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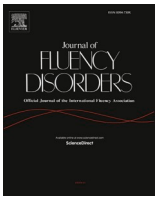

Between therapy and reality: A lived-experience analysis of the priorities, progress and barriers in stuttering management

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ABSTRACT

While numerous therapeutic approaches have been developed to assist people who stutter (PWS) in managing their condition, these interventions have been shaped by researchers' and speech-language pathologists' perspectives, showing limited effectiveness and long-term impact. Moreover, they often overlook PWS' lived realities, including their challenges, priorities, and values. This study explores the lived experiences of adults who stutter, providing insights into their priorities, needs, challenges, and perspectives to inform person-centred therapeutic practices. Nineteen adults who stutter, from diverse countries and cultural backgrounds, and with varying experiences with stuttering management, participated in this study. Using convenience and purposive sampling, in-depth semi-structured interviews were conducted. The collected data were analysed through reflexive thematic analysis. The findings revealed the self-perpetuating cycle of fear and avoidance as the core disabling experience of stuttering, restricting meaningful engagement across emotional, cognitive, social, and professional domains. Participants emphasised that breaking this cycle requires proactive self-acceptance, integrating stuttering modification, desensitisation, and non-verbal communication strategies to foster effective communication. However, sustaining progress was hindered by time limitations, inadequate support, and the misalignment of therapy models with real-world needs—particularly those that overlook the fluency trap. Many participants viewed avoidance, rather than stuttering disfluency, as their main concern, thereby highlighting the need for therapeutic approaches that prioritise psychological resilience over fluency. These findings underscore the need for a person-centred approach in stuttering research and therapy, ensuring tailored interventions that are holistic yet structured, goal-oriented, and coherent, where different therapeutic goals complement rather than contradict each other, aligning with PWS' lived realities.

1. Introduction

Direct involvement of people with lived experience has been recognised as fundamental to person-centred care (World Health Organization, 2007), as it can provide insights that expert-driven approaches can overlook. In stuttering research, this approach is particularly critical, as people who stutter (PWS) often perceive their condition in ways that diverge markedly from clinicians' and researchers' assumptions (Tichenor & Yaruss, 2019). Importantly, the perspectives of PWS have extended our understanding of stuttering beyond observable disfluencies to include psychological and social dimensions (Blomgren, 2013; Yaruss & Quesal, 2004).

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Stuttering affects the emotional well-being and quality of life (QoL) of PWS. Research has linked stuttering to heightened levels of anxiety (Iverach et al., 2011; Lowe et al., 2016), social stigma (Butler, 2013), depression (Briley et al., 2021) and increased risk of personality disorders (Iverach et al., 2009). This broader dynamic underscores the limitations of behaviour-based definitions of stuttering, which centre on the listener's perspective and primarily focus on surface-level speech behaviours. While these definitions are useful for identifying speech patterns, they do not fully capture the holistic experience of stuttering moments (Bloodstein et al., 2021; Tichenor & Yaruss, 2018; Tichenor, Herring et al., 2022; Yaruss & Quesal, 2004).

Given the complex interplay between psychological, social, and behavioural factors in stuttering, various theoretical models have been developed to explain its causes and advance understanding of stuttering (e.g. Garcia-Barrera & Davidow, 2015; Packman et al., 2007; Ratner & Wijnen, 2007; Yaruss & Quesal, 2004), as well as to guide treatment approaches (Bloodstein et al., 2021). However, only a few models (e.g. Plexico et al., 2009; Tichenor & Yaruss, 2019) integrate first-person perspectives, emphasising the subjective experience of stuttering and PWS' coping mechanisms.

Plexico et al. (2009) developed an emotion-based model to examine the coping strategies used before, during, and after stuttering. Their model conceptualises avoidance behaviours as coping mechanisms driven by the fear of negative listener reactions. They argued that avoidance provides temporary relief and helps speakers navigate challenging communicative situations, while minimising listener discomfort.

In contrast, Tichenor and Yaruss (2019) revised Yaruss and Quesal's (2004) framework by incorporating direct input from PWS and refocusing it on the immediate stuttering experience, with loss of control as its core concept. In this updated framework, speech disruption triggers an immediate cascade of emotional, behavioural, and cognitive reactions, including shame, anxiety, stuttering disfluencies, avoidance behaviours, anticipatory fear, and diminished self-esteem, highlighting both the in-the-moment experience of stuttering and its subsequent impact.

However, most models remain limited in incorporating PWS' perspectives and do not sufficiently account for how the condition evolves as a lived experience, leaving PWS' disabling experiences underexplored (Bloodstein et al., 2021; Isaacs & Swartz, 2021). In this study, disabling experiences are understood as those that limit meaningful participation and engagement in everyday life. According to Sisskin (2018), although stuttering begins as a speech motor difficulty, it often develops into a multidimensional struggle in which attempts to suppress or avoid it reinforce long-term communication restrictions. The evolving nature of stuttering has been acknowledged by the American Psychological Association (2016), which revised its diagnostic criteria to include anxiety and avoidance behaviours as integral to the condition. Importantly, as Bloodstein et al. (2021) emphasise, models that account for stuttering's disabling impact play a critical role in guiding effective interventions. Nevertheless, many existing therapies are influenced by models that prioritise the reduction of stuttering disfluencies over addressing PWS' broader lived experiences (Baxter et al., 2016).

Evidence from broader healthcare research further suggests that interventions designed with direct input from affected communities—reflecting their priorities, needs, values, and challenges—enhance patient satisfaction, improve therapeutic outcomes, and positively impact overall quality of life (Birkeland et al., 2022; Miller & Reihlen, 2023). In stuttering research, scholars have similarly called for therapeutic design that is grounded in the lived experiences of PWS (Baxter et al., 2016; Connery et al., 2020), and which includes their disabling experiences, needs, and challenges.

Taken together, these considerations underline the importance of re-examining stuttering interventions and theoretical models that underpin them through the lens of lived experience. In this paper, we first critically review current treatment paradigms and their alignment with lived experiences; we then synthesise findings from prior qualitative studies of PWS' perspectives on therapy; next, we outline our study's aims, methodology, and key results; and finally, we discuss how these collective insights can inform the development of person-centred, community-anchored interventions.

1.1. Therapeutic approaches to stuttering management

Various therapeutic approaches have been developed to assist PWS in managing their condition (Blomgren, 2013; Bloodstein et al., 2021). These approaches can be broadly categorised into (a) therapies targeting fluency and (b) therapies prioritising subjective well-being, such as ease of speaking, over fluency (Constantino, 2018; Sisskin, 2018).

Fluency-shaping approaches are widely used in clinical practice and research studies (National Institute on Deafness and Other Communication Disorders, 2016; Yaruss, 2010). These methods aim to replace stuttered speech with fluent speech (Bloodstein et al., 2021; Boyle, 2018; Brignell et al., 2020). Although these approaches demonstrate effectiveness in controlled settings, they have short-lived benefits and limited real-life applicability (Blomgren, 2013; Blomgren et al., 2005; Boyle, 2018). Some studies suggest that fluency-shaping approaches may reinforce societal biases by prioritising fluency over authenticity and acceptance of neurodiversity, which could negatively influence PWS' self-perceptions (Constantino, 2018; Sisskin, 2018; Tichenor, Constantino et al., 2022).

By contrast, therapies prioritising well-being focus on strategies that enable individuals to stutter with greater ease and reduce sensitivity to their condition. Stuttering modification, first developed by Charles Van Riper, represents one such approach, shifting the goal from achieving fluency to making stuttering more manageable (Blomgren, 2013; Boyle, 2018; De Nardo et al., 2023; Van Riper, 1973). Techniques such as cancellations, pull-outs, preparatory sets, and voluntary stuttering are used to desensitise individuals to their stuttering moments and enhance their self-efficacy (Blomgren, 2013; Boyle, 2018; Van Riper, 1973). However, research on stuttering modification's effectiveness remains limited (Blomgren et al., 2005).

Structured cognitive therapies such as acceptance and commitment therapy (ACT) and cognitive behavioural therapy (CBT) have also been integrated into stuttering interventions. Evidence suggests that CBT is effective in reducing social anxiety symptoms in PWS diagnosed with social anxiety disorder (Helgadóttir et al., 2014; Menzies et al., 2008; Menzies et al., 2009). Meanwhile, ACT has been associated with improvements in fluency, speech-related attitudes, and overall QoL (Beilby et al., 2012; Hart et al., 2021, 2024;

Sønsterud, Halvorsen et al., 2020).

Although extensive research has analysed stuttering therapies, there is no consensus on the most effective method (Bloodstein et al., 2021; Baxter et al., 2016). Many treatment approaches are shaped by researchers' and speech-language pathologists' (SLPs) perspectives, with limited input from PWS (Blomgren et al., 2005). These therapies often yield positive outcomes (Baxter et al., 2016; Bloodstein et al., 2021), but those outcomes are frequently misaligned with how PWS perceive their progress and therapeutic experiences (Baxter et al., 2016; Bloodstein et al., 2021).

This misalignment extends to therapy assessment measures. As highlighted by Baxter et al. (2016), most research continues to rely on overt stuttering behaviours as the primary evaluation measures, despite evidence that PWS prioritise broader therapy outcomes, such as communicative confidence, resilience, and self-acceptance (Carter et al., 2019; Plexico et al., 2005; Sønsterud, Feragund, et al., 2020). Furthermore, PWS frequently report that therapy often overlooks their emotional and psychological needs, with limited consideration for how learned techniques apply to real-life situations (Baxter et al., 2016; Sønsterud, Feragund, et al., 2020).

Despite advancements in stuttering therapy, high relapse rates (64–70 %) remain a concern (Craig, 1998; Tichenor & Yaruss, 2020). Importantly, relapse, as described by PWS, is not solely a return of overt stuttering behaviours but also a re-emergence of fear, avoidance, and diminished communicative confidence (Tichenor & Yaruss, 2020). These high relapse rates suggest that existing approaches may not fully support sustained improvement, particularly when barriers to long-term therapeutic outcomes are not addressed. Therefore, further research is needed to address these limitations by integrating the perspectives of PWS into therapy design, aligning outcome measures with their values, and examining the factors that underpin sustained therapeutic gains over time. The following section reviews prior studies on PWS' lived experiences, focusing on their perspectives on stuttering therapies and the factors that influence their therapeutic experiences.

1.2. The lived experience of stuttering

Recent research has increasingly prioritised understanding stuttering from PWS' perspective, acknowledging the value of their lived experiences. These studies can be broadly categorised into two key areas: (a) studies that document stuttering's emotional, social, and cognitive impacts, and (b) investigations of PWS' experiences with therapy and managing stuttering. While the former provides essential context for understanding stuttering, it often stops short of offering practical insights into how therapy can be designed or refined to enhance long-term effectiveness, prevent relapse, or support skill generalisation. From a person-centred perspective, it is the latter, PWS' direct experiences of therapy, which provides more actionable guidance for developing interventions aligned with their needs, values, priorities, and challenges in managing stuttering (McCormack et al., 2017). Hayhow et al. (2002) examined PWS' views regarding the impact of stuttering on their lives, experiences with speech therapy, and expectations for future therapy. Their findings highlighted the adverse effects of stuttering on educational and occupational choices, as well as PWS' dissatisfaction when therapy fails to address individual needs. Similarly, Yaruss et al. (2002) collected responses from PWS and family member of PWS and found that participants valued therapy goals that addressed both fluency and attitudes towards communication. However, the study did not distinguish between these two respondent groups when reporting treatment preferences. Consequently, their findings may not fully represent PWS' perspectives, as family members, while having good intentions, often hold expectations and misconceptions about stuttering that may lead them to prioritise fluency (Hughes et al., 2011).

Plexico et al. (2005) analysed the factors contributing to the successful (or unsuccessful) management of stuttering from PWS' perspective. Their findings highlighted cognitive and behavioural changes, self-acceptance, fear reduction, and motivation and sustained effort as key components of successful management. However, the study noted that participants had difficulty identifying specific therapeutic techniques or approaches that supported their success. This lack of detail suggests that either the original interviews did not sufficiently probe for concrete strategies, or that PWS find it challenging to articulate how they navigate day-to-day practice. In either case, it leaves a critical gap: without eliciting details about which strategies contribute to successful long-term management, it remains difficult to provide practical guidance for therapy and self-management. Future studies should aim to elicit these details to better inform actionable guidance for sustained stuttering management. Further variations in therapy goals were highlighted by Venkatagiri (2009), who found that preferences for fluency or freedom from stuttering varied among participants. Specifically, 34 % consistently prioritised fluency, 23 % consistently preferred the ability to speak freely without concern for fluency, and 57 % displayed ambivalence. Venkatagiri (2009) noted that these preferences varied slightly according to demographic and therapy-related factors, with younger individuals and those with no prior therapy history leaning towards fluency. They also suggested that older PWS might prefer freedom over fluency because of their failure to completely overcome stuttering over many years. However, these interpretations risk reinforcing societal judgments against stuttered speech as they frame the preference for freedom as a consequence of failed fluency rather than as a valid and autonomous choice, underscoring the need to critically examine the underlying motivations behind these preferences rather than relying on subjective interpretations.

Carter et al. (2019) explored how the self-efficacy beliefs and lived experiences of adults who stutter shape their communicative confidence. Some participants reported that heightened confidence improved their fluency, whereas others felt more confident when they perceived their speech to be more fluent. Consequently, Carter et al. (2019) argued that fluency and confidence are inextricably linked. However, they did not examine the extent to which these beliefs are products of internalised societal norms that position fluent speech as a prerequisite for confidence. A more nuanced examination of how socio-cultural expectations shape self-efficacy would thus offer deeper insight into the complex—and potentially problematic—interplay between fluency, confidence, and the lived realities of PWS. Similarly, Sønsterud, Feragen, et al. (2020) investigated personal goal setting and motivation for stuttering therapy, identifying four primary goal areas valued by participants: improving speech fluency, enhancing emotional functioning, increasing participation in social and professional activities, and gaining a better understanding of stuttering. Notably, improving coping mechanisms to

manage stuttering in real-life situations was emphasised. Further research must explore the challenges associated with these goals, as such barriers may affect therapeutic outcomes and interventions' effectiveness.

Existing research lacks a broad understanding of how stuttering is managed in real-world settings. Specifically, studies have examined what therapy goals PWS prioritise but not why these preferences emerge. Additionally, while there have been broad calls for holistic therapy, little research has investigated how PWS integrate behavioural and psychological therapies in real-world practice. Without clear guidance from lived experiences that combine different therapeutic dimensions, holistic approaches risk remaining aspirational rather than actionable in real-world contexts. Importantly, the barriers affecting long-term stuttering management remain underexplored. Without addressing these barriers, therapy risks being shaped by stated goals rather than the practical realities that PWS face in maintaining their progress.

To bridge these gaps, research must move beyond therapeutic goals and outcome measures to explore how PWS experience and navigate stuttering management over time. This study addresses these research gaps through a qualitative interview-based approach, gathering insights from PWS regarding their experiences with stuttering management. Specifically, it aims to:

- Explore disabling experiences that should be prioritised in therapy.
- Investigate key values and preferences in management approaches, as well as their underlying motivations and real-life applications.
- Identify barriers affecting long-term stuttering management, focusing on factors influencing therapy effectiveness and sustainability.

By examining these aspects, this study seeks to inform the development of therapies and support systems that extend beyond controlled clinical settings to better align with the lived experiences and needs of PWS.

2. Methodology

A qualitative approach was adopted using semi-structured interviews to gain a deeper understanding of PWS' lived experiences with stuttering management. The following sections outline the recruitment process, participant selection, data collection, and data analysis.

2.1. Recruitment

Convenience and purposive sampling methods were employed to recruit participants. Convenience sampling was used to reach participants through online advertisements published on the British Stammering Association (BSA) website (Stamma.org) and online stuttering communities on social networks, such as Stuttering to Confidence and Stuttering Mind Community. In contrast, purposive sampling was used to target "information-rich" individuals (Patton, 2002), including those who stutter and hold specialised roles, such as certified stuttering coaches, who provide one-on-one or group coaching; certified instructors of intensive stuttering courses, who, in addition to coaching, deliver structured training programmes; psychologists; and founders of active stuttering communities. This combination of methods was chosen to capture numerous perspectives—particularly in terms of expertise and approaches to managing stuttering—to maximise our understanding (Braun & Clarke, 2022).

The participant inclusion criteria were as follows: (1) PWS; (2) English speaker, either as a first language or as an additional

Table 1
Demographic Information of Participants.

ID	Gender	Age Range (Years)	Country	Education	Therapy	Additional Information
P1	Male	40–50	UK	Bachelor's	Yes	
P2	Male	30–40	Netherlands	PhD	Yes	Certified stuttering coach
P3	Male	25–35	India	Bachelor's	Yes	
P4	Male	25–35	India	Master's	Yes	
P5	Male	25–35	UK	Bachelor's	Yes	
P6	Male	25–35	Kuwait	Bachelor's	Yes	
P7	Male	30–40	Nepal	Bachelor's	Yes	
P8	Male	40–50	Belgium	Bachelor's	Yes	
P9	Male	45–55	France	Bachelor's	Yes	Certified stuttering coach and intensive course instructor
P10	Male	50–60	Australia	Bachelor's	Yes	Psychologist
P11	Male	50–60	UK	Bachelor's	Yes	Certified stuttering coach
P12	Female	30–40	UK	Master's	Yes	Certified stuttering coach
P13	Male	35–45	UK	Bachelor's	Yes	Certified stuttering coach
P14	Male	25–35	UK	Bachelor's	Yes	
P15	Female	65–75	US	High School	Yes	Leader and founder of stuttering community
P16	Female	30–40	Egypt	Bachelor's	Yes	
P17	Male	30–40	Nigeria	Bachelor's	No	
P18	Female	40–50	UK	Bachelor's	Yes	Certified stuttering coach and intensive course instructor
P19	Male	25–35	UK	Bachelor's	Yes	

language; and (3) over 18 years of age. In total, 19 participants were recruited, with ages ranging from 25 to 75 years. The sample included 15 male and 4 female participants, reflecting the gender ratio 4:1 observed among PWS (Yairi & Ambrose, 2013). Conducting interviews via Zoom broadened the sample's diversity by including participants from various countries. A detailed overview of participant demographics is provided in Table 1.

2.2. Sample size

This sample size was deemed sufficient based on the dataset's volume and richness and the concept of meaning saturation. First, the principle of information power was applied to assess the dataset quality. This principle suggests that the greater the information power of a sample, the smaller the required sample size, and vice versa (Malterud et al., 2021). In-depth interviews (Section 2.2) and purposive sampling enhanced data richness by referring to the depth and quality of the insights captured (Braun & Clarke, 2022). Additionally, the sample's heterogeneity contributed to data volume, with volume referring to the amount and breadth of data collected, which, in this case, represented a broad and diverse range of perspectives (Braun & Clarke, 2022). Second, the concept of saturation was considered when evaluating the sample's adequacy. Saturation refers to the point at which no new information—e.g. codes, themes, or meanings—emerges from the data (Braun & Clarke, 2021, 2022). However, it is important to note that saturation is not universally applicable across all qualitative approaches. For example, reflexive thematic analysis (Section 2.4.1), which was used in this study, does not strictly rely on saturation as it acknowledges that new and meaningful insights can continue to develop throughout the analysis (Bager-Charleson & McBeath, 2023; Braun & Clarke, 2022, 2021). This study adopted the concept of meaning saturation, which focuses on achieving a sufficiently comprehensive understanding of a topic without developing new conceptual dimensions (Braun & Clarke, 2021). This allows for a more interpretative and nuanced judgement of when the data are sufficient.

2.3. Data collection

To gather detailed insights into participants' subjective experiences and perspectives, this study conducted in-depth, one-on-one, semi-structured interviews. To ensure best practice, the interview questions were reviewed and approved by the BSA research panel (BSA, 2024). The study deliberately refrained from framing stuttering in a narrow or stereotypical manner—e.g. associating it with defects—or using leading questions (BSA, 2024). This approach enabled participants to highlight aspects that were meaningful to them based on their lived experiences.

The questions covered topics such as internal and external experiences of stuttering, non-verbal interactions, stuttering-management preferences, strategies, challenges, support, progress and desires. To facilitate the expression of complex emotions and thoughts, a context board was integrated into the interview process using the online Miro platform (Miro, n.d.). This context board allowed the participants to describe their stuttering experiences across four contexts: work or university, social settings with family and friends, interactions with fellow stutterers, and speaking out loud while alone. By visually comparing their internal and external stuttering experiences, both the participants and the interviewer were able to explore the underlying triggers for these differences more effectively.

To better understand the interview process and refine the clarity of the questions, a pilot interview was conducted with a volunteer who stutters (McGrath et al., 2019).

Due to the low prevalence of stuttering, interviews were conducted via Zoom. The interviews lasted 45–105 min, with each Zoom session scheduled for up to three hours to minimise time pressure. All interviews were audio recorded with the participants' verbal consent, and no compensation was provided.

2.4. Analysis method

2.4.1. Reflexive thematic analysis

Considering the foundational value of thematic analysis approaches, reflexive thematic analysis (RTA; Braun & Clarke, 2006) was considered the most suitable analytical method for this study. This was informed by its ability to address the research objectives effectively and its alignment with the researcher's positionality. First, RTA is particularly well-suited for exploring participants' experiences, needs, motivations, and practices (Braun & Clarke, 2022; Byrne, 2022). Second, a researcher's positionality as an insider is a critical factor in selecting an RTA. Personal experience, background, and familiarity with the subject matter provide valuable insights that enrich analytical processes (Braun and Clarke, 2022). RTA actively acknowledges and leverages the researcher's subjectivity, treating it as an asset rather than a limitation (Bager-Charleson & McBeath, 2023; Braun & Clarke, 2022).

RTA allows flexibility in its theoretical underpinnings, requiring researchers to construct a framework that aligns with their study objectives (Bager-Charleson & McBeath, 2023; Braun & Clarke, 2019, 2022; Byrne, 2022). Consequently, this study employed an inductive experiential orientation combined with a critical realist perspective to achieve a balance between preserving participants' subjective perspectives and uncovering the underpinnings of the investigated phenomena. An inductive approach was adopted to prioritise the interpretation of participants' experiences, perspectives, and insights, as they were developed from the dataset without the imposition of predetermined theoretical constructs (Anderson & Clarke, 2019). Simultaneously, an experiential orientation was selected to emphasise understanding participants' thoughts, feelings and experiences (Bager-Charleson & McBeath, 2023). This orientation is particularly effective in exploring under-researched topics as well as addressing research focused on lived experiences (Bager-Charleson & McBeath, 2023; Byrne, 2022), making it appropriate for this study. Additionally, this study's critical realism perspective allowed it to acknowledge the interplay between subjective interpretations and the underlying objective structures and

mechanisms that influence participants' realities (Fletcher, 2017). This dual perspective supports a comprehensive and nuanced analysis by bridging the subjective and structural dimensions of participants' lived experiences within specific contexts.

2.4.2. Analysis process

The RTA was conducted by the first author, an insider researcher, following Braun and Clarke's six-phase framework (2006, 2022), and, consistent with the study's theoretical framework, member checking was not employed (Creswell & Creswell, 2023). Interviews were transcribed verbatim, with stuttering disfluencies omitted because the focus was placed on content rather than phonatory features. Familiarisation was achieved through repeated reading of the transcripts, observational notes were recorded to capture initial reflections, and a dataset-wide familiarisation document was developed to guide subsequent coding (Bager-Charleson & McBeath, 2023; Braun & Clarke, 2006). Coding was then applied inclusively, comprehensively, and systematically, with both semantic and latent codes assigned to small and large data segments and detailed labels used to preserve analytic depth and facilitate data recall (Braun & Clarke, 2006, 2022; Byrne, 2022). Initial themes were actively constructed through an iterative, interpretative process by clustering related codes according to conceptual coherence and prevalence (Bager-Charleson & McBeath, 2023; Braun & Clarke, 2022). Themes were reviewed and refined to ensure they remained analytically meaningful, which contributed to a coherent narrative (Braun et al., 2016). A thematic map was generated to illustrate the relationships among themes, facilitating a structured and conceptually sound interpretation of the data. Themes were then given concise, "mini-abstract" names rather than broad topic labels (Bager-Charleson & McBeath, 2023). Each theme was reviewed thoroughly, and a concise abstracts was written before finalising its name to ensure clarity and conceptual precision. Finally, analytic writing was integrated throughout all phases, and the final write-up was produced with a 50:50 ratio of data extracts to interpretative commentary, thereby presenting a structured, evidence-supported account of the findings (Bager-Charleson and McBeath, 2023; Braun et al., 2016).

3. Results

3.1. Theme I: the avoidance–fear cycle

This theme presents the core struggle in the stuttering experience, which is characterised by a self-perpetuating avoidance–fear cycle that reinforces isolation, shame, and self-rejection, making it difficult to navigate daily tasks (see Fig. 1). P15 encapsulated the profound impact of this cycle by stating, "It was causing me to be sure that my stuttering is ruining my life […]"

For many participants, stuttering was not solely characterised by stuttering disfluencies but also by the profound emotional and mental burden tied to a fear that was driving avoidance. This fear shaped their perception of stuttering and reinforced behaviours that perpetuated a self-reinforcing avoidance–fear cycle. Many participants reported actively avoiding speaking situations, specific words or particular sounds as strategies to manage a fear that originated in childhood.

P13: I remember my grandfather used to say I was a man of few words as a child, because I just did not say much […] but I probably put that down to my stutter. It is not that I did not have things to contribute but that I did not want to open my mouth and stammer them out.

P8: I hesitated to participate in some contexts because of my stammer. It was—how can I say it?— easier to avoid participation than

Fig. 1. The avoidance–fear cycle and its impact on the internal, external, social and professional dimensions.

stuttering.

P15: If I did not have to speak, I would not do it. Therefore, even if there was a family gathering, I would listen but rarely speak.

This avoidance, initially a deliberate and conscious choice, gradually transformed into an automatic, reflexive response, making it increasingly difficult for individuals to overcome it.

P12: "Avoidance makes the fear even greater than it is, so it amplifies how I am feeling. I feel embarrassed […] If I am not able to express myself […]. Avoidance leads to more avoidance.

P9: It is like a snowball effect. It starts with avoidance because I do not want to be in a specific situation because of my speech; but this avoidance will grow […] and have an even larger impact.

P4: Whatever you do, the fear grows […] you are stuck in that loop that you want to come out of, but you cannot.

These accounts underscore the distinction between the visible aspects of stuttering, such as stuttering disfluencies, and its emotional and cognitive challenges. Participants identified addressing avoidance as a higher priority than reducing stuttering disfluencies. For instance, P9 stated, "It is better to block [stuttering] than to avoid [it]."

3.1.1. Internal impact

The avoidance–fear cycle's impact on participants' inner self was evident as they linked avoidance to intense negative emotions, such as shame, fear, and frustration. This emotional burden often drove them to avoid confrontations, leaving them mentally and emotionally exhausted.

P13: […] it feels quite bad, it feels like shame, shame of not being able to do something that should be quite simple.

P2: Constantly having these thoughts about stuttering situations ahead and how to avoid them […] I often found myself feeling annoyed about being unable to say exactly what I want […] just being occupied by stutter thoughts constantly, it is upsetting for me.

More importantly, fear of stuttering extends beyond speech, influencing PWS' identity and the way they present themselves to the world, ultimately limiting their genuine self-expression and engagement.

P10: […] that influences who I am in the world […] I do not express myself in the exact way I want to because I avoid certain words or situations […] I might not use humour because I am concerned about my capacity to tell the story.

This highlights the cycle's profound impact, affecting even seemingly simple decisions such as sharing stories. It shows how these challenges deeply infiltrate PWS' everyday life, turning spontaneous communication into significant barriers.

3.1.2. External impact

The external impact of the avoidance–fear cycle was evident in the participants' non-verbal behaviours, particularly those associated with shame, such as avoiding eye contact and adopting closed-off body language.

P3: I felt this shame due to my stuttering so, yeah, I did not really engage in eye contact.

P15: […] I could not maintain eye contact because of the shame [I felt about] stuttering.

P18: […] mostly, I am hunched over or looking down […] even the way that [I am] sitting or standing [I am] unconsciously just looking down […]

These accounts illustrate how internal struggles with shame manifest through non-verbal behaviour, restricting interpersonal connections and reinforcing feelings of isolation and inadequacy, thereby creating a feedback loop that amplifies the emotional toll of the avoidance–fear cycle.

3.1.3. Social impact

The avoidance–fear cycle extends into social life and, over the long term, can result in skill decay, a phenomenon in which trained skills or knowledge deteriorate because of periods of non-use (Nofi et al., 2023). In the context of stuttering, continuous avoidance behaviours negatively affect social skills.

P17: I do not know how to socialise. Even if I am with my friends, I am a person of few words. So, I just try to say, "Oh, fine" or "Nice." Most times, I use one or two syllables to communicate with people. In most cases, this makes the conversation boring. Even though I have a lot to say […] I will just keep it to myself […] In fact, you are the first person that I am having a conversation with today—just imagine. I have had team calls with colleagues but I do not have a conversation with them. I simply cannot.

This withdrawal reinforced deeper feelings of self-rejection, guilt and disconnection, further intensifying participants' sense of isolation.

P18: It was like I did not exist in that crowd […] I felt lonely, as if I wanted people to see me but I was invisible […] because I am not part of what they do or say or act. I did feel lonely, and I hated myself for it.

P13: Stammering is a super lonely thing […] and the sense of isolation can be quite powerful.

Moreover, avoidance behaviours frequently result in misunderstandings within relationships, as these actions are often misinterpreted by others as disinterest or disrespect, thereby inadvertently straining interpersonal connections.

P4: My relationships have suffered [due to] misunderstandings. I avoid picking up phone calls or responding to voice notes.

3.1.4. Career impact

The repercussions of avoidance were equally significant in professional settings, where missed or compromised opportunities amplified participants' frustration and sense of inadequacy.

P15: I do not have a college background because of my fear of stuttering.

P16: I feel like it makes me miss opportunities […] if I participated more […] it would help me in my career as well.

P18 provides an example of how avoidance during a job interview undermined her ability to present her true potential:

I just felt shame within myself that I could not speak and say what I wanted to say. I knew I was the right candidate but I had to prove it to them; however, I could not prove it to them because of my stutter, and that let me down.

The impact of avoidance behaviour extends beyond the individual, influencing those around the PWS. P1, a team leader, described the ripple effect in a professional setting as follows:

I am the spokesperson of these individuals. I am responsible for speaking up on all of their issues […] it is not an acceptable situation if other people who I am responsible for are now being affected.

3.1.5. The core struggle

Recognising the avoidance–fear cycle encouraged participants to break free from it, identifying avoidance as the driving force behind seeking support, and emphasising its importance as the primary issue to address.

P15: My worst avoidance experience was when I needed to give a presentation and I made up the excuse that I had an emergency at home and needed to leave. However, it was not true […] Then, I decided, okay, I really need to do something about my stutter.

P1: I am honest, I mean I joined it [the intensive stuttering course] because I was just avoiding a really important situation in my career.

However, if the cycle remained unaddressed, the participants noted that it could lead to severe consequences, including emotional distress and feelings of hopelessness. P14 offered a sobering perspective:

It could get to a point where some people could become suicidal […] if you do not have the necessary support and techniques […] you can feel isolated or hopeless.

3.2. Theme II: a proactive self-acceptance approach beyond the fluency trap

This theme comprises participants' preferences, values, and approaches to managing avoidance. By fostering self-acceptance, participants modified their speech behaviours and reduced their sensitivity to stuttering. Based on these narratives, Fig. 2 presents a researcher-developed conceptual model of self-acceptance that illustrates the progression from avoidance to consistent effective communication, emphasising the role of proficiency in techniques and desensitisation. The self-acceptance line highlights the transition through the transformation area where relapse and inconsistent behaviours are common.

3.2.1. Fluency trap

A recurring concern among participants was what several explicitly described as the *fluency trap*—a dynamic in which societal expectations of fluency perpetuated the avoidance–fear cycle. While prioritising fluency may offer a short-term solution, it reinforces shame, guilt, and helplessness, thereby hindering long-term progress. Additionally, participants recognised that fluency may emerge as a by-product of addressing fear; however, reliance on fluency techniques often leads to stuttering concealment, thus hindering progress.

P11: I think that as somebody who prioritised fluency an awful lot […] I learned some hard lessons from it […] [it] is not a good way of going about things.

P4: You will fall prey to those avoidance behaviours [Avoiding stuttering] that you essentially resort to in order to show people that you are a normal person […] You create a sense of normalcy and fluency but it only makes things worse. [Consequently], one becomes stuck in a conundrum of peer pressure, shame, and guilt. You try to escape it, but you may feel helpless and unable to break free, repeatedly falling prey to those fluency traps […] I feel that I am falling back in the fluency trap, which I absolutely do not want […]

P14: In terms of worry, the only worry I would have is trying to be fluent. If I try to be too fluent, I will most likely regret it.

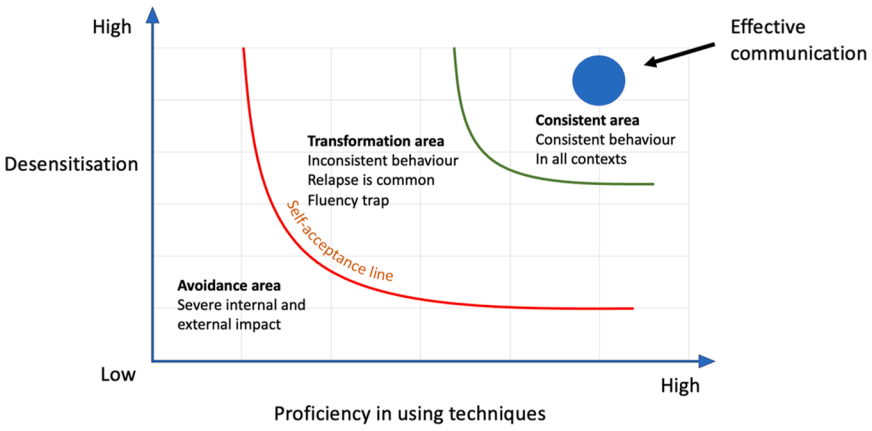

Fig. 2. A lived-experience model of proactive self-acceptance in stuttering.

3.2.2. Self-acceptance as a cornerstone for escaping the avoidance–fear cycle

In contrast, self-acceptance was identified as crucial in overcoming avoidance, fostering personal growth and effective communication. The participants identified speech behaviour and desensitisation as the core components of this process.

3.2.2.1. Speech behaviour. Participants described employing deep breathing, strategic pauses, slower speech rates, and stuttering modifications to stutter with greater ease and reduced intensity. These techniques were not perceived as fluency tools but as mechanisms for regaining control, mitigating anxiety, and enhancing confidence.

P18: Being disfluent, I am in control of my speech and am exaggerating my techniques. I do not want to be part of the crowd […] so having fun using all these techniques […] gave me confidence.

P15: I accept stuttering as part of me, but I also practice techniques to smooth it out so that I can communicate confidently.

P2: So speaking from the basic cycle [deliberate order of pausing, breathing, speaking and releasing the air out of lungs, with stuttering modification strategies]. Costal breathing and slow speech were definitely what helped me the most.

3.2.2.2. Desensitisation strategies. Participants emphasised desensitisation as critical for fostering self-acceptance and effective communication. Two primary strategies were identified:

1. Voluntary stuttering and self-disclosure: Participants reported that openly acknowledging their stuttering helped them confront fear and engage in conversations with increased ease (Van Riper, 1973).

   P13: I use deliberate disfluency [voluntary stuttering]—which is a particularly powerful psychological tool—in which we purposefully stutter to get ahead of it […] Just be yourself and show yourself as a stutterer and then, as a proxy of that, you will gain control. If we resist [stuttering], it will control us, and many of us allow it because we resist being who we are.
2. Maintaining eye contact and adopting positive facial expressions reduced shame and tension, allowing participants to communicate in an authentic and confident manner.

P12: When I speak, the impact of non-verbal communication is important for me […] particularly eye contact and facial expression—like a smile. I think this instantly helps me feel like I am communicating. […] This helped me concentrate on my speech. I am not hiding; I feel like I am able to express the full sense of what I want to say without hiding or having any embarrassment, as perhaps would have been the case before. All the habits I had before, such as closing my eyes, made it easier for me to deal with shame and embarrassment. But then I do not have to see their [listeners] reactions. Now, if I see them, I feel like I am able to communicate […] It is nothing to be worried about. It also relaxes me because I feel like I am on an equal footing with the listener.

P14: I think with eye contact, it definitely removes any tension building up. The more you maintain eye contact, it builds your self-esteem and confidence.

Together, these strategies form a robust framework for self-acceptance, shifting the focus from fluency to meaningful communication and personal empowerment.

3.2.3. Impact of proactive self-acceptance

Participants described self-acceptance as a transformative process that reshaped their internal narratives, reduced their reliance on external validation, and enabled confident communication. By embracing rather than avoiding stuttering, participants' focus shifted from concealment to authentic expression.

P10: I have gained a lot from self-acceptance […], manage my shame and anxiety, and simply be myself as an individual (to be the healthiest and happiest versions of myself) have had the greatest impact. Removing the emphasis on fluency and focusing on myself as a whole person has probably been the most impactful change I have made over the years.

P9: Exposing ourselves to our own fears […] over time, we start to realise that people do not care; it is me making up stories in my head, my own anxiety. Over time, these ideas become beliefs […] It is really about exposing ourselves to embrace and increase our confidence and acceptance of who we are.

P12: By saying "I have a stammer," I think my openness […] has changed the way I think. I am not beating myself up about having that block or do not perceive myself as not very confident or incapable because of my block.

Participants noted that their progress was gradual but rewarding, with self-acceptance slowly increasing. As they continued to engage in desensitisation and communication strategies, their confidence grew, leading to lasting improvements in their ability to communicate effectively.

P18: I could see the difference in me compared to a non-stammerer. I feel much more confident. I can speak in front of a crowd and enjoy it. But it took time to do that and have fun with my speech.

P13: Suddenly you might realise that you have not stuttered for a whole day […] [That you] did not think about stuttering. Therefore, although we should not prioritise perfect speech flow, it might happen unintentionally.

This gradual progression reinforces the idea that self-acceptance is not a fixed endpoint but a dynamic process that evolves through lived experience.

3.2.4. Self-acceptance's fluctuating nature

Analysis of the context board (Section 3.2) revealed significant variation in self-acceptance levels depending on the context. Correspondingly, the effectiveness of communication fluctuated in relation to these contextual factors. Participants emphasised that

self-acceptance fluctuates depending on external pressures and personal circumstances.

3.2.4.1. Key contexts and their influence. In professional and social settings, most participants employed certain techniques but struggled with full desensitisation, leading to moderate communication effectiveness. In stuttering interventions or support groups, where techniques and desensitisation were fully integrated, several participants achieved highly effective communication, even with strangers outside the training sessions. However, during interviews with an insider researcher who also stuttered, some participants exhibited high desensitisation but a lack of stuttering modification techniques, likely due to irregular practice, which reduced communication effectiveness. Fig. 3 illustrates all participant experiences across different contexts, mapping effective communication levels in relation to desensitisation and proficiency in speech techniques. The yellow-highlighted points represent Participant 1's data, highlighting that individual's unique pattern of contextual fluctuations.

Participant 1 reflected on these contextual variations as follows:

P1: In our office […] I have openly talked about the speaking technique […] everyone tells me […] "just slow down if you need to, it is okay…" Everybody is super supportive. However, what I do not do enough is advertise it. [What I mean by this is] to really acknowledge it and show other people who I am [as a PWS] […] It is important to advertise it.

[…]

When I am with my friends, I feel comfortable and confident in everything else except for how I speak […] I mean, it is not like I feel ashamed but I am unhappy in those situations.

[…]

Absolutely if I'm talking with other PWS [on stuttering intensive course or support groups] I do tend to feel much more confident and because I feel more confident, I am able to control how I speak […] it is similar to talking with members of the public and stuttering on purpose with control.

[…]

Even in this interview [the interviewer is also a PWS]… I absolutely feel comfortable in this situation […] also just being consistent […] using all the techniques […] but I honestly still find that difficult […] I stutter out of control a lot more.

These insights underscore that self-acceptance is not static; it fluctuates based on personal experiences, the use of techniques, and the environment. Maintaining this requires consistent and deliberate efforts to integrate desensitisation strategies and speech techniques across diverse situations.

3.3. Theme III: perseverance through unseen effort and challenges

This theme highlights the challenges of sustaining the ongoing efforts required to manage stuttering. Barriers such as time constraints and insufficient support resources complicate this process, often resulting in inconsistent and effective communication. Consequently, PWS may feel compelled to exert forced effort, leading to health issues, emotional exhaustion and minimal progress, leaving them trapped in an endless loop (Fig. 4). P1 reflected on this experience, stating, "I honestly think I struggle because I am not

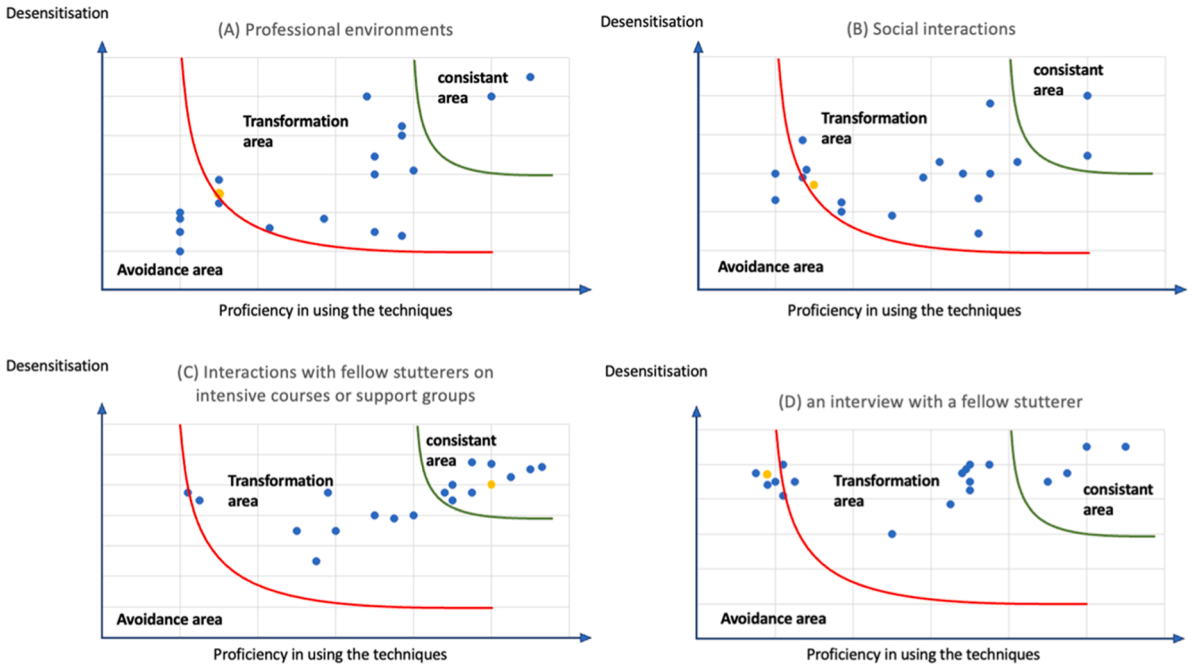

Fig. 3. Participants' experiences across different contexts, with P1's data highlighted in yellow.

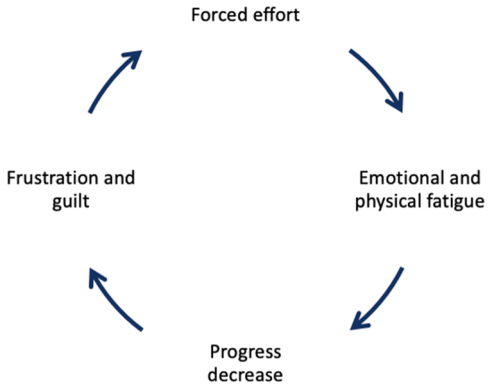

Fig. 4. Infinite loop of forced effort.

disciplined or consistent enough all the time […] I am guilty of just being inconsistent."

3.3.1. The need for ongoing effort

All participants emphasised that continuous effort is essential in breaking free from the avoidance–fear cycle. Their accounts highlight that, while the process is challenging and demands significant effort and commitment, it results in positive outcomes and increased confidence. The recurring emphasis on persistence and deliberate practice underscores that managing stuttering is not a one-time solution but a process requiring sustained engagement.

P14: It is about repeating actions daily. So, we have to stay consistent for our confidence to build momentum to thrive […] it is about simultaneously forming new habits and making sure we are reducing the possibility of the old habits returning.

P9: It requires continuous effort […] if I do not pay any attention to my speech, I can go on for a couple of days, but then I will end up in a worse situation […] It is not about doing it once and avoiding it the next time… It is very hard but it works. It works gradually.

However, owing to the lack of acknowledgement by society and speech therapists regarding the sustainable support needed by PWS, the latter often face time constraints and the limitations of clinical therapies for PWS.

3.3.1.1. Time constraints. Time constraints force individuals to exert significant effort to stay connected and navigate daily life, preventing them from slipping into isolation. Several participants described feeling trapped in a cycle in which inconsistent practice exacerbated feelings of guilt, frustration, and emotional overwhelm, further intensifying the challenges of managing their stuttering (Fig. 4). P13 expressed his frustration as follows:

I was not always comfortable with that [continuous effort] […] generally, when I am in a negative mindset […] when I start to think "…but I have to exercise, cook, take care of my children, nourish my relationships, studying, etc…" You just think, "Why do I have to work on my speech as well? No one else does."

This ongoing effort often results in health issues, emotional exhaustion, and sacrifice of personal interests, as hobbies that are essential for well-being yield minimal progress.

P10: I wish that [ongoing effort] was not needed […] I have had some health issues because of that […] I have struggled with fatigue, stress, and headaches […] because of that ongoing effort […] it has become harder as I age, and it is harder when I have had a long day at work.

P18: We all have a busy life […] it is hard to stay on top of everything, and it is sometimes emotionally draining.

P6: I also have different hobbies […] spending too much time trying to overcome stuttering can make you sacrifice your hobbies.

3.3.1.2. Limitations of clinical therapies for PWS. Participants expressed dissatisfaction and highlighted their poor experiences with clinical speech therapy, emphasising its limitations in addressing their needs. Speech therapy is often approached as a fixed-time intervention with minimal recognition of the need for ongoing support, reflecting a lack of effective discharge planning. Additionally, therapies frequently prioritise fluency and fail to consider psychological factors, treating communication as solely verbal and neglecting a broader system of interaction.

P11: I referred myself for speech therapy that was with the NHS […] [The speech therapist] really got me to break down my speech into single words […] We met for one-hour sessions over six weeks […] As soon as the six weeks were up, it was, "That is it, you are done, and I am going to release you from therapy" […] There was no going back there to say, "I am having a bad time, can you please advise me?" That was the one place that really disappointed me.

P3: In my life, I have undergone three speech therapy programs. After finishing each program, I was probably the most fluent for two or three months. Subsequently, there was a relapse. You still require someone to guide you. You also have to work on your anxiety and depression and, unfortunately, most speech therapists, at least as far as I am concerned, do not care about that. What they care about is fluency. If you go to a SLP and ask for speech therapy, they give you a time frame and say, "If you pay X amount of money, you will be fluent in three or four months." I think this is a bad way of thinking about speech therapy. Speech therapy requires constant maintenance, and is not a one-time fix.

The impact of limited access to speech therapy was highlighted by one participant who emphasised the challenges faced by individuals in certain regions. The absence of tailored, evidence-based resources compels PWS to rely on self-directed approaches (e.g. online research) to manage their stuttering.

P17: It also affects me because I do not have access to SLP. I have conducted extensive research online but because of where I am from and my background, I do not have the resources to access this kind of thing. What I do most times is research online; I study how I can manage it.

These accounts underscore that the priorities, challenges, and needs of PWS are inadequately addressed in clinical speech therapy, as well as the lack of support resources available.

3.4. Theme IV: progress and self-empowerment

Building on the earlier themes, this theme highlights participants' desires and perspectives on progress.

3.4.1. A redefined understanding of progress

Participants' reflections collectively highlight a shift away from traditional fluency-focused goals towards a broader and more individualised understanding of progress. Progress was conceptualised as actively embracing stuttering rather than avoiding it, enabling participants to confront their fear and embrace their authentic selves.

P13: Progress is more just to show myself as a stutterer equally in every situation […] to be able to use stuttering techniques just as efficiently in a support group or speaking to the Prime Minister of a country.

P12: I think progress is doing what you want to do; it is not avoidance. It involves tackling a challenge that I genuinely want to take on […] Now I am a bit more authentic about what I want to pursue.

P15: Progress means to come out of that shell that constrains you. So if you are bound by fear […] you will go from feeling intimidated or ashamed to being able to smile and say your name, stutter, or not. That is progress.

These accounts demonstrate that progress is not measured by fluency but by the ability to face challenges with confidence and authenticity.

3.4.2. Desires for emotional freedom and self-acceptance

Participants also expressed shared aspirations for emotional freedom, self-acceptance, and a life unburdened by the fear of stuttering. They aimed to move away from the internalised pressure to "fix" stuttering and instead embrace it as a natural and integral part of their identity.

P5: I should try to focus on the desensitisation part of stuttering. I do not really talk about it with friends [or] family, to be honest. I think that is something I want to change in the near future.

P7: I do not want my stuttering to stop me from doing anything. I would like to be in a place where I am happy with my speech, whether I stutter or not, and I would also like to be less worried about other people and what they think of my speech.

P10: I would like to feel more acceptance, ease, and safety regarding my speech and socialising.

P16: I would like to get to a state where it does not bother me as much. Like, yes, it is there […] so maybe [I would like to] just accept more so I do not think about it constantly. I do not want to keep thinking, "Oh, because of my stutter, I am not able to do this or that."

These reflections highlight the participants' desire to feel more comfortable and confident in social settings, redirecting their focus from external judgments to internal acceptance and emotional well-being. By embracing stuttering, participants envisioned a life that was less constrained by fear and avoidance.

4. Discussion

This study contributes academically and practically to the understanding of stuttering management as a lived experience. Academically, it advances existing paradigms by introducing a participant-driven model rooted in PWS' lived experiences, demonstrating how the avoidance–fear cycle reinforces barriers to communication. By emphasising the nonlinear nature of self-acceptance, this study shifts the focus from fluency as an outcome to the dynamic interplay between desensitisation, communication confidence, and real-world adaptability. Practically, these findings provide insights for refining therapy models to better align with the values, priorities, and aspirations of PWS. Specifically, they underscore the need for speech therapists to move beyond structured sessions to address PWS' real-world challenges in daily communication. By recognising avoidance not merely as a behavioural response but as a deeply ingrained, disabling cycle, this study advocates for therapeutic approaches that prioritise breaking avoidance patterns and fostering sustainable, adaptive communication strategies.

4.1. The avoidance–fear cycle in stuttering: A lived-experience perspective

This study identified the core disabling experience of stuttering as a self-reinforcing cycle of fear and avoidance extending beyond stuttering disfluencies. Participants described how fear drives avoidance behaviours and feelings of shame, reinforcing patterns that emerge in childhood and gradually intensify. Thus, this cycle becomes ingrained, restricting meaningful engagement and affecting PWS' emotional, cognitive, social and professional lives.

Avoidance has been widely discussed in the literature as a learned coping mechanism driven by social stigma and fear (e.g. Butler,

2013; Connery et al., 2020; Corcoran & Stewart, 1998). For example, in Tichenor and Yaruss's (2019) updated framework, avoidance is categorised as a behavioural response, along with cognitive and affective responses at the moment of stuttering. Furthermore, Plexico et al.'s (2009) model closely examines avoidance as an immediate coping behaviour that occurs before, during, and immediately after stuttering, highlighting how avoidance is primarily motivated by the fear of negative listener reactions. This study highlights the fact that avoidance evolves gradually, from a coping mechanism to an ingrained and disabling force that reshapes PWS' identity, beliefs, and life decisions. For instance, P15 recounted opting out of educational opportunities. Additionally, participants expressed feeling "trapped" in the avoidance–fear cycle. This contrasts with Plexico et al.'s (2009) assertion that avoidance is driven by fear of negative reactions, and that PWS can discontinue avoidance by assessing listener responses that are likely to be positive. The present study's findings challenge this assumption by demonstrating that avoidance becomes deeply ingrained and persists, with listener responses no longer being the primary drivers of avoidance.

Furthermore, this study highlights both the immediate and long-term effects of the interplay between fear and avoidance, extending Plexico et al.'s (2009) model, which posits that avoidance provides reprieve from communication. The avoidance–fear cycle model presented in this study was associated with additional immediate consequences, as participants described feeling shame and frustration at being unable to perform simple tasks, as well as a profound sense of isolation, particularly when surrounded by others, while they felt unable to engage meaningfully. For instance, P18 recounted experiences of social withdrawal, which reinforced a sense of invisibility and deep loneliness. Additionally, the avoidance–fear model incorporates external manifestations of avoidance in both verbal (e.g. increased stuttering disfluencies) and non-verbal (e.g. avoiding eye contact and adopting closed-off body language) behaviours, further reinforcing communication barriers and social disengagement.

The key finding was that the avoidance–fear cycle contributed to skill decay, as prolonged avoidance led to the deterioration of communication abilities. For instance, P17 described the loss of socialisation skills, restricting verbal contributions to one- or two-syllable words, and relying on text communication during online meetings. This demonstrates that avoidance progressively erodes self-confidence and exacerbates stuttering disfluencies, fear, and anxiety. These patterns align with observations made during the COVID-19 pandemic, during which prolonged social isolation heightened anxiety and worsened the severity of stuttering disfluencies in PWS (Chesters et al., n.d.). Studies have linked disengagement from face-to-face interactions due to excessive technology use to cognitive decline (Small et al., 2020). Similarly, research on social isolation and cognition has suggested that perceived isolation negatively affects cognitive control, memory, and self-regulation (Cacioppo & Hawkley, 2009). These findings suggest that PWS' avoidance behaviours disrupt neural reinforcement, making communication more effortful. Since cognitive training enhances motor skills, reduces cognitive load, and reinforces skill acquisition (Haith & Krakauer, 2018), interventions targeting avoidance could play a crucial role in preserving speech skills and mitigate the long-term communicative and cognitive consequences of persistent avoidance for PWS.

Practically, this study's findings emphasise the need to prioritise addressing the avoidance–fear cycle in therapy rather than focusing on fluency enhancement. Participants identified avoidance as their core struggle and the primary motivation for seeking support. As P9 expressed, "It is better to block [stutter] than to avoid [communicating]." This highlights the distinction between what participants perceived as disabling factors and stuttering disfluencies themselves. These findings align with the revised diagnostic criteria for stuttering by the American Psychological Association (2016), which now recognises anxiety and avoidance behaviours as integral to the condition but not as its central features. Additionally, many participants reported that once avoidance was addressed, their stuttering disfluencies no longer diminished their QoL or self-perception. Thus, embracing stuttering disfluencies fosters confidence and authenticity, thereby enabling more meaningful engagement. Some participants even emphasised the role of stuttering disfluency in personal growth and resilience. This perspective aligns with the findings of Sisskin (2018), who advocated for distinguishing between stuttering disfluency and struggle, as well as with those of Constantino (2018) and the BSA (2024), who asserted that PWS do not "suffer from" stuttering but live with it as a natural part of their communication. This reframing shifts the focus from fluency to fostering understanding, inclusivity, and empowerment, ensuring that PWS are not defined or constrained by stuttering disfluencies.

By adopting a lived-experience lens, this study challenges the conventional focus on physical stuttering disfluencies. It emphasises the need to address evolving disabling experiences—e.g. the avoidance–fear cycle—to promote meaningful and confident engagement in communication. This conceptualisation provides a valuable framework for rethinking stuttering and therapy priorities, shifting the focus from fluency to psychological resilience. Ensuring that interventions align with PWS' priorities and lived realities is essential for achieving meaningful therapeutic outcomes. A holistic, goal-oriented approach that acknowledges the disabling impact of avoidance can bridge the gap between clinical practice and the real-world experiences of PWS.

4.2. Beyond fluency: a participant-driven model for self-acceptance and effective communication

This study's findings highlight a structured, participant-driven approach to self-acceptance, in which desensitisation and proficiency in stuttering modification techniques must be continuously applied to break the avoidance–fear cycle and foster consistent, effective communication.

Building on the widespread recognition of clients' therapy preferences in stuttering treatment, the study's analysis shows that these preferences evolve as individuals gain treatment experience, deepen their understanding of stuttering, and increase their self-awareness—particularly among those with more extensive therapy backgrounds. In line with previous research (e.g. Plexico et al., 2005; Sønsterud, Feragen, et al., 2020), participants in this study explicitly rejected fluency as a goal, emphasising that self-acceptance and communication confidence must take precedence. They observed that fluency as a therapeutic objective reinforces avoidance and its psychological consequences, a concern echoed in previous studies (Boyle, 2018; Constantino et al., 2017; Sisskin, 2018).

While fluency may emerge as a by-product of proactive self-acceptance, in line with prior research (e.g. Beilby et al., 2012; Hart et al., 2024; Sisskin, 2018), this study's findings caution against forming a limited understanding of this form of fluency. The participants identified this as a trap that hindered their progress (Fig. 2). This contrasts with Carter et al.'s (2019) position, which posits that fluency and confidence are inextricably linked. However, they did not critically examine whether this perceived link stems from internalised societal expectations that positional fluency is the ideal outcome. By overlooking how fluency-based goals interact with avoidance patterns, self-acceptance, and long-term communicative confidence in real-life contexts, fluency-centred perspectives—such as that of Carter et al. (2019)—risk reinforcing the very avoidance behaviours that participants in this study seek to overcome. Critically, participants noted that early fluency preferences often stemmed from socio-cultural influences or limited therapy experience—underscoring the need to examine and regularly revisit clients' motivations to ensure they are able make informed choices. These findings highlight a gap in research (e.g. Carter et al., 2019; Venkatagiri, 2009; Yaruss et al., 2002), which recommends incorporating fluency within psychological approaches but does not fully examine its broader impact on long-term stuttering management.

Unlike existing integrated therapies, this study highlights a structured, participant-driven approach that requires a balanced progression across both desensitisation and speech technique proficiency (Fig. 2). While multidimensional individualised stuttering therapy (MIST) (Sønsterud, Halvorsen, et al., 2020) allows participants to self-select therapy components—including fluency techniques, mindfulness strategies, and communication skills—participants in this study reported that focusing on only one of these dimensions led to inconsistent communication and reinforced avoidance in high-pressure situations. A key distinction from ACT-based approaches (Beilby et al., 2012; Hart et al., 2024) is that, while ACT promotes psychological flexibility and willingness to experience stuttering, it incorporates fluency techniques as a therapeutic goal. In contrast, the participants in this study viewed speech techniques not as a means to suppress stuttering but as a tool to stutter more openly while maintaining agency over communication. Similarly, avoidance reduction therapy for stuttering (Sisskin, 2018) discourages speech modification techniques, arguing that it reinforces struggle and avoidance behaviours by encouraging individuals to exert control over their speech rather than fully accept their stuttering. However, this study's participants critiqued this perspective, asserting that speech techniques can be integrated into therapy without reinforcing avoidance, provided that fluency is neither a short- nor long-term goal. These findings suggest that speech techniques, when used to reduce stuttering's intensity rather than increase fluency, can complement (rather than contradict) desensitisation strategies. Consequently, the proposed model moves beyond the dichotomy of fluency-goal therapies (which risk reinforcing avoidance) and acceptance-based approaches (which do not provide practical tools for speech control), offering a structured approach that prioritises communicative confidence rather than fluency. Importantly, self-acceptance is not a fixed destination but an evolving process. As the participants highlighted, self-acceptance is not linear; individuals may oscillate along the acceptance line depending on external factors, experiences, and self-perceived progress. Rather than viewing acceptance as an endpoint, this model frames it as a process in which individuals can refine their confidence, adapt their communication strategies, and build resilience throughout their lives. Therefore, this study's findings advocate for holistic yet coherent approaches, in which various therapeutic components work together consistently to support long-term goals and foster stable communicative behaviours.

A key finding of this study is its emphasis on non-verbal communication as a critical component of stuttering management. While non-verbal behaviours are widely recognised as fundamental to effective communication (Burgoon et al., 2021), existing stuttering therapies, including MIST (Sønsterud, Halvorsen et al., 2020), do not explicitly integrate non-verbal communication training as a structured component. In MIST, general presentation skills are included as an optional element, whereas this study posits that non-verbal communication is a desensitisation strategy. The participants highlighted that training in eye contact, vocal tone, and facial expressions was as important as other strategies for fostering confidence. They emphasised that maintaining eye contact and smiling were crucial for reducing shame, fostering self-expression, and enhancing communication effectiveness.

Future research should explore how the structured integration of non-verbal communication training into stuttering therapy influences communicative confidence, self-acceptance, and social engagement among PWS.

4.3. Progress and challenges in long-term stuttering management

The participants reported that maintaining progress and consistency has proven challenging. Some clinicians suggest that therapeutic techniques should be applied selectively in high-pressure situations rather than consistently used (Bloodstein et al., 2021). However, the participants in this study rejected this approach, arguing that irregular practice made it significantly more difficult to apply the techniques, even in supportive environments. This highlights the gap between clinical recommendations and real-world applicability, reinforcing the need for therapeutic models that align with PWS' lived realities and needs.

In line with Baxter et al.'s (2016) observations, this study underscores that the lack of sustained practice is not solely attributable to individual motivation, as suggested by Plexico et al. (2005), but is shaped by external constraints, such as time limitations and insufficient long-term support beyond clinical settings. These barriers hinder progress and contribute to fatigue, psychological exhaustion, self-blame, and the sacrifice of personal interests. Pierre (2013) argues that PWS are expected to perform at the same level as fluent speakers despite the additional cognitive and emotional burden of managing their speech. The participants in this study echoed this experience, emphasising that while their responsibilities were identical to those of fluent speakers, they had to dedicate significant time and effort to speech management, an effort that went largely unacknowledged by society. Consequently, the participants described that they felt compelled to exert excessive effort to control their speech, often leading to fatigue, emotional exhaustion and, in some cases, health issues, while viewing it as a personal failure rather than a consequence of external limitations. Pierre (2013) criticised how stuttering is often misconceptualised as a moral failure, implying that individuals who struggle with management lack willpower or discipline. This misconception shifts responsibility to PWS while ignoring the systemic barriers that

hinder long-term success. However, the inability to maintain progress is not because of individual weakness but the absence of sustained, structured support that accounts for external constraints such as time limitations, psychological fatigue, and the lack of real-world application of therapy techniques.

Consistent with previous research (e.g. Baxter et al., 2016; Crichton-Smith, 2002; Luterman, 2017; Tichenor & Yaruss, 2020), this study identified critical gaps in therapy practice, particularly the tendency to overlook real-life communication and psychological needs. Participants highlighted that many SLPs approach stuttering through fixed-term interventions rather than through sustained support and rarely educate and equip individuals with sustainable strategies in diverse speaking environments. Additionally, the participants noted that clinical therapy, often limited to one-hour weekly sessions, lacked continuity and real-world applications. Consequently, transferring the therapeutic gains to everyday communication remains challenging. Furthermore, participants noted that SLPs often prioritise fluency over the broader psychological and social dimensions of stuttering. As Luterman (2017) argues, purely behaviourist approaches may change surface speech behaviours but reinforce a narrow conceptualisation of progress and further impede skill transfer into clients' daily lives. This narrow focus also contradicts the growing body of research that frames stuttering as a multidimensional experience requiring comprehensive therapeutic approaches (Boyle, 2018; Plexico et al., 2009). These gaps conflict with the needs of PWS, who identify support systems as a critical component in sustaining progress. Participants emphasised ongoing support from therapists, peer networks and families, as well as workplace accommodations, as essential for long-term speech management. These findings align with research on self-help groups (Plexico et al., 2005), which emphasised that support improves therapy adherence. Part of these gaps may stem from insufficient counselling training in SLP education: "we are not adequately preparing students to counsel clients effectively, especially in the realm of personal adjustment counseling" (Luterman, 2020, p. 906). Without that person-centred foundation, clinicians risk delivering short-term, technique-focused interventions that lack the empathic support PWS identify as critical. These findings underscore the challenges faced by PWS and the need for therapies that align with PWS' lived realities.

5. Limitations and strengths

While this study provides valuable insights into PWS' lived experiences, some limitations should be acknowledged. Although participants came from diverse cultural backgrounds, the findings reflect the subjective lived experiences of the participants in this study and are not intended to be generalised to all PWS. However, as qualitative research prioritises transferability over statistical generalisability, these insights contribute to theoretical understanding and practical applications in therapy and research (Smith, 2018). A key strength of this study is its purposive sampling that targeted individuals with varied experiences, including stuttering coaches, instructors, and community leaders, which added depth through combined lived and professional insights.

6. Conclusion

This study highlighted the fundamental misalignment between current stuttering therapies and PWS' lived realities, particularly in relation to their priorities, preferences, values, needs, and challenges. Existing interventions face several issues, including an incomplete focus on the evolving nature of avoidance and fear, a static view of self-acceptance, and a disconnect between therapy settings and the long-term impact of the intervention. Although some therapies promote self-acceptance, they may not fully account for its fluctuating nature or provide a coherent, structured framework for long-term support. A key finding is that non-verbal communication remains underexplored despite its role in building confidence and reducing internalised shame. Additionally, therapy is often framed as a short-term intervention rather than a sustained management process with structured discharge planning. This study calls for a paradigm shift in stuttering therapy, moving beyond controlled settings and short-term goals, to support long-term management, real-world adaptability and participant-based strategies. Thus, future research should explore ways to integrate these insights into therapy to ensure that the therapy and research frameworks align with PWS' lived experiences.

CRediT authorship contribution statement

Manal Alatawi: Writing – review & editing, Writing – original draft, Visualization, Validation, Software, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Judith Good:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data availability

The authors do not have permission to share the data due to ethical and confidentiality restrictions.

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