

REVIEW

Parental communication dynamics with children who stutter: A scoping review

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Abstract

Background: Parents of children who stutter (CWS) are often uncertain, hesitant and uncomfortable to communicate openly with their CWS and other people on the topic of the stutter and disclosing the stutter to the child and/or other people.

Aims: To map and understand the dynamics involved when parents communicate with their CWS and other people on the topic of their child's stuttering and disclosure of the stutter to the child and/or other people.

Methods: This scoping review was conducted in accordance with Joanna Briggs Institute methodology. The following platforms and search engines were identified and searched: Google Scholar, PubMed, ProQuest Databases and EBSCOhost: Academic Search Premier, Africa-Wide Information, CINAHL (Cumulative Index to Nursing and Allied Health Literature), ERIC (Educational Resources Information Center), Health Source Nursing/Academic Edition and MEDLINE. The search was limited to studies pertaining to parents of CWS, instead of people who stutter. The first two authors screened titles and abstracts of identified records, and thereafter, full-text screening was conducted of the selected articles as well as the reference lists.

Results: The scoping review yielded 14 records that included data from 12 different countries representing five continents. The 14 records comprised one systematic review, four expert opinions, two studies with mixed methods, five with qualitative designs and two with quantitative designs. The review content provided information about the nature, advantages and disadvantages of open communication and disclosure as well as reasons why parents of CWS are reluctant or willing to communicate in an open way.

Conclusions: There is limited information available about parental communication with CWS on the topic of their stuttering and disclosure of the child's stuttering to the child and/or other people. The complexity of communication dynamics between CWS and their parents requires further in-depth research.

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Contribution: This study highlights the lack of empirical evidence about disclosure and the dynamics of open communication between parents and their CWS and the need for research to gain insight into this topic.

KEYWORDS

communication, children who stutter, disclosure, parents of children who stutter

WHAT THIS PAPER ADDS

What is already known on the subject

- Parents of CWS are often uncertain, hesitant and uncomfortable to communicate openly with their CWS and other people on the topic of the stutter and disclosing the stutter to the child and/or other people. Despite the important and indispensable role parents play in the life of their CWS, little information is available regarding the way in which parents communicate about stuttering with their CWS, and how they accomplish the process of stuttering disclosure.

What this study adds

- This scoping review confirms that limited information is available regarding the process of parental communication with CWS and disclosure of the stutter. This study forms a basis for planning further research as it assessed the current state of knowledge on the issue.

What are the clinical implications of this work?

- The results of this study have future potential in helping parents of CWS to understand the processes involved related to parental communication with CWS and disclosure of the stutter. Further research regarding this issue is encouraged.

INTRODUCTION

Parents play an influential role in the management (Bernstein Ratner, 2004) and support of their CWS (Rocha et al., 2020). They often serve as conduits for therapeutic interventions and their role remains central throughout the treatment process (Eggers et al., 2023; Franken et al., 2022; Yaruss et al., 2006). For instance, parents are often advised by clinicians to make changes to the child's communication environment (Eggers et al., 2023) and to adapt their communication style to better support their CWS. This may involve speaking at a slower pace, using simpler language and allowing the child enough time to express themselves (Sawyer et al., 2017; Yaruss & Conture, 1995; Franken et al., 2022). It is therefore important for clinicians to include parents in therapy management (Beilby, 2014; Eggers et al., 2023; Franken et al., 2022) as the positive

outcome of intervention programs may depend on addressing their needs and concerns as well as those of their CWS (Gregg, 2020; Plexico & Burrus, 2012).

Parenting CWS can be a challenging experience (Gregg, 2020; Plexico & Burrus, 2012) as parents must deal with not only the requirements of the intervention processes but also the emotions of their CWS and the way their child experiences stuttering. Stuttering can significantly impact individuals who stutter, affecting various aspects of their lives. It can also extend its effects to the mental well-being of parents of children who stutter (Carey et al., 2023). Parents often feel a mix of emotions, including worry, anxiety and concern about their child's future peer relationships, self-confidence and possible labelling as intellectually less capable (Langevin et al., 2010; Gregg, 2020). They reported feeling uncertain about how to best support their child and frustrated when faced with challenges in their child's

communication. Some parents even blamed themselves for their child's stuttering (Gregg, 2020; Plexico & Burrus, 2012). Furthermore, parents described their difficulty in managing their child's stuttering, for example, waiting for them to finish speaking and the adjustments they had to make to their own speech patterns (Carey et al., 2023; Gregg, 2020). They are also confronted by challenges they face in managing their child's frustration about stuttering (Erickson and Block, 2013). Many parents experience discomfort about stuttering and prefer to cope with their child's speech by avoiding the topic of stuttering altogether or only indirectly addressing it (Berquez & Kelman, 2018).

Parents of school-age CWS and adolescents are faced with additional challenges associated with their child's school performance and social relationships outside the home environment. They experience a variety of emotions related to their child's speech, such as helplessness, anxiety, worry, fear, distress, sadness, shame, guilt and embarrassment (Langevin et al., 2010; Plexico & Burrus, 2012); and fears regarding the child's future, school performance, peer relationships and the potential for teasing or bullying due to the stutter (Gregg, 2020; Rocha et al., 2020).

The focus on parents of CWS is not a new direction and was already addressed in 1902 in a book written by Beasley (Botterill, 2011). However, substantial research on this subject did not emerge until much later in the 20th century. Research that focussed on parents of CWS increased after 1942 when Johnson proposed his 'diagnosogenic' theory of stuttering (Nippold & Rudzinski, 1995), which theorised stuttering to be caused by parents' abnormal reactions to and inaccurate labelling of normal disfluencies (Bloodstein & Bernstein Ratner, 2008). Currently, no clinical evidence exists to explain stuttering according to the principles of the diagnosogenic theory and this theory has largely been discredited by clinicians and researchers (Gregg, 2020; Franken et al., 2022).

From the early 1900s until the 1970s, parents were often advised by professionals to ignore their child's stuttering. Claims were also made (usually without strong evidence) that parents were reluctant to be too directly involved in managing the speech of their CWS (Franken et al., 2022; Botterill, 2011). Parents commonly expressed fear that by drawing attention to the child's speech, they might worsen the disfluencies. In this regard, Sheehan referred to 'the conspiracy of silence' around stuttering (Sheehan, 1970). Since the early 1980s, direct parental involvement in the management of CWS was recommended by professionals, and parents were even advised to discuss stuttering with their CWS (Franken, 2004). The Palin-Parent-Child Interaction Therapy Program (Botterill & Kelman, 2010; Kelman & Nicholas, 2020) was one of the first programs to support direct parental involvement. During the 1990s, programs such as the Lidcombe program

(Onslow et al., 1997, 2020) and the Demands and Capacities Model incorporated direct parent-child involvement in therapy (Starkweather, 2002; Starkweather & Gottwald, 1990). The role of parents has clearly changed over the last decade from being 'silent observers' to having more direct involvement with the CWS.

Despite the important role parents play in the life of their CWS, little information is available regarding the way in which parents communicate about stuttering with their CWS, how they manage the process of stuttering disclosure and their own views on these issues. Rustin and Cook noted already in 1995 that a lack of communication about stuttering often exists between parents and CWS, and that these children may be able to manage their stuttering more effectively when they experience supportive relationships and conversations with their parents. An environment of open communication between parents regarding their child's stutter not only fosters understanding and support within the family unit but also encourages the child to feel comfortable and empowered to openly discuss their experiences of their stuttering. By acknowledging stuttering as a topic of conversation, parents may help CWS to deal with feelings such as shame, guilt and anger related to the phenomenon of stuttering (Daniels & Gabel, 2004) and help to alleviate the sense of secrecy and shame that often accompanies stuttering for the child experiencing it (Berquez & Kelman, 2018).

Disclosure forms part of communication and specifically refers to the process when someone shares personal information which they initially kept hidden or concealed (Boyle & Gabel, 2020). Some individuals who stutter try to hide their stuttering (Corcoran & Stewart, 1998), avoid talking openly about the stutter (Berquez & Kelman, 2018) or hardly ever discuss it (Blood et al., 2003). Boyle and Gabel (2020) found that there may be certain advantages when individuals who stutter self-discloses the stutter such as an increased self-esteem, empowerment, happiness and family support as well as reduced stigma, stress, anxiety and depression. However, disadvantages of stuttering disclosure such as public discrimination, isolation (Corrigan & Rao, 2012), social devaluation, stigma, risk for victimisation and increased levels of depression (Kosciw et al., 2015) have been noted. Research about disclosure included the perspective of the listener (e.g., Boyle et al., 2017; Byrd et al., 2017; Healey et al., 2007; Lee & Manning, 2010) or the self-perspective of the person who stutters (e.g., Boyle et al., 2018; Byrd et al., 2017). The available research about disclosure has mainly focused on adults who stutter and less is known about the development of openness and disclosure in children and the role that parents play in these processes.

Information in the literature about communication between parents and CWS tends to focus primarily on the management of stuttering (e.g., Eggers et al., 2023;

Franken et al., 2022; Sawyer et al., 2017; Yaruss et al., 2006). The apparent lack of research focussing specifically on how parents and their CWS talk about stuttering and disclosure, and how parents experience these conversations, prompted the authors to investigate the scientific literature for more information about these topics.

A preliminary search of MEDLINE, the Cochrane Database of Systematic Reviews and Joanna Briggs Institute Evidence Synthesis found no current or in-progress review study focussing on communication between CWS and their parents about stuttering and disclosure of the stutter to other people. To the authors' knowledge, there is limited information available on these topics and this review aims to gain more insight into these processes by examining the available research literature.

A scoping review approach is ideal for this study as the objectives are to identify and explore research evidence (Pollock et al., 2021) and to clarify key concepts in the literature related to a topic. This research will point out gaps in the existing literature and provide recommendations for future research accordingly.

This study was guided by the following review questions:

- (i) What is known in existing literature about the nature of communication between parents and their CWS on the topic of stuttering?
- (ii) What is known in existing literature about parental disclosure of a child's stuttering to the child and other people?

METHODS

The scoping review was conducted in accordance with the Joanna Briggs Institute methodology for scoping reviews (Peters et al., 2020, 2024) and in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) (Peters et al., 2020) and summarised in Appendix C. This review was conducted in accordance with a priori-protocol, which was registered as a public project with the Open Science Framework database (<https://osf.io/sv25e>) (Hartman et al., 2022).

Inclusion criteria

Participants

This review considered studies or reports that focused on parents of CWS. Data which focused on the person who stutters, or other people involved in the child's interven-

tion procedures or activities, for example, therapists or teachers, were excluded.

Concept

We considered national and international empirical studies and peer-reviewed articles, as well as theses that explored parental communication with the CWS on the topic of their stuttering and/or disclosure of the child's stuttering to the child and/or other people.

Context

No context was specified.

Types of sources

This scoping review included peer-reviewed articles and theses that met the inclusion criteria.

Search strategy

An initial limited search of Web of Science, PubMed, Scopus, and EBSCOhost: Academic Search Premier, Africa-Wide Information, CINAHL (Cumulative Index to Nursing and Allied Health Literature), ERIC (Educational Resources Information Center), Health Source Nursing/Academic Edition and MEDLINE was undertaken to identify articles on the topic. The text words contained in the titles and abstracts of relevant articles, and the index terms used to describe the articles were used to develop a full search strategy.

A second search was undertaken on 22 September 2022 and a final search on 20 May 2024. The full search strategy is provided in Appendixes A and B. The following platforms and search engines were used: PubMed, Scopus, Web of Science and EBSCOhost: Academic Search Premier, Africa-Wide Information, CINAHL (Cumulative Index to Nursing and Allied Health Literature), ERIC (Educational Resources Information Center), Health Source Nursing/Academic Edition were undertaken to identify articles on the identified topic. The text words contained in the titles and abstracts of the relevant articles, and the index terms used to describe the articles were used to develop a full search strategy. The reference list of all included sources of evidence were screened for additional studies. Following the search, all identified citations were collated and duplicates were removed. Titles and abstracts were screened by the first two authors for assessment

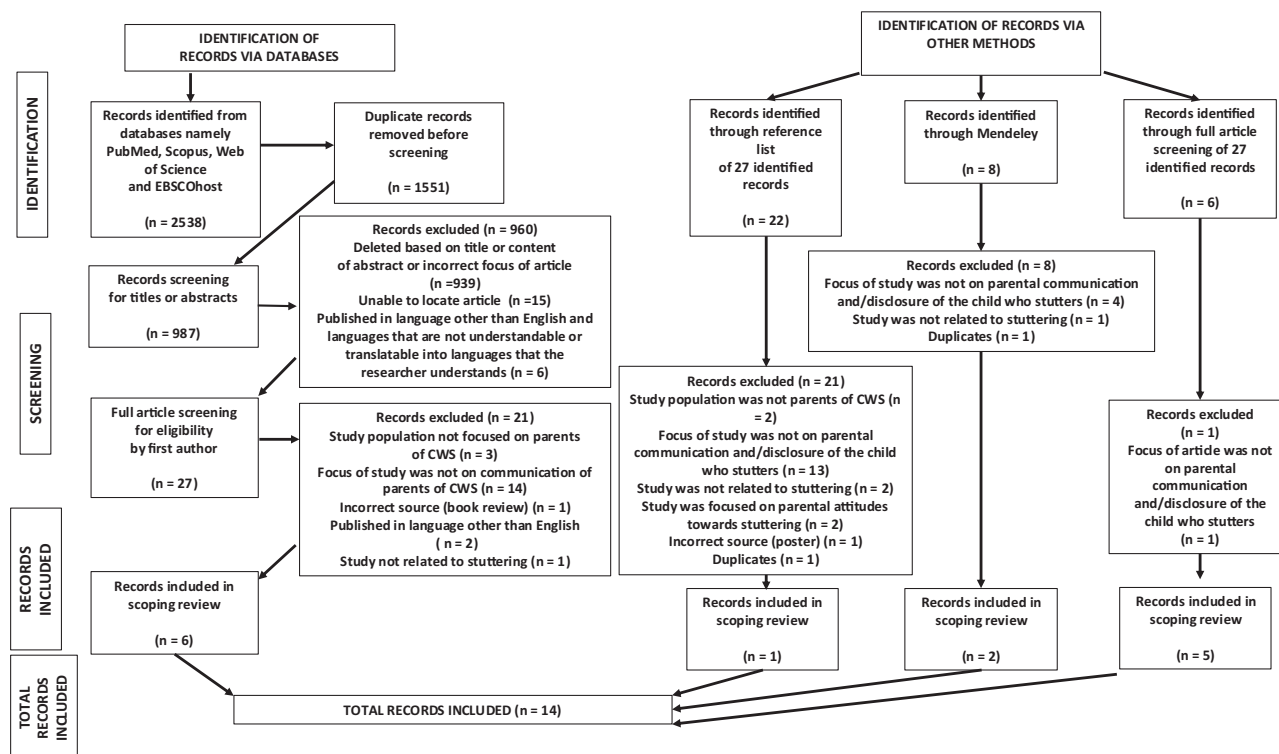


FIGURE 1 PRISMA flow diagram of study selection and inclusion process (Adapted from Peters et al., 2020). Abbreviations: CWS, children who stutter; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses.

against the inclusion criteria of this review. Potentially relevant sources were retrieved in full and assessed in detail against the inclusion criteria. Reasons for exclusion of sources of evidence that did not meet the inclusion criteria were reported in the scoping review. Disagreements that arose between the reviewers were resolved through discussion. The results of the search and the study inclusion process are presented in a PRISMA flow diagram (Peters et al., 2020) in Figure 1.

Source of evidence selection

After conducting the search, all identified records were collated and uploaded into Mendeley Version 2.116.1 and duplicates were removed. Following a pilot test, titles and abstracts were screened by the first two authors for assessment against the inclusion criteria for review. Potentially relevant records were retrieved in full. Full-text studies that did not meet the inclusion criteria were excluded. Any disagreements that arose between the reviewers were resolved through discussion.

Data extraction

Data were extracted from identified records included in the scoping review by the first two authors using a data

extraction tool developed by them. The two reviewers used a colour-coding system to select or reject identified records. The data extracted included specific details about parental communication with a CWS and/or disclosure of the stutter to the child or other people relevant to the review question. Any disagreements that arose between the reviewers were resolved through discussion.

Review findings

Study inclusion

A total number of 2145 studies were identified from various databases: PubMed, Scopus, Web of Science and EBSCOhost. After duplicates were removed 987 records were screened for titles and/or abstracts, of which 960 records were excluded, with the remaining 27 records being retrieved. The first author performed a full text and reference list screening of the 27 records. Twenty-one records were removed, and six records were included. Twenty-two records were identified through the reference list screening, with 21 records removed and one included. Another nine records were identified by the first author through Mendeley of which six were excluded and three included. Hereafter, the second author performed a full text and reference list screening of the initial 27 records. An additional five records were identified of which one

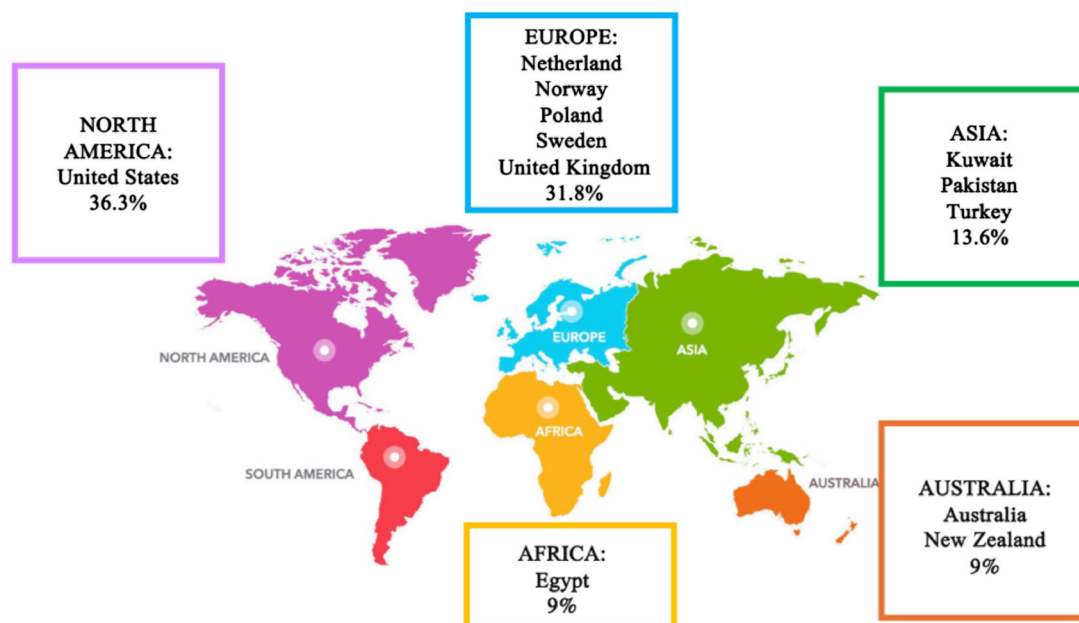


FIGURE 2 Countries and continents.

was excluded and four included. A total of 14 records were considered to meet the inclusion criteria for this scoping review (see Figure 1).

Data presentation

Data are summarised in Table 1. This includes details about the author/s, year of publication and country where the study took place or where the article was authored, main objective of the study or paper, information about the methodological design, study population, and data collection instruments used. Table 2 provides an overview of the information pertaining to the scoping review questions and objectives. This synopsis summarises the key elements of the research findings.

Characteristics of included data

Data included in this scoping review date from 1999 to 2024. During the last 3 years, 42% of the included data were published, and 64% during the last 10 years. There was a total of 1035 participants in the included studies which represented 223 parents of CWS, 171 people who stutter and 641 college students. The data included in this scoping review ranged across 12 different countries representing five continents (see Figure 2). In North America, 36.6% of the included records have been reported, 31.8% in Europe followed by 13.6% from Asia and 9% from Australia and Africa, in other words, the information varies between the

most developed continents (Europe and North America) to the most underdeveloped continent (Africa). Sixty-four percent of the records focussed on communication, 21.4% on disclosure, 7.1% on parental perception of stuttering and 7.1% on both disclosure and communication. The 14 records comprised one systematic review, four expert opinions, two studies with mixed-method, five with qualitative designs and two with quantitative designs.

Content of included data

A summary of the included data related to the research questions is presented in Table 2. Firstly, advice given by speech-language therapists to parents of CWS changed significantly over time, from paying no attention to the stutter to direct and open communication between parents and their CWS (Franken, 2004). Reasons were outlined as to why certain parents reported being hesitant, uncertain and uncomfortable to discuss stuttering openly with their CWS. These reasons included apprehensions that open communication could negatively affect the child and aggravate the stutter (Guttormsen et al., 2021) as well as concerns that the CWS might feel uncomfortable or embarrassed (Logan & Yaruss, 1999; Plexico & Burrus, 2012). Some parents reported that they were unsure how they should approach the topic of stuttering in an open way as they did not want to upset the CWS (Guttormsen et al., 2021). Methods for desensitising parents of CWS have been suggested to enhance open communication (Berquez & Kelman, 2018). Some parents believed that they could

TABLE 1 Characteristics of included data sources.

Author/s Year Title	Country of origin	Main objective	Methodological design	Participants, sample size and data collection instruments
Berquez and Kelman (2018) Methods in stuttering therapy for desensitising parents of CWS	Great Britain	To describe methods used in stuttering therapy to desensitise parents of CWS	Expert opinion	N/A
Boyle et al. (2016) Considering disability culture for culturally competent interactions with individuals who stutter	United States	To discuss issues pertaining to disability culture for individuals who stutter	Expert opinion	N/A
Franken (2004) Fifty years of treating stuttering in young children	The Netherlands	To discuss changes in the treatment of young CWS over the last 5 decades	Expert opinion	N/A
Guttormsen et al. (2021) Parents' perceptions of the overall impact of stuttering on young children	Norway	To investigate parental perceptions of the impact of stuttering on CWS	Mixed method	Parents of young CWS ($n = 38$) OASES for Caregivers (Parents and Kinder-garden Teachers; OASES-C)
Hughes (2011) The perceptions of adolescents who stutter regarding communication with their parents	United States	To investigate the perceptions of adolescents who stutter about communication with parents and other significant people about their stuttering	Mixed method	Adolescents who stutter ($n = 10$) A semi-structured interview, the Communication about Stuttering Inventory (CASI) and the Parent-Adolescent Communication Scale (PACS)
Hughes et al. (2011) Family experiences of people who stutter	United States	To investigate the family experiences of adults who stutter regarding family interactions	Qualitative	Adults who stutter ($n = 7$) Semi structured interviews
Logan and Yaruss (1999) Helping parents address attitudinal and emotional factors with young CWS	United States	To discuss an approach for helping CWS to develop accurate and constructive attitudes related to their speech and stuttering	Expert opinion	N/A
Nonis et al. (2021) Parental perceptions of stuttering: A systematic review of the literature	Australia Egypt Kuwait New Zealand Poland Sweden Turkey United Kingdom United States	To explore studies related to parental perceptions about stuttering and stuttering therapy	Systematic review	N/A

(Continues)

TABLE 1 (Continued)

Author/s Year Title	Country of origin	Main objective	Methodological design	Participants, sample size and data collection instruments
Plexico and Burrus (2012) Coping with a CWS: A phenomenological analysis	United States	To investigate how families cope with having a CWS	Qualitative	Parents of CWS ($n = 12$) Self-compiled interview guide
Safwat and Sheikhy (2014) Parental attitudes and knowledge of stuttering	Egypt	To investigate the attitudes and knowledge of parents regarding stuttering of their CWS	Qualitative	Parents of CWS ($n = 100$) Custom based questionnaire based on Parental Attitudes Toward Stuttering Inventory and Alabama Stuttering Knowledge test (Crowe & Cooper, 1977)
Shakeel et al. (2021) Parental attitudes and knowledge about their child's stuttering: In Pakistan	Pakistan	To investigate parental attitudes and knowledge about their CWS	Quantitative	Parents of CWS ($n = 73$) Questionnaire of Parental Attitude and Knowledge of Stuttering (Safwat & Sheikhy, 2014)
Snyder et al. (2020) The effects of different sources of stuttering disclosure on the perceptions of CWS	United States	To investigate the effects of different ways of stuttering disclosure on CWS	Qualitative	College-aged adults ($n = 217$) A survey using a 7-point Likert scale
Snyder et al., 2021 The effects of written stuttering disclosure on the perceptions of a CWS	United States	To investigate the effects of written stuttering disclosure by mothers or teachers of CWS	Qualitative	College-age adults ($n = 424$) Survey using the 7-point Likert scale
Węsierska et al. (2023) The experience of Polish individuals who stutter based on the OASES outcomes	Poland	To investigate the experiences of Polish individuals who stutter	Quantitative	People who stutter ($n = 154$) comprising school-age children ($n = 55$), teenagers ($n = 41$), and adults ($n = 58$) OASES-Polish (OASES-PL)

Abbreviations: CWS, children who stutter; OASES, Overall Assessment of the Speaker's Experience of Stuttering.

engage in open discussions only if they knew there was something they could do about the stutter (Plexico & Burrus, 2012). Some CWS expressed the need to openly discuss their feelings, including their experiences of isolation, embarrassment, guilt and frustration related to their stutter and although they expressed a desire to discuss their stutter with their families and siblings, they reported that they have little open communication with them (Hughes et al., 2011). Furthermore, certain children expressed that they could benefit from having open communication with their parents and some of them shared general information about their stutter with other family members who also stutter (Hughes et al., 2011).

Facilitating open communication between parents and their CWS offers numerous advantages. Firstly, it enables CWS to freely express their feelings and discuss their stuttering (Hughes et al., 2011). This openness can lead to a sense of relief for the CWS and provide parents with valuable insights into their child's experience of stuttering (Guttormsen et al., 2021). Moreover, fostering open dialogue might reduce the likelihood that the person who stutters might develop speech-related shame and embarrassment (Logan & Yaruss, 1999). Conversely, a lack of open communication may lead CWS to perceive their stuttering as taboo or wrong (Berquez & Kelman, 2018) and potentially create feelings of embarrassment and shame.

TABLE 2 Content of included data.

Author/s Year of publication Title of publication	Information pertaining to the scoping review questions and objectives
Berquez and Kelman (2018) Methods in stuttering therapy for desensitising parents of CWS	<ul style="list-style-type: none"> • Desensitisation encourages openness for both CWS and their parents. • Some CWS sometimes feel frustrated about how their parents talk to others about their stutter (Lau et al., 2012). • CWS might experience the stutter as wrong and a taboo topic if it is not handled in an open way. • Open discussions will open the way for CWS to talk about their feelings and stuttering. • When parents handle their child's stuttering in an open way, they set an example for their child to do the same. • By acknowledging the stuttering, CWS might be relieved especially when parents use neutral language and do it in an open and natural way.
Boyle et al. (2016) Considering disability culture for culturally competent interactions with individuals who stutter	<p>PWS might experience the following as inappropriate:</p> <ul style="list-style-type: none"> • Minimising their stuttering • Unasked observations or advice, for example by parents • When focusing on fluent speech rather instead of the content of the conversation <p>People who interact with persons with a disability:</p> <ul style="list-style-type: none"> • might experience discomfort as they don't always know how to respond such a person • might avoid talking to that person in an attempt not to upset the person • should try to find out how to interact appropriately with such people <p>When communicating with people who stutter:</p> <ul style="list-style-type: none"> • Avoid assumptions • Make eye contact • Use person-first language such as person who stutters instead of stutterer • Demonstrate patience • Give the PWS time to speak • Focus on the content of what the PWS says
Franken (2004) Fifty years of treating stuttering in young children	<ul style="list-style-type: none"> • The way stuttering was treated changed a lot over the past 50 years. • At the early stages of the 20th century parents were advised to ignore their child's stutter. • Since 1985, parents have been encouraged to communicate with their CWS about their speech, but in a sympathetic and accepting way.
Guttormsen et al. (2021) Parents' perceptions of the overall impact of stuttering on young children	<ul style="list-style-type: none"> • Parents experience that CWS are affected by other people's reaction towards their stutter. • Engaging in discussions about stuttering with CWS will enable parents to gain valuable insight into their child's experience of the stutter and it will also help them to understand the full impact of the stuttering on their child. • Parents are sometimes uncertain about talking to their child about the stuttering as they do not know how to communicate on the topic of stuttering. Additionally, they may experience that discussing stuttering could potentially have a negative impact on their child.
Hughes (2011) The perceptions of adolescents who stutter regarding communication with their parents	<ul style="list-style-type: none"> • Participants communicated more to their mothers compared to their fathers. • Participants indicated that stuttering was a topic of discussion with parents at home. • Conversations focused on the nature of speech, fluency skills and speech therapy activities. • Stuttering was rarely discussed with friends and siblings. • General information about stuttering experiences was talked about with other family members who stutter.

(Continues)



TABLE 2 (Continued)

Author/s Year of publication Title of publication	Information pertaining to the scoping review questions and objectives
Hughes et al. (2011) Family experiences of people who stutter	<ul style="list-style-type: none"> Some participants reported the need to openly discuss their feelings (isolation, embarrassment, guilt, frustration etc.) related to their stutter; to feel comfortable to talk about the stutter and to openly discuss the stuttering with their families and siblings.
Logan and Yaruss (1999) Helping parents address attitudinal and emotional factors with young CWS	<ul style="list-style-type: none"> Parents are regarded as most frequent and important listeners and conversational partners and models for their CWS As stuttering is not discussed in families, CWS think they should be embarrassed and ashamed of their speech and therefore hide it. Parents should communicate in a direct, supportive, relaxed, and objective way, which won't aggravate the CWS. Parents avoid open communication because they think it might aggravate the stuttering. Parents sometimes get advice to avoid talking about stuttering or draw attention to stuttering. However, by talking openly about stuttering, it might reduce the likelihood that the PWS might develop speech-related shame and embarrassment. If the CWS ask questions about their stuttering, parents should answer in a simple and straightforward manner, using age-appropriate terminology. When parents talk about stuttering, they should use concrete terminology which the child understands. One way of prompting discussions is when parents invite the child to talk about their stuttering by asking simple questions followed by follow-up questions.
Nonis et al. (2021) Parental perceptions of stuttering: A systematic review of the literature	<ul style="list-style-type: none"> Parents of CWS are just as important as the speech therapist in managing their child's stutter and their reactions would impact on the CWS well-being. Although parental perceptions about stuttering were generally positive, limited parental knowledge exist about stuttering.
Plexico and Burrus (2012) Coping with a CWS: A phenomenological analysis	<ul style="list-style-type: none"> Some participants experienced that at some time stuttering was not allowed to be discussed as parents were afraid the child might feel uncomfortable or embarrassed. Parents believed they can only discuss the stutter if they can do something about the stutter. Participants were more comfortable when alternative words were used instead of the word stuttering.
Safwat and Sheikhany (2014) Parental attitudes and knowledge of stuttering	<ul style="list-style-type: none"> Some parents were not willing to inform the teachers about their child's stuttering. Parents had limited knowledge about stuttering. Some parents showed negative beliefs and attitudes towards stuttering and PWS.
Shakeel et al. (2021) Parental attitudes and knowledge about their child's stuttering: in Pakistan	<ul style="list-style-type: none"> Almost 50% of parents experienced shame while talking about their child's stuttering.
Snyder et al. (2021) The effects of different sources of stuttering disclosure on the perceptions of a CWS	<ul style="list-style-type: none"> Professionals (for example the teacher, not necessarily the parent) can disclosure the stutter effectively.
Snyder et al. (2021) The effects of written stuttering disclosure on the perceptions of a CWS	<ul style="list-style-type: none"> CWS can benefit from stuttering disclosure when orally disclosed by themselves or selected child advocates. Disclosure by selected advocates such as the teacher may be useful. It is suggested that written and oral disclosure by the mother or teacher could be used in the intervention process.

(Continues)

TABLE 2 (Continued)

Author/s Year of publication Title of publication	Information pertaining to the scoping review questions and objectives
Węsierska et al. (2023) The experience of Polish individuals who stutter based on the OASES outcomes	<ul style="list-style-type: none"> • Some items on the OASES-PL items may be linked to a reluctance to disclose stuttering and the tendency to avoid speaking which results into hiding the stuttering (Gerlach-Houck & Rodgers, 2022). • Results demonstrated a lack of knowledge about stuttering and a limited ability and difficulty to communicate in a home environment with family members. • There is a strong belief in Poland that stuttering should not be openly discussed with CWS. • Stuttering is still treated as a taboo topic in home environments and clinical settings. • No talking about feelings or emotions occurs during therapy with school-age children. • CWS do not understand their experience regarding stuttering and do not even know how to describe this experience.

Abbreviations: CWS, children who stutter; OASES-PL, Overall Assessment of the Speaker's Experience of Stuttering-Polish; PWS, people who stutter.

Such perceptions may force individuals to conceal their stutter (Logan & Yaruss, 1999).

Individuals who stutter have identified several preferences for effective communication about their stuttering. These include the use of neutral language (Berquez & Kelman, 2018); communicating in a simple and straightforward manner (Logan & Yaruss, 1999); speaking patiently, naturally, sympathetically (Franken, 2004), directly, supportively and objectively while maintaining an accepting and relaxed communication style (Logan & Yaruss, 1999); avoiding assumptions, using first person language, granting ample time for speech, focussing on the content of the conversation (Boyle et al., 2016); using age-appropriate and concrete terminology; prompting discussions with simple questions (Logan & Yaruss, 1999); and offering alternative terms for the word stuttering (Plexico & Burrus, 2012). Some individuals who stutter also mentioned feeling uncomfortable when their stuttering is minimised, when unsolicited advice is given, and fluency is prioritised over content (Boyle et al., 2016).

When considering the phenomenon of disclosure, it is important to take cultural differences into account. For instance, research by Węsierska et al. (2023) highlights that individuals from Poland may not readily discuss their emotions or feelings in therapy or at home, leading to challenges for CWS in articulating their speech issues.

Additionally, some parents feel ashamed when openly discussing their child's stutter (Shakeel et al., 2021), causing them to refrain from disclosing the stutter to the child's teachers (Safwat & Sheikany, 2014). Studies also indicate that disclosure does not need to rest solely on parents. Snyder et al. (2021) found that individuals other than parents, such as teachers, can effectively undertake disclosure.

Furthermore, both oral and written forms of disclosure have proven to be effective methods for unveiling stuttering. It will, therefore, be important to take cultural and contextual factors into account when developing tailored approaches to disclosing the stutter.

To summarise, open discussions about a child's stutter can be a challenging experience for some parents as not all parents of CWS feel comfortable in doing so. Nevertheless, open communication on the topic of the child's stutter can lead to a positive impact on the child's experience of the stutter. When applying open communication with individuals who stutter, it is important to be sensitive towards their needs to prevent misunderstandings during such discussions. Parents must, therefore, empower themselves to engage in effective open discussions and disclosure of their child's stutter. Considering that cultural attitudes towards stuttering vary across different countries, it is important to continually examine the dynamics of disclosure and communication within the unique context of both the individual who stutters and their parents.

DISCUSSION

Open discussions about a child's stutter do not come naturally for most parents. Parental desensitisation is one technique that could facilitate these discussions, allowing parents to initiate open conversations with their CWS. Acceptance of the child's stutter through open dialogue can have a positive effect on the CWS. Conversely, withholding open communication could negatively impact the child. Given that people who stutter may sometimes experience open communication negatively, it is crucial to



explore this phenomenon in detail to ensure that such communication results in positive outcomes.

Over the past few years, parental involvement with CWS has changed dramatically, and direct involvement is now recommended. Parents must, therefore, improve and empower themselves to communicate effectively with their CWS and disclose the stutter appropriately. Investigating the communication dynamics between parents and their CWS is of utmost importance, as it can lead to a better understanding of the child's experiences.

While some individuals who stutter do communicate with their parents about their stutter, these conversations often do not address the emotional experiences associated with the stutter. Research into this theme is essential to find ways to facilitate deeper, more meaningful conversations. People who stutter have expressed a need for open discussions regarding their stutter and related issues, highlighting the necessity for further research on this topic.

Given the significant role parents play in their children's lives, it is crucial to clarify misunderstandings about open communication and to develop strategies that ensure both parents and CWS feel comfortable engaging in these discussions. Involving parents of CWS in research is critical, as they have a substantial influence on their child's experiences. Better parental insight and knowledge will benefit both the parents and the CWS. Gathering information from parents can help compile suggestions for other parents on how to communicate with their CWS effectively. Empowering parents with knowledge about stuttering will enable them to make informed decisions regarding communication and disclosure of the stutter.

It is also important to focus on parental emotions when researching communication with their CWS and the disclosure of the stutter. More information is needed to understand the rationale behind effective stuttering disclosure. Additionally, exploring the phenomenon of stuttering disclosure in various cultural contexts beyond Poland is essential, as cultural differences may influence what is considered appropriate communication and disclosure principles.

CONCLUSION

This scoping review included 14 records describing components of parental communication with CWS on the topic of their stuttering or disclosure thereof. Most of the included data focused on parent-child communication about stuttering rather than on the act of disclosure. Only a few studies have investigated parents' perspectives as research participants. Given the significant influence parents commonly have on their relationship with their CWS, their

involvement in research concerning parental communication and disclosure is crucial. Both CWS and their parents will benefit from such transparent communication and disclosure of the stutter. These actions should be supported by a clear understanding of parental strategies to overcome barriers to communicate openly and to disclose the stutter. Regarding levels of evidence, it should be noted that only one systematic review was found and that four of the records were expert opinions. There is, therefore, a need for in-depth empirical research to understand the complex phenomenon of open communication and disclosure of the stutter, as this forms an essential part of the parent-child relationship. Qualitative research has the potential to give insight into such parents' everyday realities regarding their CWS and may provide valuable knowledge into the dynamics involved in communication with a CWS on the topic of stuttering and disclosure thereof. The findings of this scoping review proved the necessity for further exploration to understand the rationale behind effective parental communication with a CWS and disclosure of the stutter.

Implications and recommendations

Based on the results of this scoping review, future research should delve into the perspectives of parents regarding communication with their CWS and disclosure of the stuttering. This could shed light on parental experiences, concerns, and decision-making processes related to discussing stuttering with their children and others. By investigating the dynamics involved in communication between parents of CWS and their children could help identify effective communication strategies and interventions to support both the child and their family members. Furthermore, considering cultural and contextual factors is crucial in understanding how communication and disclosure practices vary across different cultural backgrounds and contexts and further research into this aspect is warranted for a deeper understanding of the topic.

Strengths and limitations

The strengths of this review include the fact that the records were not limited by time frame or geographic region. A limitation is that this search included only English literature and records which were published in languages other than English, but understandable or translatable to the first author. This may have caused the omission of relevant research which could have been related to this study and impacted on the findings.

Furthermore, this scoping review exclusively incorporated peer-reviewed articles and grey literature. However, a more comprehensive understanding of the field could be achieved by also incorporating relevant books and chapters into the study.

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CONFLICT OF INTEREST STATEMENT

The authors declare no conflicts of interest.

DATA AVAILABILITY STATEMENT

A review protocol was registered as a public project with the Open Science Framework database (<https://osf.io/sv25e>).

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APPENDIX A

Search strategy conducted on 22 September 2022

PubMed

Search conducted on 22 September 2022. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	"parents"[MeSH Terms] OR "parent*"[Title/Abstract]	533 336
#2	"stuttering"[MeSH Terms] OR "stutter*"[Title/Abstract]	5559
#3	#1 AND #2	389

Scopus

Search conducted on 22 September 2022. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	TITLE-ABS (parent*)	834 626
#2	TITLE-ABS (stutter*)	8117
#3	#1 AND #2	525

Web of Science

Search conducted on 22 September 2022. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	TS = (parent*)	666 870
#2	TS = (stutter*)	6764
#3	#1 AND #2	397

EBSCOhost: Academic Search Premier, Africa-Wide Information, CINAHL (Cumulative Index to Nursing and Allied Health Literature), ERIC (Educational Resources Information Center), Health Source Nursing/Academic Edition and MEDLINE.

Search conducted on 22 September 2022. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	parent*	994 214
#2	stutter*	10 492
#3	#1 AND #2	923

APPENDIX B

Search strategy conducted on 20 May 2024

PubMed

Search conducted on 20 May 2024. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	"parents"[MeSH Terms] OR "parent*"[Title/Abstract]	580 429
#2	"stuttering"[MeSH Terms] OR "stutter*"[Title/Abstract]	5870
#3	#1 AND #2	428
#4	Filters applied: from 22 September 2022 to 31 January 2024	35

Scopus

Search conducted on 20 May 2024. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	TITLE-ABS (parent*)	922 351
#2	TITLE-ABS (stutter*)	8702
#3	#1 AND #2	576
#4	Limit: 2022–2024 (Can only select year, not month)	82

Web of Science

Search conducted on 20 May 2024. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	TS = (parent*)	747 343
#2	TS = (stutter*)	6855
#3	#1 AND #2	444
#4	Limit: 2022–2024 (Can only select year, not month)	60

EBSCOhost: Academic Search Premier, Africa-Wide Information, CINAHL (Cumulative Index to Nursing and



Allied Health Literature), ERIC (Educational Resources Information Center), Health Source Nursing/Academic Edition and MEDLINE.

Search conducted on 20 May 2024. Records were not limited by time frame or geographic region.

Search	Search string	Records retrieved
#1	parent*	1 663 765
#2	stutter*	17 171
#3	#1 AND #2	1459
#4	Limit from 22 September 2022 to January 2024	127

APPENDIX C

Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist.

Section	Item	PRISMA-ScR Checklist Item
TITLE:		
Title	1	Parental communication dynamics with children who stutter: A scoping review
ABSTRACT:		
Structured summary	2	Background, aims, methods, results, conclusion and contribution that relate to the review questions are provided
INTRODUCTION:		
Rationale	3	The rationale for the review in the context of what is already known is described as well as reasons why this review lend itself to a scoping review approach
Objectives	4	The review questions as well as the participants, concepts and context are described

METHODS:

Protocol and registration	5	This review was conducted in accordance with a priori-protocol which was registered as a public project with the Open Science Framework database (https://osf.io/sv25e) (Hartman et al., 2022).	2 and 9
Eligibility criteria	6	The records were not limited by time frame or geographic region. This search included only English literature and records which were published in languages other than English, but understandable or translatable to the first author	20
Information sources	7	The following platforms and search engines were identified and searched namely Google Scholar, PubMed, ProQuest Databases and EBSCOhost: Academic Search Premier, Africa-Wide Information, CINAHL (Cumulative Index to Nursing and Allied Health Literature), ERIC (Educational Resources Information Center), Health Source Nursing/Academic Edition and MEDLINE.	2 and 10
Search	8	See detailed searches for PubMed, Scopus, Web of Science and EBSCOhost	25–29
Selection of sources of evidence	9	See search strategy and PRISMA flow diagram of study selection and inclusion process	Figure 1
Data charting process	10	See data extraction	12
Data items	11	Not applicable	
Critical appraisal of individual sources of evidence	12	Scoping reviews do not aim to produce a critically appraised and synthesised result/answer to a particular question. Scoping reviews, aim to provide an overview or map of the evidence	
Synthesis of results	13	See characteristics of results	13

RESULTS:

Selection of sources of evidence	14	See PRISMA flow diagram	Figure 1
Characteristics of sources of evidence	15	See Tables 1 and 2	Table 1 and 2
Critical appraisal within sources of evidence	16	Scoping reviews do not aim to produce a critically appraised and synthesised result/answer to a particular question. A brief statement about levels of evidence was included	Page 18 Line 19–23
Results of individual sources of evidence	17	See Table 2	Table 2
Synthesis of results	18	See characteristics and content of evidence	13–16

DISCUSSION:

Summary of evidence	19	See summary of characteristics and content of evidence	13–16
Limitations	20	See strengths and limitations	20
Conclusions	21	See conclusion	18–19

FUNDING:

Funding	22	See funding	20
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Adapted from Tricco, A.C., Lillie, E., Zarin, W., O'Brien, K.K., Colquhoun, H., Levac, D., et al. (2018). *PRISMA Extension for Scoping Reviews (PRISMA ScR): Checklist and Explanation*. *Ann Intern Med*. 169:467–473. <https://doi.org/10.7326/M18-0850>.