gordon, 2005) and relationship satisfaction (Montesi et al., 2011; Valvano et al., 2018). Communication in romantic relationships is intertwined with sexual satisfaction, relationship satisfaction and emotional intimacy (Mallory, 2022; Yoo et al., 2014). These associations appear true for verbal and non-verbal communication (Blunt-Vinti et al., 2019). It is clear that communication is an important variable in sexuality and sexual relationships.

## Communication impairments may impact sexuality

Given the link between communication and sexuality, it is reasonable to believe that adults with acquired communication impairments may experience changes to their sexual wellbeing. Acquired communication impairments, sometimes called acquired communication disorders, are changes to communication functioning in adulthood as the result of a neurological or physiological issue. These include such as a stroke, brain injury, neurodegenerative disease, or cancer (Aldridge et al., 2023). Aphasia, an acquired language disorder that is common after stroke (Flowers et al., 2013), is one such acquired communication impairment. Some research outlines the impact of communication impairments, such as aphasia, on sexuality. Stead and White (2019) noted a loss of physical and emotional intimacy for people with aphasia (PWA), and Kitzmüller and Ervik (2015) found that aphasia leads couples to no longer be able to discuss their relationship or work through sexual problems. Lemieux et al. (2001) studied six PWA and their spouses. All their participants with aphasia and 83% of spouses felt that aphasia had affected their sex lives, outside of other stroke-related factors. Acquired communication impairments also affect unpartnered individuals' opportunities to experience intimacy and sexuality due to difficulty forming new relationships (Moreno et al., 2013). Therefore, people with acquired communication impairments may need support to enable them to discuss and participate in their sexuality in ways associated with consent, sexual health, physical intimacy and relationship formation and maintenance.

### There is little clinical support for sexual issues

Across countries, such as Australia (Speech Pathology Australia, 2023), Canada (College of Audiologists & Speech-Language Pathologists of Ontario, 2015) and the United States (American Speech-Language-Hearing Association, 2016), clinical guidelines for speech-language pathologists (SLPs) indicate that they have a responsibility to help patients with communication impairments participate in the activities that are relevant to their lives. As an integral component to quality of life, sexuality has clear relevance as a life participation activity (WHO, n.d.). The WHO's International Classification of Functioning and Disability Framework (ICF) (WHO, 2001, 2006, n.d.) designates ability to participate in one's sexual life as a vital component of overall health and wellbeing. Therefore, it is the responsibility of healthcare professionals to evaluate patients' goals and functional status and offer appropriate

treatment to enhance overall sexuality participation. However, SLPs rarely address issues of sexuality, intimacy, romance, or dating in their own practices, even if they recognize the importance of these topics and believe it is their responsibility to do so (Exell et al., 2021; Wolford &

Jansen, 2024a, 2024b).

SLPs are not alone in their reluctance to address sexuality in clinical practice. This trend is true for healthcare providers at large. Despite multidisciplinary clinical guidelines recommending health professionals provide sexuality rehabilitation to people with acquired neurological impairments (such as stroke, brain injury or neurodegenerative disease) (Consortium for Spinal Cord Medicine, 2021; Foley & Beier, 2015; Stroke Foundation, 2021; University Health Network, 2023), multiple review articles have found that healthcare providers do not engage in discussion about sexuality or provide sexuality education with a frequency or depth that would meet patients' needs (Fennell & Grant, 2019; Kelder et al., 2022; Zhang et al., 2020). Often, they do not engage in the conversation at all. A 2020 Stroke Foundation audit, for example, found only 24% of stroke survivors had received information on sexuality after their stroke from any health professional (Stroke Foundation, 2020).

Healthcare providers cite personal discomfort, role confusion, and lack of training as reasons they do not regularly discuss sexuality with their patients (Dyer & das Nair, 2014; Haboubi & Lincoln, 2003; Haesler et al., 2016; Zhang et al., 2020). Clinicians see the topic as intrusive and embarrassing (Exell et al., 2021), likening it to 'opening a can of worms' (Dyer & das Nair, 2014). As a result, sexuality is addressed reactively more than proactively (Dyer & das Nair, 2014; WHO, 2001). Clinicians often may not believe sexuality is relevant to people with communication or cognitive impairments (Bonder et al., 2021; Lepage et al., 2021; Schmidt et al., 2022; Wolford & Jansen, 2024a, 2024b). Together, this can create a 'silence within the silence' around what can be a taboo topic (McGrath et al., 2019).

### The current state of the literature

Since clinicians are unsure of the relevance or impact of acquired communication impairments on sexuality, understanding the current literature in this area is of particular importance. Acquired communication impairments are often secondary to other diseases or disorders (e.g., stroke, neurodegenerative disease) and should also be understood in that context. However, studies about these disorders often systematically exclude people with communication impairments or do not describe them clearly (Shiggins et al., 2022; 2024; Vaughan & Manning, 2023). Therefore, their experience is likely to be under-described

and poorly understood within the broader literature of sexuality and acquired disability. The literature can also be difficult to find, as it spans a wide swath of literature bases, and sexuality-related topics are often interwoven with other life participation measures. Therefore, the exact state of the knowledge in this area is presently unclear.

### Research aim

This study aimed to map and describe how the impacts of communication ability and communication impairments on sexuality are studied and presented in the literature. The concepts of 'communication ability' and 'communication impairment' were chosen over specific communication disorders, as research into communication impairment aetiologies (e.g., stroke) is often nonspecific about the nature of the communication concern.

### **Research questions**

Within the research on sexuality following acquired communication disability:

- Where, when, and how are researchers studying the impacts of communication ability on sexuality?
- How are people with communication impairments included or excluded from the research?
- How is the impact of communication ability on sexuality described?
- What studies focus specifically on the impact of communication impairments?

#### **METHODS**

### Design

Due to the emerging nature of the field of sexuality and neurogenic communication impairments, we conducted a scoping review as the most appropriate review format. We aimed to determine the scope of the literature in the area, any critical gaps, and the nature of inclusion of people with communication impairments in sexuality (Munn et al., 2018). The design and reporting of the review were guided by Arksey and O'Malley's (2005) scoping review framework and the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist (Vaughan & Manning, 2023) (see Appendix A for the completed checklist). The study protocol was registered prior on Protocols.io to commencing the search, #77111 (Wolford et al., 2023).

### Search strategy

A search was conducted in March 2023 and rerun in January 2024 to identify available literature that addresses the impact of communication impairments on sexual and intimacy-related quality of life. Titles, abstracts, and keywords were searched in the following six databases: CINAHL, PubMed, MEDLINE, PsycINFO, Web of Science and Scopus. Manual searches of the reference lists of articles were also conducted.

### Search terms

The search included acquired communication impairments and their common aetiologies, including stroke, head injury, neurodegenerative diseases (Parkinson disease, amyotrophic lateral sclerosis, motor neuron disease, muscular dystrophy), neuromuscular disorders (multiple sclerosis, myasthenia gravis), cognitive impairment, executive dysfunction, and head and neck cancers. These terms were informed by the search conducted by Eadie et al. (2018) and broadened to include neurodegenerative diseases. These population terms were combined with sexuality-related terms:

Population terms: 'aphasi\*' OR 'dysphasi\*' OR 'dysarthri\*' OR 'apraxi\*' OR 'dyspraxi\*' OR 'motor speech disorder\*' OR 'dysphoni\*' OR 'aphoni\*' OR 'hoarse' OR 'voice disorder\*' OR 'Communicat\* disorder\*', OR 'cognitive-communicati\*' OR 'stroke' OR 'cerebrovascular accident' OR 'Parkinson\* Disease' OR 'Multiple Sclerosis' OR 'Amyotrophic Lateral Sclerosis' OR 'Muscular dystrophy' OR 'myasthenia gravis' OR 'Motor neuron disease\*' OR 'head and neck cancer' OR 'oral cancer' OR '\*pharyngeal cancer' OR 'laryngeal cancer' OR 'laryngeatom\*' OR 'cognitive impairment' OR 'TBI' OR 'ABI' OR 'brain injury' OR 'head injury' OR 'post-concussi\*' OR 'executive dysfunction' OR 'dysexecutive syndrom\*'

AND

<u>Sexuality terms</u>: 'sexu\*' OR 'intimacy' OR 'marriage' OR 'personal relationship' OR 'dating' OR 'spouse' OR 'spousal' OR 'romance' OR 'romantic' OR 'courtship' OR 'courting' NOT 'violent' NOT 'violence'

### Inclusion criteria

Studies were selected for inclusion if they were original research including quantitative, qualitative and mixed method studies and written in English. Included studies focused on (1) the sexuality impacts of an acquired communication impairment or an aetiology thereof for participants 18 years of age or older, (2) communication

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between sexual/romantic partners was directly discussed within the text, and (3) evaluation of the experience of people with the named disorder or their partners. No time limits were placed on the search.

### Exclusion criteria

To focus on the quality-of-life impacts of communication ability on patients' sexuality, studies where the outcome measures were solely physical phenomena—such as neurochemical changes, erectile dysfunction, or fertility—were excluded. Since the review focused on the experiences of people with the named disorder or their partners, studies focusing on clinician perceptions or that solely validated a survey/questionnaire were excluded. Studies that solely focused on sexual paraphilias, disinhibited sexual behaviours, or inter-partner violence were also excluded. Other exclusion criteria included discussing developmental communication impairments and/or participants under age 18.

### **Data screening**

The reviewers used the Covidence systematic review management application to organize the review. Two reviewers independently completed title/abstract screening ( $\kappa = 0.90$ ) and full-text screening ( $\kappa = 0.81$ ) for 20% of the studies identified in the search. A Cohen's kappa value of above 0.8 indicates a high level of interrater reliability (Eadie et al., 2018). Disagreements were resolved through consensus between the two raters and in consultation with other authors if required. Figure 1 contains a flow diagram of the screening process.

### **Data extraction**

Data extraction items included title, author, publication, participant demographics, study design, outcome measures, diagnoses studied, whether communication impairment was a factor in exclusion criteria, accommodations for communication impairments and how communication/communication impairments were discussed in the text. For full extraction items, see the table headings in the corpus, available as supplementary materials 1.

Identified studies sometimes combined multiple areas of interest. For example, sexuality was often considered within a larger set of quality-of-life measures. These studies were retained when sexuality was evaluated and described independently from other quality-of-life concepts within the results section. Similarly, populations

were sometimes broader than the populations of interest. Stroke survivors, for example, were at times discussed within larger studies of skilled nursing facility residents or ageing individuals. Such studies were retained when the populations of interest were analysed independently from the larger group.

### **Analyses**

Quantitative data were explored with descriptive statistics. Qualitative data were analysed using meta-qualitative approach, including latent content analysis, to identify the meaning of the data (Downe-Wamboldt, 1992; Landis & Koch, 1977). One article written by a research team member was included in the search results. To manage potential conflicts of interest, other members of the team reviewed the article for all stages of the process.

### **RESULTS**

A total of 97 publications were included in the review. A total of 91 (of 97, 93.8%) addressed a communication impairment aetiology (e.g., stroke, traumatic brain injury) while six (of 97, 6.2%) focused on a specific communication impairment. The full corpus can be found in the supplemental material. The results first map the overall data and then focus more on the specific communication-focused papers.

### **Question 1: Publication characteristics**

### Where the research was conducted

Included studies were conducted in 25 countries, with the majority (60.8%) originating from the United States (n = 24), Australia (n = 14), Canada (n = 12) and Turkey (n = 9). There were a further 21 countries in which more than six studies were conducted (e.g., Sweden, Iran, Italy, UK), with 15 of these only conducting a single study (e.g., Austria, Brazil, Czech Republic).

### When the research was conducted

Few publications were identified from 1957 to the 2000s, with an increased number over the last 15 years. From 1957 to the 1990s, such research was infrequent, with small increases in articles published per year. In the 2000s, publications increased from an average of 1.5 articles per year in the period 2000–09 to an average of 4.9 per year for

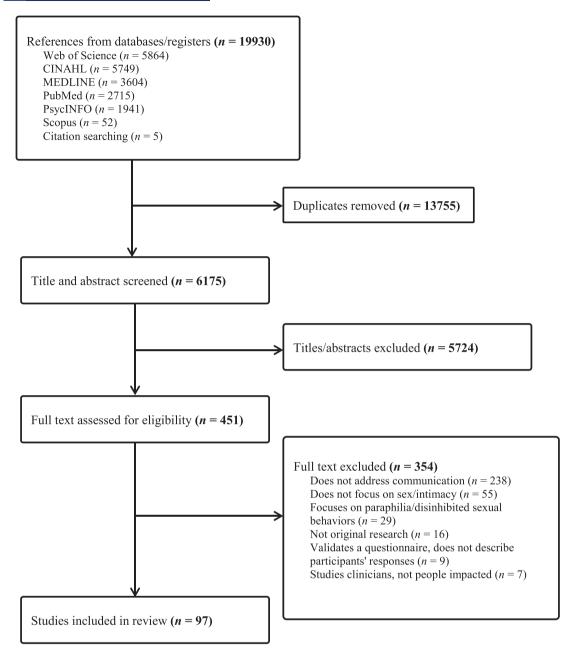


FIGURE 1 Flow diagram of the screening process.

2010–19, and five per year for 2020–23. Figure 2 presents the average number of publications per year across each decade.

### How the research was conducted

### Professions involved in research

The research was unclear as to the professional background(s) of the researchers leading the individual studies. While these details may be assumed from the department of the author or type of journal, the information was not extracted, as it was rarely explicitly stated.

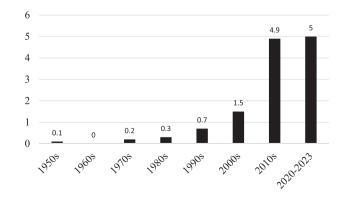


FIGURE 2 Average publications per year.

**TABLE 1** Distribution of disorders assessed.

Disorder(s) studied	n
Stroke	28
Traumatic brain injury	24
Multiple sclerosis	20
Head/neck cancer	7
Aphasia	6
Parkinson disease	4
Dementia/mild cognitive impairment	3
Amyotrophic lateral sclerosis	1
Aphasia and hemiplegia	1
Dystonias	1
Stroke and multiple sclerosis	1
Stroke, multiple sclerosis and Huntington disease	1

### Study populations

Studies about the effects of stroke (n = 28), acquired brain injury (n = 24), and multiple sclerosis (n = 20) on sexuality were the most widely represented in the corpus. Table 1 contains the full distribution of disorders studied.

A total of 49 studies (of 97; 50.5%) included only patients with the assessed disorder. Six (6/97) included only romantic partners of the people with the disorder. A total of 28 (of 97; 28.9%) included both patients and partners. The rest assessed combinations of patients and control participants (10/97; 10.3%), patients and clinicians (3/97; 3.1%), and patients, partners and clinicians (1/97; 1.0%).

### Study designs

Quantitative studies (39/97, 40.2%) and qualitative studies (42/97, 43.3%) were relatively evenly represented. A total of 13 (of 97, 13.4%) were mixed-methods, which commonly included a questionnaire and a qualitative focus group or interview. Three (3/97, 3.1%) were case studies.

### Measures used to evaluate sexuality

Studies commonly used multiple measures to evaluate sexuality. A total of 33 published measures of sexuality were utilized in the corpus, with almost half of the studies (45/97, 46.4%) using at least one. The most frequent assessments were questionnaires: the Derogatis Sexual Functioning Inventory (DSFI; n=4) (Derogatis et al., 1975), Brain Injury Questionnaire of Sexuality (BIQS; n=4) (Stolwyk et al., 2013), International Index of Erectile Function (IIEF; n=4) (Rosen et al., 1997) and Female Sexual Function Inventory (FSFI; n=4) (Wiegel et al., 2005). The DSFI is a self-report of the current quality of sexual functioning; the BIQS compares sexual functioning for people before and after their brain injury; while the IIEF and FSFI focus on the physical aspects of sexual function. Authordeveloped questionnaires specific to each study were also

common (25/97, 25.8%). Roughly one-third of studies utilized semi-structured (28/97, 28.9%) or structured (7/97, 7.2%) interviews to qualitatively explore participants' experiences. Descriptive observation (2/97, 2.1%) and medical note reviews (2/97, 2.1%) were also present. Appendix B provides a list of all published measures that were referenced.

# Question 2: How people with communication impairments are included in the research

### Inclusion of people with communication impairments

People with communication impairments were infrequently included or described in the subject pools. Communication impairments were listed as exclusion criteria in 48.5% (47/97) of the studies. Exclusion criteria explicitly referenced a communication impairment in 30 studies (30/97, 30.9%), such as 'presence of speech disturbance led to study exclusion' (Bivona et al., 2016). Of these, most (20/30, 66.7%) specified the severity or nature of the communication impairment that would be excluded, such as 'moderate-to-severe communication difficulties' (Yilmaz et al., 2015) or 'aphasia that significantly limited their verbal comprehension' (Kimura et al., 2001). A total of 10 (of 30, 33.3%) studies did not specify severity, leaving it unclear whether more mild impairments would have led to inclusion or a blanket exclusion, and the remaining studies with communication impairments as exclusion criteria (10/47, 21.3%) referenced communication in relation to an ability to independently complete a communication task/activity, such as an interview or a questionnaire. Most studies (50/97, 51.5%), did not describe inclusion or exclusion of people with communication impairments at all. Only seven (7/97, 7.2%) described purposefully recruiting people with communication impairments.

### Accommodations for communication impairments

A total of 17 (of 97, 17.5%) studies described providing accommodations so that people with communication impairments could participate. Nine (9/17, 52.9%) described these accommodations broadly, such as 'in case of some language disturbance, a speech-therapist was present' (Aloni et al., 1994) or 'interviews were [...] adapted according to each patient's needs and cognitive function' (Vikan et al., 2021). The other half (8/17, 47.1%)

described the accommodations in a specific and replicable way. Of these studies, four described using Supported Conversation for Adults (SCAs) with Aphasia (Kagan et al., 2001) techniques, including purposeful use of gesture, incorporating spoken and written keywords, shortening phrases and using pictographs to improve comprehension and expression (Espeleta et al., 2022; Lemieux et al., 2001; McGrath et al., 2019; Stead & White, 2019). While three of these were specifically studying PWA (Espeleta et al., 2022; Lemieux et al., 2001; Stead & White, 2019), one was studying stroke survivors more broadly (McGrath et al., 2019). An SLP was part of the research team, and SCA and other communication accommodations were utilized to allow PWA to participate as part of the sample.

Other accommodations that researchers provided included dividing complex questions into multiple, smaller questions and reducing the number of potential choices in a questionnaire (e.g., changing a 7-point Likert scale question to a yes/no or high/moderate/low scale) (Aloni et al., 1999). They also used simplified language (Fraser et al., 2023; Guo et al., 2015) and easy-to-understand measures (Aloni et al., 1999) to improve comprehension. In studies where interviewers anticipated their participants would all have communication difficulties, interviews were adapted by using close-ended questions (Espeleta et al., 2022), repeating and summarizing the participant's points (Fraser et al., 2023) and asking clarifying questions (Fraser et al., 2023).

Of these eight studies that described replicable communication accommodations, only three were specifically studying individuals with communication impairments (Espeleta et al., 2022; Lemieux et al., 2001; Stead & White, 2019). The other five (Aloni et al., 1994; Espeleta et al., 2022; Fraser et al., 2023, Guo et al., 2015; Korpelainen et al., 1999) were assessing the impacts of a communication impairment aetiology (4 stroke, 1 traumatic brain injury) on sexuality. They incorporated accommodations so that people with communication impairments were part of their sample. Six of the studies with replicable communication accommodations (Aloni et al., 1994; Espeleta et al., 2022; Guo et al., 2015; Lemieux et al., 2001; McGrath et al., 2019; Stead & White, 2019) noted having a SLP involved with the planning or implementation of the study and two (Fraser et al., 2023; Korpelainen et al., 1999) did not.

### Measures of communication ability

A total of 23 (of 97, 23.7%) studies included a process for characterizing communication ability. Three utilized a standardized evaluation for aphasia (Boston Diagnostic Aphasia Exam or Western Aphasia Battery) (Backhaus et al., 2019; Bugnicourt et al., 2014; Espeleta et al., 2022).

Six used published clinician rating scales, such as the Australian Therapy Outcome Measures (AusTOMS) Activity Limitation or Functional Independence Measure (FIM) scales (Ek et al., 2023a; Lemieux et al., 2001; McGrath et al., 2019; Monga et al., 1997; Ng et al., 2017; Sansom et al., 2015) Nine included questionnaires that included components related to communication ability (Bartnik et al., 2017; Buhlmann et al., 2017; Ek et al., 2023b; Fraser et al., 2008; Guo et al., 2015; Nilsson et al., 2017; Redelman, 2009; Seymour & Wolf, 2014; Shalash et al., 2020). Two utilized a medical records review to determine eligibility for the study, including communication impairment severity (Beal & Millenbruch, 2015; Vikan et al., 2021). In three cases, the researchers described clinician perception outside of a standardized scale (Aloni et al., 1999; Beal & Millenbruch, 2015; Boldrini et al., 1991), such as 'patients with aphasia were excluded if impairment in comprehension appeared to affect the reliability of the answers' (Boldrini et al., 1991).

Of these studies, only four described including an SLP in their methodology or research team (4/23, 17.4%) (Aloni et al., 1999; Espeleta et al., 2022; Lemieux et al., 2001; McGrath et al., 2019). Seven (7/23, 30.4%) solely used this communication ability information for exclusionary criteria (Backhaus et al., 2019; Boldrini et al., 1991; Ek et al., 2023a; Korpelainen et al., 1999; Moreno & McKerral, 2017; Ng et al., 2017; Sansom et al., 2015). Two (2/23, 8.7%) were specifically researching the impacts of aphasia on sexual functioning (Espeleta et al., 2022; Lemieux et al., 2001). Interestingly, while these two studies evaluated the nature of the participants' aphasia, they did not use information about the type or severity of the participants' aphasia within their analyses. A total of 10 (of 23; 43.5%) studies used the severity or presence/absence of communication impairment as an independent variable (Aloni et al., 1999; Bartnik et al., 2017; Beal & Millenbruch, 2015; Bugnicourt et al., 2014; Ek et al., 2023b; Fraser et al., 2008; McGrath et al., 2019; Ng et al., 2017; Seymour & Wolf, 2014; Sjögren & Fugl-Meyer, 1982). Further, four (4/23, 17.4%) collected this information but reported it as demographic data or did not report on it within the results (Beal & Millenbruch, 2015; Buhlmann et al., 2017; Nilsson et al., 2017; Redelman, 2009).

# Question 3: How the impact of communication on sexuality is described in the literature

In the next section, we explore the issue of communication in relation to sexuality raised in the studies generally and with reference more specifically to communication impairments.

# Importance of communication ability to sexuality, outside of communication impairments

Though the studies did not often measure communication skills directly, they commonly highlighted how important communication is in the context of sexuality for people with acquired disabilities. A total of 19 (of 97, 19.6%) studies described that being able and willing to talk openly about their sexual relationship was crucial for participants to keep it strong or help it recover. Eight (8/97, 8.2%) studies described participants' feelings that communication between the relationship partners had kept their intimate relationship intact after diagnosis (Ek et al., 2023b; Esmail et al., 2007; Fugl-Meyer et al., 2019; Koch et al., 2002; Kralik et al., 2003; López-Espuela et al., 2018; O'Brien et al., 2012; Sayari et al., 2022). As described in a study about women with multiple sclerosis, 'All the women who participated in the study felt communication was vital in maintaining and improving their sexual relationship with their partner. [As one participant stated,] "communication. To me, that is the most sexual thing ... " (Koch et al., 2002).

Some (3/97, 3.1%) even noted an improvement in partnered communication following the participants' diagnoses of multiple sclerosis (Beal & Millenbruch, 2015; Valvano et al., 2018) or stroke (Fugl-Meyer et al., 2019), because the diagnosis forced partners to confront issues together. Of note, none of these three studies included people with communication impairments. In addition to communication's effects on the quality of existing relationships, its importance in creating new relationships post-diagnosis was also discussed. Sander et al. (2016) described the importance of communication to overall social participation, which in turn impacted participants' opportunities to create new romantic connections and sexual relationships.

Negative sexual impacts stemming from lack of communication

Eight (8/97, 8.2%) studies described participants' beliefs that poor communication with their partner had led to sexual relationship breakdown due to interpersonal dynamics unrelated to communication impairments (Akkuş & Duru, 2011; Fraser et al., 2022; Guo et al., 2015; Kneipmann & Kerr, 2018; Kotková & Weiss, 2013; O'Keeffe et al., 2020; Viitanen et al., 1988; Yilmaz et al., 2015). As Kneipmann and Kerr (2018) wrote in their study of sexuality after stroke,

Even for those who have unaffected speech, sexuality and intimacy are often difficult and awkward topics of conversation. Many couples found that poor communication was more difficult to handle than physical limitations. A lack of communication poses a threat to intimate relationships and the maintenance of sexuality.

These studies described participants' reluctance or inability to communicate about sexual topics with their partners for reasons outside of any communication impairment. Authors attributed this lack of communication to feelings of awkwardness and partners' desires not to upset one another. As Nilsson et al. (2017) describe of partners following stroke,

Communication with their current partner was brought up as an important aspect of having a fulfilling and positive sexual life. Although open communication was important, for some, it was also important not to communicate (e.g., pain) to not overburden their partner and to facilitate having sexual relations with their partner.

Authors often described the interplay between communication and feelings of closeness and affection, which impacted participants' overall desire for physical intimacy. As O'Brien et al. (2012) describe in their study about intimate relationships following head and neck cancer:

Communication was generally considered the key to establishing trust and aiding the move towards a physical connection [...] From the women's perspective, intimacy relates strongly to a sense of emotional security and desirability. The women ascribe great importance to their emotions, and intimacy enables the sharing of these emotions that are often verbally communicated.

Similarly, a study of traumatic brain injury on relationships (O'Keeffe et al., 2020) found that 'lack of emotional communication in the relationship was experienced by both TBI survivors and partners as one of the most difficult changes in the relationship and also as a barrier to intimacy'.

This complex interaction between communication, relationship satisfaction, feelings of emotional intimacy, and sexual intimacy, was discussed at length by Valvano et al. (2018) These authors described multiple models of how sex-related communication, relationship satisfaction and sexual satisfaction might affect one another and the clinical implications thereof. These descriptions were in line with Akkus and Duru's (2011) study of people with multiple sclerosis, which found that half of their

patients did not speak with their spouse about their sexual issues, which was in turn associated with increased sexual dissatisfaction.

### Sexuality changes attributed to communication impairments

Nearly half (45/97, 46.4%) of studies discussed the impact of communication impairments on sexuality. Of these, 25 (25/97, 25.8%) studies included communication impairments as an independent variable or qualitative demographic area of interest within a broader analysis of a communication impairment aetiology's impacts on sexuality. A total of 14 (of 97, 14.4%) did not assess the effects of a communication impairment directly but discussed communication impairments as possibly contributing to their results. Six (6/97, 6.2%) had a specific communication impairment as the focus of their research.

Communication impairment as an independent variable A total of (of 97, 25.8%) studies of communication disorder aetiologies included communication impairment as an independent variable. These are listed in Table 2.

The majority were quantitative studies (16/25, 64.0%). Nearly all of them (14/16, 87.5%) found that communication impairments were statistically correlated with sexual difficulties. For example, Bartnik et al. (2017) found that dysarthria was the only sign of multiple sclerosis that was significantly associated with sexual dysfunction. As they noted, 'This relation may be justified by a particularly psychologically disabling effect of problems with speech, which have a significant impact on almost every aspect of life' (p. 6). Another study of patients following total laryngectomy (Polat et al., 2015) found that speech restoration with a tracheoesophageal shunt improved their total scores on a scale of sexual satisfaction and physical sexual functioning. A study of young ischemic stroke survivors (Bugnicourt et al., 2014), 34.6% of whom had aphasia, found that patients with impaired sexual functioning were significantly more likely to have aphasia than those with intact sexual functioning.

The remaining studies (9/25, 36.0%) were qualitative or mixed-methods. Each described participants' experience of communication difficulties negatively influencing sexuality. For example, van Sluis et al. (2020) described, 'one [laryngectomized patient] indicated that she did not feel comfortable having sex because of her changed voice and the risk of coughing'. Qualitatively, researchers described how communication impairments interacted with participants' emotional well-being, their sense of self and their relationships. Researchers often directly stated or implied that these complex socio-emotional changes in

turn affected participants sexually. As Kitzmüller and Ervik (2015) noted of couples affected by aphasia, 'Communication problems added to couples' difficulties and some spouses decided to end the frustrating sexual relationship with their partner'.

Researchers also found associations between communication impairments and more specific symptoms, such as decreased coital frequency after stroke (Guo et al., 2015) and reduced vaginal lubrication for women with brain injury (Ek et al., 2023a). To explain the latter, the authors posited: 'we believe that speaking difficulties among women in our study can make it even more difficult to specify intimate wishes in sexual interactions and thereby make it difficult to maintain arousal and lubrication' (Ek et al., 2023a).

Two quantitative studies (2/25, 8%) did not find significant associations between communication impairment and the sexual impacts they measured. One study of stroke survivors found no statistical relationship between aphasia and coital frequency (Sjögren & Fugl-Meyer, 1982). Monga et al. (1997) also found no correlation between a clinician rating of speech intelligibility and participants' sexual functioning after treatment for head and neck cancer.

Some results were also mixed. In a study of stroke survivors, although 60% of participants with communication impairments were dissatisfied with their sexual lives, 40% were satisfied (Beal & Millenbruch, 2015). Even within a single participant, there were sometimes conflicting feelings about the effects of communication impairments on sexuality. One participant in López-Espuela et al. (2018) whose wife had aphasia following a stroke, described the aphasia as being very limiting to their physical intimacy. Yet, he also described how the necessity of finding ways to purposefully communicate brought them closer together emotionally.

Communication impairment as a rationale for results

Though they did not study communication ability directly,

14 studies (14/97, 14.4%) described communication impairments in their literature review, discussion or conclusion sections as potential contributors to participants' sexual difficulties. For example, Kimura et al. (2001) found an association between sexual dysfunction and left hemisphere lesions, which they believed might be due to the impact of communication impairments. Similarly, in describing why people with Parkinson disease might have difficulty with intimate relationships, Shalash et al. (2020) noted, 'cognitive impairment results in difficulties in communication and sexual passivity'. However, these studies did not make attempts to evaluate whether their participants had communication impairments outside of exclusion criteria, nor did they ask questions about the participants' communication ability.

Disorders

**TABLE 2** Studies in which communication impairment was analysed as a variable or demographic of interest.

					Communication impairment	n (%) with communication
Author(s)	Year	Title	Study design	Diagnosis studied	described	impairment
Aloni et al. (1999)	1999	Incidence of sexual dysfunction in TBI patients during the early post-traumatic in-patient rehabilitation phase	Quantitative questionnaire	Traumatic brain injury	Broadly described communication difficulties	12 (27.3%)
Bartnik et al. (2017)	2017	Sexual dysfunction in female patients with relapsing-remitting multiple sclerosis	Quantitative questionnaire	Multiple sclerosis	Dysarthria	19 (27.4%)
Bugnicourt et al. (2014)	2013	Impaired sexual activity in young ischaemic stroke patients: An observational study	Quantitative cross-sectional study	Stroke	Aphasia	36 (34.6%)
Crowe et al. (1999)	1999	The role of imagery in sexual arousal disturbances in the male traumatically brain injured individual	Quantitative questionnaire	Traumatic brain injury	Broadly described communication difficulties	Not clear
Dombrowski et al. (2000)	2000	Rehabilitation treatment of sexuality issues due to acquired brain injury	Qualitative case study	Traumatic brain injury	Cognitive– pragmatic changes	Not clear
Downing and Ponsford (2018)	2013	Sexuality in individuals with traumatic brain injury and their partners	Quantitative questionnaire	Traumatic brain injury	Cognitive- pragmatic changes	Not clear
Ek et al. (2023a)	2023	Sexuality > 1 year after brain injury rehabilitation: A cross-sectional study in Sweden	Quantitative questionnaire	Traumatic brain injury	Broadly described communication difficulties	80 (32.0%)
Ek et al. (2023b)	2023	Unmet need for sexual rehabilitation after acquired brain injury (ABI): A cross-sectional study concerning sexual activity, sexual relationships, and sexual rehabilitation after ABI	Quantitative questionnaire	Traumatic brain injury	Broadly described communication difficulties	Not clear
Fraser et al. (2008)	2008	Correlates of sexual dysfunction in men and women with multiple sclerosis	Quantitative questionnaire	Multiple sclerosis	Broadly described communication difficulties	Not clear
Fraser et al. (2023)	2023	Experience of adapted cognitive behaviour therapy to address sexuality problems after traumatic brain injury: A qualitative study	Qualitative interviews	Traumatic brain injury	Cognitive- pragmatic changes	Not clear
Iravani et al. (2022)	2022	Is there any association between total laryngectomy and sexual disorders in men?	Quantitative questionnaire	Total laryngectomy	Aphonia	Not clear
Kitzmüller and Ervik (2015)	2015	Female spouses' perceptions of the sexual relationship with stroke-affected partners	Qualitative interviews	Stroke	Aphasia	6 (50%)

(Continues)

### TABLE 2 (Continued)

TABLE 2 (Contr	,				Communication	10 (01) vyith
Author(s)	Year	Title	Study design	Diagnosis studied	impairment	n (%) with communication impairment
Korplainen et al. (1999)	1999	Sexual functioning among stroke patients and their spouses	Quantitative questionnaire	Stroke	Aphasia	21 (10.9%)
Layman et al. (2005)	2005	Exploring the impact of traumatic brain injury on the older couple: 'Yes, but how much of it is age, I can't tell you'	Qualitative interviews	Traumatic brain injury	Cognitive– pragmatic changes	Not clear
López-Espuela et al. (2018)	2018	Critical points in the experience of spouse caregivers of patients who have suffered a stroke. A phenomenological interpretive study	Mixed methods	Stroke	Broadly described communication difficulties	Not clear
Monga et al. (1997)	1997	Sexuality in head and neck cancer patients	Quantitative questionnaire	Head and neck cancer	Broadly described speech difficulties	Not clear
Polat et al. (2015)	2015	The effects of indwelling voice prosthesis on the quality of life, depressive symptoms, and self-esteem in patients with total laryngectomy	Quantitative cross-sectional study	Total laryngectomy	Aphonia	30 (100%)
Ponsford et al. (2003)	2003	Sexual changes associated with traumatic brain injury	Quantitative questionnaire	Traumatic brain injury	Cognitive- pragmatic changes	Not clear
Seymour and Wolf (2014)	2014	Participation changes in sexual functioning after mild stroke	Quantitative questionnaire		Broadly described communication difficulties	Not clear
Sjögren and Fugl-Meyer (1982)	1982	Adjustment to life after stroke with special reference to sexual intercourse and leisure	cross-sectional	Stroke	Aphasia	37 (33.6%)
Thomas (2016)	2016	Sexual function after stroke: A case report on rehabilitation intervention with a geriatric survivor	Mixed methods case study	Stroke	Aphasia	1 (100%)
van Sluis et al. (2020)	2020	Women's perspective on life after total laryngectomy: A qualitative study	Qualitative interviews	Total laryngectomy	Aphonia	8 (100%)
Vikan et al. (2021)	2021	Sexual satisfaction and associated biopsychosocial factors in stroke patients admitted to specialized cognitive rehabilitation	Quantitative cross-sectional study	Stroke	Broadly described communication difficulties	20 (22.0%)
Wedcliffe and Ross (2001)	2001	The psychological effects of traumatic brain injury on the quality of life of a group of spouses/partners	Quantitative questionnaire	Traumatic brain injury	Cognitive– pragmatic changes	Not clear
Yilmaz et al. (2017)	2017	Sexual life of women with multiple sclerosis: A qualitative study	Qualitative interviews	Stroke	Aphasia	Not clear

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### Question 4: Studies focusing specifically on communication impairments

Six studies (6/97, 6.2%) assessed the effects of an acquired communication impairment on sexuality as a primary research question. Information about these studies is found in Table 3. All these studies focused on aphasia. No research was found that specifically assessed the effects of verbal apraxia, dysarthria, aphonia or dysphonia on sexuality, although since communication impairments often co-occur, it may be that these impairments were present but not described sufficiently or were not the focus of the research. Of these six studies, five solely evaluated the effects of aphasia on sexual satisfaction, sexual readjustment, and sexual rehabilitation after stroke. One (Kinsella & Duffy, 1979) compared aphasic participants to hemiplegic participants with and without aphasia in examining the effects of aphasia on the married relationship and adjustment to disability, above and beyond changes caused by physical disability.

### Participant characteristics

The nature of the patients' aphasia was rarely assessed or defined. Two studies described characterizing the nature and severity of aphasia. The majority of the studies about aphasia included PWA and their partners. Participants' ages were not consistently described. Most studies (4/6) included both PWA and their partners, although only two described the nature and severity of the aphasia (Table 3).

### Aphasia's effects on sexuality

All the studies found that aphasia affects sexual relationships separately from other co-occurring physical or psychosocial changes. As Kinsella and Duffy (1979, p. 131) noted, 'Marriages where aphasia is part of the stroke disability show marked impairment and, more innovatively, [...] these marriages are significantly more impaired than marriages where aphasia is not part of the disability'. These effects included difficulty initiating sexual activity (Espeleta et al., 2022; Lemieux et al., 2001; Stead & White, 2019), expressing sexual interest (Espeleta et al., 2022; Lemieux et al., 2001) and sending and receiving nonverbal cues/body language (Espeleta et al., 2022, Wiig, 1973). Included studies describe PWA's feelings of frustration and rejection in the face of these difficulties (Biorn-Hansen, 1957; Espeleta et al., 2022; Lemieux et al., 2001; Stead & White, 2019; Wiig, 1973). Participants often discussed how role changes caused by the aphasia and acquired disability had negatively impacted sexual attraction and intimacy (Biorn-Hansen, 1957; Espeleta et al., 2022; Kinsella & Duffy,

1979; Lemieux et al., 2001; Wiig, 1973). As Wiig (1973, p. 112) noted, 'the majority of the aphasics who discussed their sexuality (70% of subjects) expressed concern about their sexual adequacy and masculinity or femininity'. Two studies (Espeleta et al., 2022; Lemieux et al., 2001) found that PWA believed a resolution of the aphasia would positively affect their sexual lives. Aphasia also limited participants'

ability to discuss these changes with their partners directly

(Espeleta et al., 2022; Stead & White, 2019).

For the partners of PWA, the research described feelings of loneliness (Kinsella & Duffy, 1979) and reduced emotional intimacy (Lemieux et al., 2001; Stead & White, 2019). Again, partners of PWA described the aphasia as affecting their sexual relationship in a way separate from the physical symptoms following stroke (Lemieux et al., 2001; McGrath et al., 2019). Though more recent work has found that partners were often still interested in a sexual relationship with the person with aphasia (Espeleta et al., 2022; Lemieux et al., 2001; Stead & White, 2019), many studies described reduced interest due to the caretaking role and altered attraction (Biorn-Hansen, 1957; Kinsella & Duffy, 1979; Lemieux et al., 2001; Wiig, 1973).

Two studies described patients' beliefs that an improvement in their aphasia would improve their sexual relationships (Espeleta et al., 2022; Lemieux et al., 2001). However, it was not common for participants to have received rehabilitation services that addressed sexuality. The participants also rarely discussed the changes in the sexual relationship directly with their partners (Espeleta et al., 2022; Lemieux et al., 2001). Spontaneous improvements to sexuality and sexual communication were observed in rare instances, which researchers linked to partners' willingness to try new communication strategies and adjust to the aphasia (Espeleta et al., 2022; Wiig, 1973). More commonly, though, the sexual relationships were greatly reduced or ended. As described by Kinsella and Duffy (1979, p. 130) all their participants 'reported problems in their sexual relationship and for 83% of couples sexual intercourse had ceased altogether. Spouses of patients with aphasia were significantly more reticent than spouses of non-aphasics [...] and they also experienced more friction in their marriages than spouses of non-aphasics'.

### **DISCUSSION**

Communication ability and communication impairments impact sexual functioning. They appear to do so in a way not otherwise accounted for by the physical or social–psychological impacts of the communication impairment aetiology. Researchers have been discussing the effects of communication impairments on sexuality since at least the 1950s (Biorn-Hansen, 1957) and have called for rehabilitation professionals to address these effects. Though the

Characteristics of the published literature about sexuality in communication impairments, which was solely focused on aphasia. TABLE 3

Sexuality measures	Review of general case worker notes and medical chart	Qualitative observation during counselling sessions	Semi-structured interviews	Structured interviews and written questionnaire	Open-ended survey	Structured interviews
% Married	> 50% married	'nearly 80%'	100% married	100% married	Not described	%68
Sexual	Not described	Not described	Not described	100% heterosexual relationships	Not described	100% heterosexual relationships
% Male <sup>a</sup>	87%	70%	30%	83% PWA, 17% partners	Not described	75% PWA, 25% partners
Samule	30 PWA	'About' 100 PWA	79 partners of PWA (8), hemiplegia (43) or both (28)	6 PWA and their partners	36 PWA and their partners	20 PWA and their partners
Location	USA	USA	UK	Canada	USA	d Philippines
Title	Social and emotional aspects of aphasia	Counselling the adult aphasic for sexual readjustment	Psychosocial readjustment in the spouses of aphasic patients: A comparative survey of 79 subjects	Aphasia and sexuality	Loss of intimacy: A cost of caregiving in aphasia	Sexual communication and functioning among adult stroke patients with non-fluent aphasia: A cross-sectional study
Vear	1957	1973	) 1979	2001	2019	2022
Author(s)	Biorn-Hansen (1957)	Wiig (1973)	Kinsella and Duffy (1979) 1979	Lemieux et al. (2001)	Stead and White (2019) 2019	Espeleta et al. (2022)

Note: <sup>a</sup> All studies only described participants' genders as male or female.



topic has not received a concerted effort since that time, interest has been increasing in the last decade. Research into communication impairment aetiologies often discusses the importance of communication in helping partners surmount the physical and psychological hurdles to sexuality that these disorders cause. However, researchers rarely assess the impact of the resulting communication impairments on this intimate communication.

## Communication impairments' impacts on sexual functioning

The research that does exist related to communication impairments and sexuality indicates that these impairments can have a substantial impact on sexuality. In particular, studies of aphasia's impacts on sexuality have found that it creates many barriers to sexual wellbeing and intimacy. Though in its infancy, the current research indicates that people with communication impairments experience changes to the way they express their thoughts, feelings and desires, which can be detrimental to the way they experience relationships, intimacy and sexuality. These impacts appear to be interwoven with people's selfconcept and their feelings of safety and satisfaction with the relationship itself. Researchers tend to assume communication is integral to sexual functioning and intimate relationships, even if they do not directly study it. People with communication impairments also note that their communication impairment has negative effects on their sexual lives, above and beyond the other impacts of the aetiology of their disability.

## Exclusion of people with communication impairments from the sexuality literature

Relatively recent meta-analyses and literature reviews have described the experiences of patients and partners after stroke (McGrath et al., 2019; Park et al., 2015; Rosenbaum et al., 2014), acquired brain injury (da Silva et al., 2022; Latella et al., 2018), neurodegenerative diseases (Albert et al., 2022; Poletti et al., 2018; Zhao et al., 2019), dementias (Holdsworth & McCabe, 2018; Holdsworth & McCabe, 2018) and head and neck cancer (Babin et al., 2023; Rhoten, 2016; Sant'Ana et al., 2021). However, the current study casts doubt on whether these literature bases reflect the experiences of people with communication impairments resulting from these aetiologies. The studies of communication impairment aetiologies included in this review often excluded people with communication impairments, whether explicitly in their exclusion criteria (42.3%) or implicitly with their methods. This is inevitably an under-representation of the exclusion present in the broader literature, as the present study only included publications that discussed communication in some way. Thus, the omitted studies are even more likely to have excluded those with communication impairments.

The exclusion of people with communication impairments from the broader literature has been previously described, with particular attention to the exclusion of PWA from stroke research (Shiggins et al., 2022, 2024; Vaughan & Manning, 2023). The literature on sexuality does not appear to be an exception. Although there is reason to believe that the sexuality of people with communication impairments may be disproportionately affected after a physiological or neurological diagnosis (Bugnicourt et al., 2014; Ek et al., 2023b; Kimura et al., 2001; Kinsella & Duffy, 1979), leading to poorer outcomes (Downing & Ponsford, 2018; Ek et al., 2023b), people with communication impairments are often excluded from the research. Providing accommodations so that people with communication impairments can participate in sexuality research would improve the quality and generalizability of the research as a whole. For example, a clinician who is treating a person with aphasia following a stroke will find very minimal research to support their understanding of their patient's sexuality needs. If they look to the broader stroke literature, it is unlikely to be representative of their patient's experience, because patients with aphasia are often excluded. For researchers who would like to make their studies inclusive for PWA, Shiggins et al. (2022) provides recommendations. These include creating videos or 'aphasia-friendly' adaptation for written information, using adaptations for communication similar to those listed in the 'accommodations for communication impairments' section of this manuscript or SCAs with Aphasia (Kagan et al., 2001) to improve access to spoken communication. They also suggest collaborating with SLPs to create inclusive environments that make accessibility feasible for people with communication impairments in each aspect of study recruitment and data collection.

### Addressing the impacts of communication impairments on sexuality

For SLPs and other clinicians who are interested in addressing the impacts of communication impairments on sexuality, there is not a wealth of resources or guidance. Continuing education and online training modules for clinicians supporting sexuality are available. For example, the Stroke Foundation has published a training program for clinicians who work with stroke survivors and their partners (Power et al., 2023). There are continuing education offerings for SLPs (Wolford, 2021, 2022) and those

TABLE 4 Recommended steps to conduct research into sexuality and communication impairments.

#	Recommendation
Before you start	
1	Engage with a communication specialist such as an SLP to maximize communication inclusion
2	Consider communication inclusion early on in the research/grant planning process
3	Consider a way to identify participants with aphasia and other communication impairments, including assessments of the communication impairment (e.g., Frenchay aphasia screening test, functional outcome measures)
4	Include measures of sexual communication ability and satisfaction with sexual communication ability in the study $design^a$
5	Include measures of sexual satisfaction and feelings of emotional intimacy <sup>a</sup>
6	Include measures of ability to discuss and participate in sub-topics of sexuality, such as consent, ability to initiate intimacy, and flirting/dating <sup>a</sup>
7	Include participants' sexual identities, partners' genders, and relationship statuses in demographic information, in addition to racial and gender identities
8	Compare current sexual function to pre-diagnosis functioning
During data collection	
9	Consider communication inclusion needs in recruitment, consent, assessment or outcome measures, data collection and feedback to participants
10	Consider sexuality, gender, and relationship structure diversity in the way questions are phrased
11	Allow the participant to choose how they are most comfortable discussing the topic (e.g., alone versus with partner, written versus interview)
12	Provide communication support through all stages. Supportive communication accommodations may include: (a) provision of communication friendly written resources with simple language and images, (b) supportive communication from researchers, including simplifying spoken language and supporting speech with gestures or key words, and/or (c) providing multimodal ways for participants to respond, such as pictorial options, yes/no/unsure options, answer boards, and using alternative modalities such as gesture or augmentative/alternative communication options
During research write	-ир
13	Describe the nature of communication accommodations that were available across study recruitment, interventions, and evaluations
14	Describe the nature of accommodations that participants needed or benefitted from
15	Include the results of communication impairment assessment(s) (e.g., Frenchay aphasia screening test, functional outcome measures)
16	Evaluate and describe the sexuality-focused results in relation to characteristics of the communication impairment

*Note*: <sup>a</sup>Published measures have not been written in a way tailored to clients with communication impairments. Appendix B provides a reference list of the published measures used by the authors in this corpus. However, these authors would recommend tailoring questions to the needs of people with communication impairments. This would likely require qualitative exploration for a more detailed view of their needs.

addressing sexuality and disability more broadly (Kattari, 2024; Laureano, 2024). Clinicians can also draw upon the BETTER model (Mick et al., 2004) and Ex-PLISSIT model (Taylor & Davis, 2007) for structuring their conversations addressing sexual wellbeing in acquired disability. Kelder et al. (2022) provides insight into conversational techniques that healthcare professionals use to discuss sexuality with patients. An analysis by Contrada et al. (2023) includes an overview of common sexuality measures for healthcare professionals, with an overview of post-stroke sexual changes from a biopsychosocial perspective. However, none of these resources or assessments are explicitly designed for patients with communication impairments.

An SLP might consider administering a standardized sexual health assessment using some of the accommodation options discussed in the results section of this paper, though such an assessment is unlikely to include questions targeting changes that are unique to individuals with communication disorders.

### Recommendations to broaden the literature base

The clear need to address the topic of sexuality, coupled with the lack of clear guidance on how to do so, places SLPs

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and others who work with patients with communication impairments at an uncomfortable crossroads. More research is warranted. For researchers who are interested in developing the evidence base related to communication impairments and sexuality, we have provided a preliminary checklist of recommendations in Table 4. We hope that these recommendations, while non-exhaustive, help to encourage researchers to include sexual topics in their studies of communication impairments' impacts.

### LIMITATIONS AND FUTURE DIRECTIONS

### Limitations

The search strategy limited the scope of this review and may therefore have affected the results. To focus on studies that included communication about intimacy and sexuality, studies that focused solely on physical impairments (e.g., erectile dysfunction or fertility) or sexual disinhibition/paraphilias were excluded. It is therefore likely that this study underrepresents of the percentage of studies that exclude people with communication impairments. It is also possible that studies that included in-text references to communication were excluded during initial screening for this reason. Additionally, while the authors took care to include common communication impairment aetiologies in the search terms, the search was not exhaustive of all possible aetiologies. Therefore, it is possible that relevant studies were not included.

### **Future directions**

Studies focusing on communication impairments other than aphasia were missing from the corpus, yet studies of communication impairment aetiologies often ascribed sexuality-related changes to speech, cognitive-linguistic, voice and pragmatic concerns. Additionally, when communication impairments were discussed in the sexuality literature, the nature of communication impairment was not consistently characterized or reported, making the clinical applicability of any results unclear. Future research across communication impairments that characterizes the nature of those communication impairments would help to illuminate the nature of their impacts on sexuality.

Across all studies, there was also a notable lack of reporting related to sexually relevant demographics, including participant ages, racial or ethnic identities, gender identities across the gender spectrum, sexuality and relationship status. Of the studies that reported on

these characteristics, participants were most commonly in heterosexual-presenting, married relationships. No studies in the corpus reported inclusion of polyamorous or non-monogamous relationships. Further research that centres the experiences of people with minoritized sexual, racial and gender identities, as well as relationship structures, would provide a more inclusive look at communication impairments' impacts on sexuality.

Finally, at present, there is not a thorough, validated measure of the sexuality impacts of communication impairments. We hope that as the literature base begins to incorporate more people with communication impairments and more fully characterize the nature of those impairments, such a measure can be developed.

### CONCLUSIONS

Though the literature indicates that patients with acquired communication impairments are likely to need support with sexuality-related concerns, more research is needed to support clinicians in addressing these issues. This scoping review may serve as a guide to clinicians and researchers in determining where to search for the extant literature across fields and disorder types. The included recommendations may assist researchers in including sexuality-related measures and participants with communication impairments in their research. We hope that this work will also help to raise SLPs' awareness about the importance of sexuality in rehabilitation services and provide them with the encouragement and knowledge to bring the topic up with their clients.

### CONFLICT OF INTEREST STATEMENT

The first author is a certified member of the American Association of Sexuality Educators, Counselors, and Therapists and is co-chair of the Disability Justice special interest group. She has also given invited and reimbursed talks about sexuality and communication impairments. The last author has ongoing grants from the Stroke Foundation and the Agency for Innovation NSW for sexuality research. She is also an author of an online e-learning module on sexuality for the Stroke Foundation and has recently completed a term on the research advisory committee.

### DATA AVAILABILITY STATEMENT

The corpus used for this review is freely available as supplementary material.

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#### SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

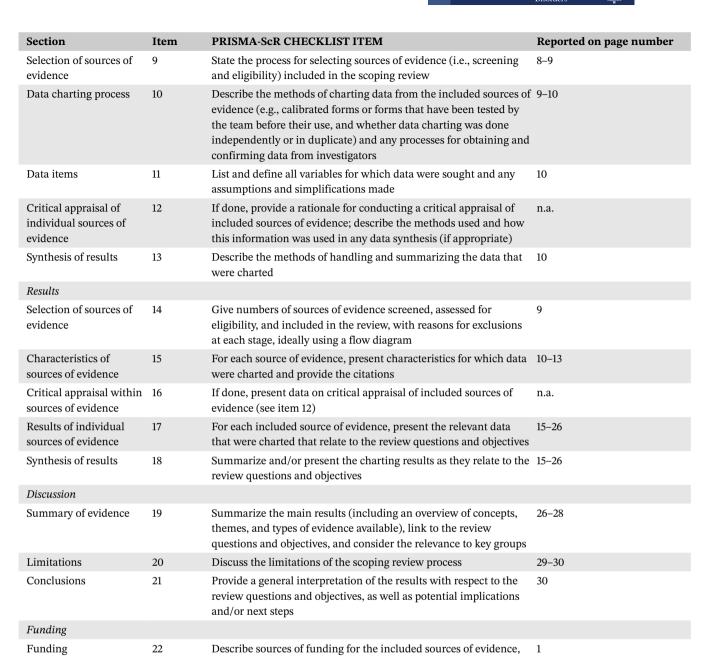
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### APPENDIX A

Table A1. Preferred reporting items for systematic reviews and meta-analyses extension for scoping reviews (PRISMA-ScR) checklist (Vaughan & Manning, 2023).

Section	Item	PRISMA-SCR CHECKLIST ITEM	Reported on page number
Title			
Title	1	Identify the report as a scoping review	1
Abstract			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives	2-3
Introduction			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach	3–5
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives	6
Methods			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a web address); and if available, provide registration information, including the registration number	6
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale	8
Information sources	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed	7
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated	7
			(Continues

(Continues)



### APPENDIX B: PUBLISHED MEASURES USED TO EVALUATE SEXUALITY REFERENCED IN THE CORPUS

role of the funders of the scoping review

as well as sources of funding for the scoping review. Describe the

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