

## **Scoping Review Protocol:**

**Title:** A Scoping Review of the **impact of acquired communication impairments on sexuality, intimacy, and sexual health**

**Anticipated start date:** 18 January 2023

**Anticipated completion date:** 01 April 2024

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**Organizational affiliation of the review:** None

**Funding sources:** None

### **Conflicts of interest:**

The lead reviewer (LW) is a certified member of the American Association of Sexuality Educators, Counselors, and Therapists, runs a business teaching speech-language pathologists to communicate about sexuality with their clients, and has given invited and reimbursed talks about the topic at conferences.

EP has ongoing grants from the Stroke Foundation and the Agency for Innovation NSW for sexuality research. She is also an author of an in-process online e-learning module on sexuality for the Stroke Foundation and has recently completed a six year term on the research advisory committee.

NB is a Senior Lecturer at City, University of London and has previously published work related to dating and communication interventions.

VA is a clinical speech pathologist and program coordinator for LifeWorks Sexuality Service.

### **Collaborators:**

Dr. Nicholas Behn, City University of London; Vanessa Arattia, Royal Rehab; Associate Professor, Emma Power, University of Technology Sydney

### **Overall methods and design/rigor**

Due to the unknown nature of the field identified in the introduction, a scoping review was conducted to assess the potential size and scope of available research literature, and identify any gaps in the current research and highlight areas that require further research and inquiry.

The review will be guided by relevant frameworks (Arksey & O'Malley, 2005) and reporting guidelines (Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR; Page et al., 2021).

**Review question:**

How is the impact of acquired communication disorders on intimacy, sexuality, and sexual health addressed in the literature?

**Literature review:**

For many people, sexuality is an important part of individual well-being, self-concept, and romantic relationships. Communication is a crucial part of sexuality. Communication ability has been linked to individuals' ability to participate in consent-related discussions (Giampieri, 2011; Willis et al., 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).

Given the link between communication and sexuality, it makes sense that people with acquired communication impairments would experience changes to their sexual wellbeing. Early studies have borne out this conclusion. Stead and White (2019) noted a loss of physical and emotional intimacy with an acquired communication disorder called aphasia. 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. (2014) studied people with aphasia and their spouses. They noted that 100% of people with aphasia and 83% of spouses in their small study felt that aphasia affected their sex lives, outside of other stroke-related factors.

In addition, these communication impairments can be seen as a barrier for clinicians to discuss sexuality (McGrath et al., 2019a; 2019b; 2021). This barrier to care for people with acquired communication impairments is coupled with the overarching reluctance of clinicians to discuss the topic (Dyer & Das Nair, 2013; Haboubi & Lincoln, 2002; Haesler et al., 2016; Zhang et al., 2020) and clinicians' beliefs that the topic of sexuality is not relevant to people with communication or cognitive impairments (Bonder et al., 2021; Lepage et al., 2021; Schmidt et al., 2022). Together, this can create a "silence within the silence" (McGrath, 2019) around what can be a taboo topic.

Therefore, understanding the current literature in sexuality and communication impairments is of particular importance. Acquired communication disorders 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). Therefore, their experience is likely to be under-described and poorly understood within the broader literature. The exact state of the knowledge in this area is presently unclear. To commence a program of research, it would be beneficial to understand the scope of the literature in acquired communication impairments and sexuality, the way the impacts of communication impairments on sexuality are discussed in the broader neurological literature. This scoping review addresses those to aims.

**Sources:**

- CINAHL, PubMed, MEDLINE, PsycINFO, Web of Science, and Scopus. No date limits will be placed on the search.
- Search will be re-run one approximately month prior to final analysis to identify and retrieve any further studies.
- Given the exploratory nature of the scoping review, unpublished studies will be retrieved for analysis. Hand searches will also be completed for resources identified from reference lists.

**Search Strategy:**

A search will be conducted to identify available literature that addresses the impact of communication impairments on sexuality and intimacy. The search will include acquired communication disorders and disorders that often cause acquired communication disorders. This will use the following search 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 “laryngectom\*” OR “cognitive impairment” OR “TBI” OR “ABI” OR “brain injury” OR “head injury” OR “post-concussi\*” OR “executive dysfunction” OR “dysexecutive syndrom\*”

AND

Sexual health terms: “sex\*” OR “intimacy” OR “marriage” OR “relationships” OR “dating” OR “spouse” OR “romance” OR “romantic” OR “courtship” OR “courting” NOT “violent” NOT “violence”

To increase the likelihood of incorporating all possible studies, a search using Medical Subject Headings (MeSH) will also be completed. The MeSH headings, “communication disorders”, “brain diseases”, “head and neck neoplasms”, “respiratory tract diseases”, and “neurodegenerative diseases” will be combined with the MeSH headings “sexual behavior” and “interpersonal relations”.

**Domain being studied:**

Acquired communication disorders

**Participants/population:**

Inclusion: Adults (18 years or over) with acquired communication disorders, adults with disorders that often cause acquired communication disorders (see above)

Exclusion: Children and adolescents, adults with developmental communication disorders (e.g., ...), adults without communication disorders or conditions that cause acquired communication disorders

**Sexual health concepts:**

Inclusion: This study uses the World Health Organization definition of “sexual health” and includes studies that address access to sex education, sexual and reproductive healthcare, sexual expression, relationships, and pleasure. Studies addressing any of these concepts as related to the target populations will be included.

Exclusion: Studies where the search term “sex\*” relates only to biological sex, rather than sexual health, will be excluded. Studies related solely to interpartner violence or relationship violence will be excluded. Studies related solely to relationships that are platonic or non-romantic in nature will be excluded.

**Types of studies to be included:**

Studies using experimental, observational, or mixed methods designs will be included. Metanalyses, review articles, and opinion pieces will be excluded from the analysis but reserved for hand searches of the references.

**Data extraction:**

Study Selection

Reviewers will use Covidence to organize their work. Two reviewers will independently screen the titles/abstracts for 20% of studies for inclusion. If Kappa scores are 0.8 or above, one author will continue to review. If Kappa scores are below 0.8, all articles will be reviewed by a second team member, with disagreements resolved through consensus. If consensus is not achieved, a third reviewer will act as moderator. The same process will then be repeated for full-text appraisal.

Data Extraction

An extraction tool will be developed with all authors based on the research questions. The tool will be piloted on several articles and discussed with the team and any revisions to the tool completed at that time. A single reviewer will extract study data, with a second reviewer appraising a representative sample of 20% of the studies to ensure reliability. Disagreements will be discussed to reach consensus, with a third reviewer acting as moderator if consensus is not achieved.

The following data will be extracted:

- Author/s
- Year of publication
- Disorder area
- Specific communication impairment studied (if any)
- Study aims/purpose
- Country
- Number of participants
- Population

- Context of communication (Text referencing communication, talking, or otherwise sending/receiving messages between sexual or relationship partners in the introduction or methods will be extracted verbatim.)
- Specific communication disorder addressed (if any)
- Whether communication impairment was a factor in inclusion/exclusion criteria
- Accommodations made for communication difficulties in the methods (extracted verbatim, if any)
- Explicitly stated impacts of communication disorders on sexuality/intimacy
- Effects of communication on sexuality, intimacy, and/or sexual health (Text referencing communication, talking, or otherwise sending/receiving messages between sexual or relationship partners in the discussion or conclusions will be extracted verbatim.)
- Communication impairments limited study participation (Text referencing participants' communication disorders, communication ability, or the exclusion of people with communication disorders as a limitation will be extracted verbatim.)

Missing details will be coded as “not present”.

### **Strategy for data synthesis**

Studies that focus on the relationship between a specific communication disorder and sexual health will be individually described. We will count and compare them directly.

Quantitative data will be explored with descriptive statistics.

Qualitative data will be analysed using meta-qualitative approach, including latent content analysis, to identify the meaning in the qualitative data (Downe-Wamboldt, 1992; Kondracki et al., 2002).

### **Health area of review**

Rehabilitation

### **Language**

English

### **Countries**

Australia, UK, USA

### **Dissemination plans**

A peer-reviewed journal article will be submitted to a journal in the field of communication sciences and disorders.

### **Keywords**

Communication disorder, aphasia, apraxia, sex, sexual health, intimacy, marriage, dating, stroke, brain injury, neurologic

### **Current review status**

Not yet started

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