

RESEARCH REPORT

Examining the understandings of young adult South African men who stutter: The question of disability

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Abstract

Background: A disability studies approach seeks to understand and address political and social issues that affect disabled individuals. Disability studies scholars employ various models of disability to address and oppose the oppression and discrimination of disabled individuals. A disability studies approach, however, has largely been absent in studies that have investigated the lived experiences of people who stutter.

Aim: To examine the understandings young adult South African men who stutter hold of whether, and in what way, stuttering may be considered to be a disability.

Methods & Procedures: A total of 15 men who stutter, aged 20–39 years, participated in the study. Semi-structured interviews and two focus groups discussions were conducted to collect data for the study. The data were analysed according to a phenomenological approach and the affective turn in social research.

Outcomes & Results: The results indicated that some men in this study understood stuttering as a speech disorder that can be controlled, while other men constructed stuttering as a disability, subjectively positioning themselves either as disabled or non-disabled men.

Conclusions & Implications: This article emphasizes the importance of adopting a disability studies approach when examining the lived experiences of people who stutter and enhancing intervention strategies to adequately address the disabled needs of such individuals.

KEYWORDS

deductive thematic analysis, disability, phenomenology, rehabilitation, South Africa, young adult men who stutter

WHAT THIS PAPER ADDS

What is already known on the subject?

- The past few decades have seen researchers investigating the personal and social experiences of people who stutter. However, empirical studies exploring the disabling experiences of people who stutter have been absent from the existing body of knowledge.

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What this paper adds to existing knowledge?

- This research aimed to provide comprehensive insight into the disabling experiences of people who stutter. The results gave an insight into the oppression and disablism experienced by people who stutter. More specifically, the findings demonstrated how individuals who stutter are disabled by oppressive communication practices that dominate spaces of education and employment.

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

- Several men in this study attended speech therapy to gain control over their stuttering. For a number of participants, speech therapy proved a valuable experience, while others saw speech therapy as being out of touch with their lived reality of stuttering. Speech and language therapists are encouraged to employ a disability studies approach in order to enhance intervention strategies to adequately address the disabling needs of people who stutter.

INTRODUCTION

Stuttering has traditionally been described as a multifaceted communication disorder that affects approximately 1% of the global population (Butler, 2013; Connery et al., 2020; Gilman, 2012). The prevalence of stuttering is four times greater in males than in females (Butler, 2013). Recent South African research with South African men demonstrates the ways in which men who stutter experience stuttering in relation to their masculinities. Isaacs and Swartz (2020b) explored the discourses of masculinities among 15 young adult South African men who stutter. The authors found that stuttering had largely a negative impact on men's construction of their masculine identities. For example, they struggled to negotiate their stutter with hegemonic or dominant practices of masculinities. This resulted in a reduced self-esteem and self-confidence and negative emotions and feelings of weakness, powerlessness, shame and emasculation (Isaacs & Swartz, 2020b). Occupying this marginalized position, resulted in men who stutter to improve their performance of hegemonic masculinities by gaining control over their stuttering through the attendance of speech therapy and self-help groups. For other men, experiences of oppression and marginalization resulted in the rejection of hegemonic ideals of masculinities and the construction of positive, affirmative identities accepting of their stutter (Isaacs & Swartz, 2020b).

A promising framework within which to explore stuttering in relation to social factors, including the social construction of gender roles, is that of disability studies. A disability studies approach seeks to understand and

address political and social issues that affect disabled individuals (Ferguson & Nusbaum, 2012). The social model of disability was introduced in the 1960s and 1970s in response to the limitations of the medical (or biomedical) model of disability (Ratief & Letšosa, 2018). The medical model views disability as a medical condition that resides within the individual (McTigue, 2015). The overarching focus of the medical model is to diagnose, treat and cure the impairment of the disabled individual, and to assist individuals to adjust their impairment to fit in with the conditions of their social environment (Jackson, 2018; McTigue, 2015; Ratief & Letšosa, 2018). By contrast, the social model emphasizes barriers found within society (Bampi et al., 2010). Social model scholars argue that an individual is not disabled by their physical impairment, but by physical, social and cultural barriers in the environment (Campbell et al., 2019; Ferguson & Nusbaum, 2012). In this view, individuals who stutter are not disabled by their dysfluent speech (Bailey et al., 2015), but by dominant stigmatizing and oppressive practices and regimes of communication (Bailey et al., 2015).

Until recently, stuttering has largely not been considered or studied within disability studies (St. Pierre, 2012, 2019). The past few years have seen the emergence of a small body of literature aiming to address the disabling issues of stuttering (Isaacs, 2021b). The first of these was a collaborative autoethnographic piece written by Calderwood and Degenhardt (2010), addressing reasonable accommodation for students who stutter in a social work programme. These authors showed how courses that place a great emphasis on oral abilities may be disabling for individuals with communication impairments. In a similar vein,



Gilman (2012) addressed the discrimination individuals who stutter experience seeking employment in the United States, arguing that individuals who stutter in the United States experienced difficulty finding employment and were overlooked for promotion. St. Pierre (2012, 2017) sought to locate stuttering within the broader body of disability studies research, contending that people who stutter are disabled by societal norms and practices of communication, which emphasizes efficient and fluent speech. As a result, people who stutter are commonly viewed as having abnormal, irregular speech. St. Pierre (2012) brought to light the liminal nature and moral failure of stuttering to describe the disabling experiences of people who stutter (see also Isaacs, 2021b). In a more recent book, *Stammering Pride and Prejudice: Difference Not Defect* (Campbell et al., 2019), speech and language therapists and other disability scholars attempted to describe and discuss issues of disablement and stuttering through the social model of disability. The authors emphasized the value of a disability studies approach to the field of stuttering, particularly for moving beyond the individual focus of stuttering and bringing to the fore the disabling, social and political issues of stuttering (Campbell et al., 2019).

Disability studies researchers and some speech and language therapists have also stressed the importance of a disability studies approach in guiding professional responses to people who stutter and the design of interventions for these individuals (Boyle et al., 2016; Campbell et al., 2019; Connery et al., 2020; St. Pierre & St. Pierre, 2018). Nevertheless, authors such as Campbell et al. (2019), St. Pierre and St. Pierre (2018), and Watermeyer and Kathard (2016) claim that several approaches to treatment used within the profession of speech and language therapy (SLT) continue to approach stuttering as a biological disorder or speech defect that can be fixed, managed or overcome. These authors have called for transformation in the field of SLT—stressing the importance of incorporating a disability studies approach in the design of intervention strategies, particularly for promoting the disability needs and rights of people who stutter (Bailey et al., 2015; Boyle et al., 2016; Campbell et al., 2019; Connery et al., 2020; St. Pierre & St. Pierre, 2018).

While the above literature sought to illuminate the disabling dimension of stuttering, limited empirical studies have investigated the lived experiences of people who stutter through a disability studies lens (Isaacs & Swartz, 2020a). One of the few studies to investigate stuttering through a disability studies lens was conducted by Meredith and Packman (2015). Meredith and Packman (2015) investigated the experiences of 102 Australian university students who stutter. The authors found that while students who stutter experienced academic success, their stuttering negatively impacted on their social and academic

performance. The study also found that few students who stutter had access to disability support services (Meredith & Packman, 2015).

What is not yet clear is the extent to which people who stutter identify with a disability studies approach, and whether they find it helpful. This paper reports on data from a broader qualitative study examining the discourses of masculinities among young adult men who stutter (Isaacs, 2021a). Within men's discursive accounts of their masculinities, the complex disabled identity associated with stuttering was also apparent (Watermeyer & Kathard, 2016). Therefore, this paper will examine the understandings young adult South African men who stutter hold of whether, and in what way, stuttering may be considered a disability.

METHOD

Participants

Two sampling strategies were used to recruit the men for the larger study, namely purposive and snowball sampling. These men were recruited through various sources, including participants and poster advertisements, at a local hospital that offers speech therapy services, a university disability unit, and a programme for people who stutter, all in the Western Cape province of South Africa. The inclusion criteria were: (1) young adult men between 20 and 39 years of age, (2) who identified themselves as a person who stutters, (3) who were willing to participate in three interviews with the first author, and (4) who were able to communicate in English or Afrikaans, the languages spoken by the first author, who collected the data.

After data saturation was reached, the final sample consisted of 15 men who stutter. In this article, the men are referred to by pseudonyms, and minor details of identity have been changed to protect confidentiality. Table 1 shows the age, residential area, occupation and education of the participants.

Participants resided in Cape Town and Stellenbosch (a small town 45 km from Cape Town). It should be noted that the men who participated in this study had predominantly high education levels. A total of 11 of these men indicated attending speech therapy at least once in their lifetime. At the time of the study, five of the 15 participants were members of a support group for people who stutter.

Data collection

Ethical approval for the broader study was obtained from the University Research Ethics Committee (Ethics number

TABLE 1 Biographical profiles of participants

Participant	Age (years)	Residential area	Occupation/education
Luqmaan	29	Cape Town	Medical doctor
Thabo	32	Cape Town	Manager
Natheer	38	Cape Town	Business owner
Allie	23	Cape Town	University student
Mathew	31	Cape Town	Engineer
Agmad	27	Cape Town	Teacher
Tom	22	Stellenbosch	University student
Ayanda	20	Stellenbosch	University student
Nur	30	Cape Town	Accountant
Luke	21	Stellenbosch	University student
Liam	28	Cape Town	Model
Maliek	30	Cape Town	Financial advisor
David	25	Stellenbosch	University student
Frank	34	Stellenbosch	Candidate attorney
Eusibo	29	Cape Town	Geologist

PSY-2017-0468-528). Semi-structured interviews and two focus groups discussions, facilitated by the first author, were used to collect data for this study. The authors were mindful of the fact that interviews and focus group discussions are oral situations, which may be challenging for people who stutter. Thus, all participants were given the choice of expressing themselves verbally or in writing. They all chose to verbally participate in the interviews and focus groups. With regards to the semi-structured interviews, due to the deeply negative and emotional experiences that commonly characterize the narratives of people who stutter, the authors felt it important to interview the participants over a period of three interviews in order to establish a safe and comfortable research relationship. Furthermore, the first author, who identifies as disabled and as a person who stutters, used his insider position to establish rapport with the participants. Each interview lasted approximately 60 to 90 min and was guided by a semi-structured interview schedule.

Although the primary aim of the semi-structured interviews was to investigate the discourses of masculinities among young adult men who stutter, men's discursive accounts also brought to the fore the complex disabled identity of stuttering. The authors thus felt it important to give additional attention to men's understanding of stuttering as a disability. Additional probing questions were added to the protocol that guided the semi-structured interviews. Examples of these probing questions included: Would you define your stutter as a disability? Has your stutter disabled you in any way? How would you define your stutter? Moreover, previous research has shown that the most difficult and traumatic experiences of stuttering happen during the schooling career of people who

stutter (Butler, 2013; Daniels et al., 2012). Therefore, during the semi-structured interviews, participants were also asked about their primary and high-school experiences of stuttering, to gain a comprehensive understanding of their disabling experiences of stuttering. The first author refrained from providing participants with a definition of disability as the interest here was in understanding perceptions of stuttering and disability from the participants' point of view.

Following the interviews, participants were invited to participate in two focus group discussions. Since the broader study focused on young adult men, the sample included university students and young professionals. Therefore, the focus groups were divided into a group for university students and a group for young professionals. Each focus group discussion lasted approximately 90 min.

Based on the themes that emerged from the semi-structured interviews the focus group schedule was developed. During the focus group discussions, the authors were also interested in men's collective understanding of stuttering as a disability. Similarly, to the semi-structured interviews, the first author asked the question of disability (e.g., Do you define stuttering as a disability?) during the two focus group discussions.

Data analysis

The interviews and focus groups were tape recorded by the first author and transcribed. The transcripts were entered into Atlas.ti 8.4 qualitative data analysis software by the first author.



For the current paper, a deductive thematic analysis was employed. The authors specifically analysed participants responses to the question of disability and related probes. After reading and re-reading the data, the first author organized participants' responses into themes. The second author reviewed these themes. The first author revised the themes accordingly. This saw the finalization of the three themes outlined in the findings section.

The first author proceeded to apply the theoretical framework to the themes. Since the focus of the paper was to examine men's understanding of disability in the context of stuttering and their disabling experiences, a phenomenological approach was adopted. In addition, the analysis was interested in the emotions and feelings that underlined men's disabling experiences of stuttering. Cromby (2011) has argued that feelings and emotions are pivotal to understanding individual experience. Stuttering, consistent with other impairments, is characterized by negative and painful emotions and feelings (Alqhazo et al., 2017). For this reason, the first author drew on the affective turn in social research (Cromby, 2011) to examine the feelings and emotions that characterized participants' disabling experiences. Goodley et al. (2018) argue that a focus on affect in disability studies is important for highlighting the emotional impact of oppression and marginalization on the individual.

Rigour of findings

The quality and accuracy of the transcriptions were checked by the first author (Isaacs & Swartz, 2020b, *passim*). Consistent with the current focus of this article, Pereira (2012) argued that rigour in phenomenological research can be established through revealing the researcher's understanding or subjectivity during the analysis process. The first author is himself a young adult man who stutters. In many ways, the first author's disabling experiences of stuttering were similar to the participants' experiences. This insider position allowed the first author to identify and examine the nuances associated with men's disabling experiences of stuttering. However, participants' experiences also differed from those of the first author. Therefore, after the first author completed his analysis, it was checked by the second author (who is not a person who stutters nor who identifies as a disabled individual) to ensure the differences in participant's narratives were adequately represented in the findings presented below (Isaacs & Swartz, 2020b). As a way to further address bias in the analysis of the data, earlier versions of the article were also sent for external review before submission.

RESULTS

Men's responses to the question of disability can be categorized according to three main themes, namely: My stutter is a disability; Stuttering is a disability, but I am not a disabled man; and Stuttering is not a disability. It is important to note that men's responses to the question of disability were not exclusive. Due to the complex nature of the disabled identity of stuttering, men often navigated in between these three responses when discussing issues of stuttering and disability.

My stutter is a disability

When asked if stuttering is a disability, some participants perceived their stutter as a disability. In this study, this was a narrative commonly shared by university students who had a severe stutter. In the first example, David, a final-year student, stated that his stutter is a disability. However, he perceived his stutter to be a 'mild disability' in comparison with other seemingly 'worse' physical disabilities. He stated that stuttering only becomes a disability when there is an inability to communicate with other people:

David: It's [stuttering] definitely a handicap. Definitely a disability, but there are people who have worse disabilities than I do. I think mine is actually quite mild if you think about it. ... When you talk about someone who can't walk or who can't see and that kind of thing. But at the same time, sometimes we can't communicate with people and it's important to communicate with people. So, I think that most definitely it [stuttering] is a handicap. Ja [Afrikaans slang for 'yes'], most definitely in my view.

In another example, Allie perceived his stutter as a disability. However, unlike David who attributed his disability status with his severity of stuttering, Allie actively positioned himself as a disabled man. In the excerpt below, Allie described how completely disabled his stutter has made him in response to his social environment:

Allie: I see myself as disabled because I am disabled. I firmly believe that I am disabled. ... Socially I see myself as a conservative to an extent, and I'm not trying to portray myself as anything, I'm just saying my disability shapes who I am. So, you won't see me downstairs in the cafeteria. ... For as long as I've been here, I



have never sat in the cafeteria and had a meal. ... This [disability unit at university] is where I sit to eat my lunch and this is where I feel at home. ... In my first year, you know, you are new: you want to explore the university. In my first year, I bought me a sandwich and coffee. ... It's the c word I'm stuttering on. ... So, things like this, I've always never done.

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Allie: My mom must still keep my hand, buy my food. ... A simple example, today, my mom took the taxi with me. She didn't have to take the taxi with me. But she came with just to tell the sliding door operator where I need to get off. Once I was in the university shuttle, she got back into a taxi and went home. ... When someone calls me, I give the phone to my mother. I can't speak to people on the phone. Things like that toddlerises me. ... That makes me feel ashamed and embarrassed.

In the above excerpts, Allie described the negative impact his stutter has had on his social well-being. He particularly described the negative impact his stutter has had on his social interaction at university, and his ability to perform key social tasks, such as answering the telephone and traveling on public transport. Allie experienced his disabled identity as embarrassing and emasculating. As a result of his marginalized, disabled identity, Allie, took a keen interest in issues of disability relating to stuttering, and advocating for the disability rights of people who stutter:

Allie: When I started university, someone introduced me to the disability services here at university. Ever since I joined the disability unit my entire mind-set about disability changed. Something I realised, was that disability in the standardised narrative focused specifically on people with physical impairments. For example, people who are semi-paralysed, being in a wheel chair, blind and deaf. But not much is known about people who are speech impaired. So, basically, standing up for stuttering and the disability unit is the reason I joined the disability unit.

Similar sentiments were shared by Luke in the following excerpt :

Luke: [P]eople don't recognise it [stuttering] as a disability. Like it is as if people think people with no legs are like that ... but the whole stuttering cycle, it's like there's a huge gap and nobody intervenes or touches that actually. ... It's like most people are blind to the fact that there is something like stutterers, and that is the thing I would want to change that in my lifetime. It [stuttering] must be a recognised thing.

In both the above excerpts, Allie and Luke stated that stuttering is not sufficiently addressed and recognized as a disability in society. Allie and Luke stated that the failure to recognize stuttering as a disability, and the sole emphasis on physical disability in mainstream discourses of disability, conceal the disabling nature of stuttering, which holds negative implications for issues of redress. These participants were determined to be activists for the disabling rights of people who stutter. However, contrary to Allie who confidently perceived his stutter as a disability and defined himself as a disabled man, when Luke was asked if he thought his stutter was a disability, he brought to the fore the complex disabled identity associated with stuttering:

Luke: Ja, it's [stuttering] definitely a disability ... mine is. I think you get lots of stuttering ... but I think my level of stuttering most times is a form of a disability. ... But how I'm talking now, it does not feel like disability. So sometimes, it is a disability.

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Luke: Stuttering in my life is one thing that has led me having a lot of depressive thoughts; thoughts like, I'm not going to have a good future and stuff. I really stress about my future, and being a man means that I must get a wife and it means that I must get a job and it means that I must work and I must get money for my family. ... And from a stuttering viewpoint, those things ... can be quite challenging sometimes with the stutter because there are lots of difficulties or stresses or fears that come with job interviews and getting a job and doing well in the job.

Luke (in the first excerpt above) explained how the severity of his stutter constructed stuttering as a disability.



Due to the severity of his stutter, Luke reported experiencing depressive thoughts and expressed concern and fear about his future—specifically finding employment, a wife, and providing for his family. Despite this, Luke did not explicitly define himself as a disabled man. As a result of the liminal nature of his stutter, Luke, instead, described his disabling experience as not a constant phenomenon, but varying from one social context to another depending on the severity of his stutter. The complex disabled identity demonstrated by Luke was also evident in several other men's narratives in this study. This complex identity of stuttering will be taken further in the next theme.

Stuttering is a disability, but I am not a disabled man

In other instances where participants were asked if stuttering is a disability, they stated that stuttering was a disability, but that they did not define themselves as disabled men. This theme dominated the narratives of young professionals who participated in this study. Mathew, in the excerpts below, acted as a fitting example:

Mathew: stuttering in front of your in-laws, is something which can be I think very embarrassing and I fear that they would see me as a disabled man. ... And it's a question if they want their daughter with that. ... Of course, you want to portray yourself as perfect or as flawless to them. You don't want to be too vulnerable towards your in-laws.

< Setter note the line space here >

Mathew: It [stuttering] is definitely. I can't see how it [stuttering] could not be a disability. Because even if you say now that if you work with your hands, you become a technician or a plumber and then you don't stutter. It [stuttering] may not be a disability in what you do then. However, it [stuttering] disables you in the amount of choices that you have. It [stuttering] disables you because you may be good at something, but you don't do it because even though speech is only a small part of it, but you think because the chance that you could not speak properly by doing that, you wouldn't do it. So, for example, becoming a lecturer, becoming a teacher, becoming a journalist, even if the university would accept you,

but would you in the first place try to sign up for that? So, I think stuttering is in many ways a disability, but I don't see myself now as a disabled man. I'm a full man even though I stutter.

Mathew spoke about the disabling nature of stuttering in the context of his eligibility as a male intimate partner to his girlfriend and in the context of career success. In the first excerpt, Mathew shared his concerns about being perceived as a disabled man by his in-laws. He feared that his suitability and competence as a male partner would be brought into question if he were perceived as disabled by his in-laws. At the same time, as evidenced in the second excerpt, Mathew also spoke about the disabling nature of stuttering in the context of career success. He explained that despite stuttering providing an individual with possibilities to explore career options that do not emphasize good communication skills, other career paths that value fluency are exclusionary and disabling for people who stutter. Even though Mathew stated that stuttering is a disability, he did not position himself as a disabled man. Similarly, to Mathew, participants in this study who did not see themselves as disabled indicated previously being disabled by their social environment and occupying the subject position of a disabled man. However, as explained by Nur below, once he gained control and was able to exercise power over his stutter, he no longer identified himself as a disabled man:

Researcher: When you think of yourself as a man, has your stutter disabled you in any way when you reflect upon your life back then and now?

Nur: Yes, it [stuttering] has back in the past. ... That was the reason I left UCT [i.e., University of Cape Town] and went to UNISA [i.e., University of South Africa, which is a distance learning institution similar to the Open University in the UK]. What basically happened was the fact that at UCT it was more physical interaction with regards to tutorials, lectures and so on. I mean at that time it was very hard for me. It was quite a challenge. Where as opposed to UNISA, there is no lectures, there are no tutorials. Basically, there is no physical interaction but your exam. So, it took me out of that difficult zone. ... But it [stuttering] does not bother me anymore. In the past, it was the fact that I couldn't exercise power on how to get pass the block of speech. So, then

that disabled me to speak. So that's what used to happen in the past. Whereas now, I know how to exercise power.

Like Nur and Mathew, in the excerpts above, participants in this study who no longer identified themselves as disabled reported significant career success. Despite acknowledging the negative impact of stuttering on career prospects and advancements, a number of participants in this study reported significant career success, for example, Maliek, in the following excerpt:

Maliek: [I]f I have to be absolutely honest, is that fortunately, for various reasons, I find myself in a wealthy position. . . . The success in my career has contributed so much to the fact that now I have a stutter and it doesn't impact me as much. . . . At the beginning of my career, I would be worried about it [stuttering] and see it as a disability, because if someone finds out or someone sees I have a stutter, they'd be like, 'Oh, well, how is this guy going to be a successful financial advisor if he has a stutter?'

A similar narrative was shared by Natheer who is a successful business owner in Cape Town:

Natheer: I had so many dreams, so many things that I wanted to do in life, and I always thought that none of that was possible if I stuttered. . . . The options for a man who stutters are quite limited . . . one can so easily see it as a disability and I can't afford to start seeing it as a disability because if I lose my momentum, I could lose everything and I've got no safety net, no one to look after me or anything to fall back on. So, I've got to generate for myself every single day.

For this reason, professional men in this study commonly dissociated themselves from the identity of a disabled man. As explained by Natheer and Maliek above, there was a belief that ascribing to the identity of a disabled man will stifle and compromise their success as professional men. Similarly, in the focus group discussion with the professional men, some participants perceived the corporate spaces they were exposed to as not accepting of dysfluency:

Liam: I wanna go back to my first year of varsity. I was in the faculty of law for the first week, and I stuttered badly. So, because of my stutter, that very week, I was like it's not gonna

happen, I am not gonna be a lawyer. I couldn't see myself in court defending someone, being someone's spokesperson. . . . I changed the faculty. I did a B.A. with an English and Psych major because the fear of going and speaking in front of people, trying to represent someone, just got the better of me. Currently, I work as a full-time model and I find it restricting in the sense that there could have been roles I could have gone for . . . acting, T.V. presenting. But the fear . . . I don't think it's [stuttering] accepted in the workplace. I don't think it's [stuttering] accepted in the entertainment industry as well because there are no television friends that stutter. I haven't seen anyone who stutters. The only actor I know is Hugh Grant. Besides him, I don't know.

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Frank: I think if you are there representing someone. Like, for instance, I am in law. So, I usually have a client which I represent. So, when you get to a meeting. Like a round table meeting—you need to initiate . . . you need to say this why we are here. And if you are there and you feel a difficult word—you block on a difficult word. . . . Or the situation is so tensed—or the situation is so loaded with fear that you block. You immediately think the other party might think: 'Ag, this guy is a walkover' Ja, he is just an easy guy because he is not really strong with communication. So, I can use that to my advantage. So, that is usually the question, mindset, idea that usually comes up when you are for instance in my situation—when you need to represent someone as an attorney. . . . So, you immediately, you think you are the weaker party firstly because you have a block, you have a stutter, or you not able to communicate because obviously you are going to compare yourself to the . . . other lawyer.

Liam, in the excerpt above, explained how the severity of his stutter positioned him as a misfit for the legal profession. As a result of his position as a misfit, Liam decided to alter his career choice and pursue a career within the entertainment industry. However, Liam described how his stutter has also positioned him as a misfit within the entertainment industry. While Liam reported success



as a full-time model, he believed that the entertainment industry was not accepting of his stutter. He believed that his stutter had stifled and limited his career success. In the second excerpt, Frank also described how incompatible stuttering is to the legal profession. He particularly described the negative effect stuttering may have on his professional identity as an attorney. He believed that dysfluency denoted weakness and vulnerability, and brought into question his competency and success as an attorney. As a result of the stigma associated with stuttering, Frank, similar to a few other participants in my study, were hesitant to assume the identity of a disabled individual within the corporate spaces they were exposed to. For example, there was a hesitance among these participants to list stuttering as a disability on application forms for employment and advocate for the creation of spaces or systems that are more able and sensitive to the needs of people who stutter. Frank and Mathew acted as fitting examples for the above. When Frank was asked if he would indicate on a job application that he was disabled, he said that he would not:

Frank: No, I won't indicate it as me being a disabled person because of my stutter. ... You can control stuttering ... there are a lot of programmes or ways out there, therapy programmes and things you can do, there are like technical things you can do. ... What's currently on my CV, I say that it's [stuttering] one of my achievements or something. I said that I overcame the stutter through a programme and I have been able to communicate in control of it [stuttering]. So, they do know that I have a stutter, but I also say that it's [stuttering] an ongoing ... process, and I do sometimes still stutter.

A similar sentiment was shared by Mathew in the following excerpt :

Mathew: Even though I define stuttering as a disability. ... I don't want to say that stutterers must be treated differently from people who do not stutter. I'm not sure if it's good to give more time in the presentation or not. ... I would only put on and say it's a disability if I would think that they need to fill a quota and disabled people get the job easier. I mean, if you run a company and you have 10 applicants and one stutters, and you need to find the best three for the interview, the marks are the same or they all have a similar profile but one stutters, very likely you'll rather go for the three

who don't stutter because it will be easier. And I can't really blame them. I mean, why not? Why would they go through the extra effort?

The ability to pass as 'un-disabled' and exercise control over stuttering made disability 'optional', and in the case of Mathew, advantageous in securing certain employment opportunities. For other participants in this study, the possibility of gaining control distinguished stuttering as a speech disorder as opposed to a disability. This will be examined in greater detail in the next theme.

Stuttering is not a disability

In a number of participants' narratives stuttering was not presented as a disability but as a challenging speech disorder that can be overcome. For a few participants who held this view of stuttering, this was a view also shared by their family members. The families of participants in this study frequently perceived stuttering as a minor issue that at times existed in the mind of the participants:

Luqmaan: It's still seen in my family as something that's in my head that's not really there, so I must just deal with it.

< Setter note the line space here >

Agmad: I was made to believe by my family that I don't stutter. Yes, there's absolutely nothing wrong with you and it's all in your mind.

Participants who spoke about stuttering as a challenge constructed their experience of stuttering as developmental. In other words, stuttering was viewed as a developmental challenge throughout participants' schooling career. This challenge was characterized by negative primary and high-school experiences, which included being bullied and teased by their peers:

Luqmaan: I started stuttering when I was about seven, so grade 1. Didn't really bother me much back then until people pointed it out to me, that there was something different that should be bothering me. In primary school, I think I was more focused on sport and things so it never really became a hindrance. And then in high school when you become a teenager, you start noticing it. That's

when it started ... the first time I actually got proper anxiety on it was during orals and readings and things like that. I was able to overcome it.

< Setter note the line space here >

Eusibo: At high school I think it [stuttering] had more of an impact because you are expected to speak a certain way. If you are a young man, you are expected to be a confident speaker. ... In high school I used to limit my interactions with girls because at that time I would become more nervous and therefore more susceptible to stuttering. ... I felt like I was the only one who knew what it was like to stutter, and it did lead to a certain degree of loneliness because of the people in my class I thought that I was the only one who had this anxiety when it came to speaking in public.

As seen in the excerpts above, these experiences negatively impacted on participants' self-esteem and self-confidence. In addition, participants reported feelings of fear, loneliness, inadequacy, alienation, vulnerability and weakness. These negative experiences often resulted in participants limiting their interaction with peers and, more specifically, females, as in the case of Eusibo in the second excerpt above. At university, participants were determined to counter these negative experiences by gaining control over their stutter. Accordingly, participants spoke about attending speech therapy. A few participants in this study identified speech therapy as helpful in terms of gaining control over their stutter, as in the case of Luqmaan and Mathew (in the excerpts below), while others perceived speech therapy as unhelpful and being out of touch with their social reality, as in the case of Luke, in the excerpt below:

Luqmaan: I have been stuttering since I was seven and a half. My stutter actually comes and goes in phases. It was at its worse when I was at university. I actually approached a speech therapist in my fourth or fifth year. She actually helped me a lot with my perception of stuttering. As you can hear, I am not bad most of time. Can you see? There I blocked up, but I have techniques. My speech therapist taught me how to overcome those blocks. I have been using those techniques close to seven years.

< Setter note the line space here >

Mathew: Going to stutter therapy, yes, you learn some techniques and so on, but in the end, you have one and a half hours where you only focus on yourself. I think that we need to have a secure environment where you can speak about yourself, where you can speak about how you are. That helped. It's like doing a bit of self-reflection. That helped tremendously, just having that secure space. I have told other people not to go to stutter therapy, just go to a psychologist.

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Luke: A lot of speech therapists are not stutterers, so for them stuttering is treatable. I mean, it's [stuttering] a medical condition and they don't see it [stuttering] as a social impairment because they have never faced it.

Therefore, some of these participants joined self-help programmes to gain control of their stuttering, but also to gain access to a social environment that is empathetic and knowledgeable of their personal and social experience of stuttering. Participants attributed various positive outcomes to these self-help courses:

Tom: When I went on the programme, now this semester, ... I've spoken to more lecturers and more people in my class than I have spoken to in three years. It also played a big role in me charming my girl. That sort of aspect of control, like I can walk up to them and be like ... I'll go to my lecturers first without sending them an email. I can walk into their office spontaneously and be like, 'Good afternoon, sir, I'm in your class. Please could you help me with this question?'

Though participants stated that gaining control over stuttering enhanced their self-perception and self-confidence as men, some participants, as seen in Eusibo's and Tom's excerpts below, stated that gaining and exercising control constructed stuttering as a challenging speech disorder as opposed to an uncontrollable disability:

Eusibo: Looking at it now and having been on the stuttering course, it's [stuttering] more



of a challenge that I now need to overcome. I wouldn't call it [stuttering] a disability because I know exactly how I can overcome it. The onus is now on me to have that courage to back myself and also put in the necessary hard work to overcome my stutter. So now it's [stuttering] not a disability, it is a challenge.

< Setter note the line space here >

Tom: No, it [stuttering] is not a disability. I suppose the definition of a disability would be like something that prevents you from doing the expectation of a person. Like if you are crippled, for example, you're disabled in that you can't walk or move properly or whatever, which is what's expected of you. So, the reason I don't like using that word is because it sort of puts you in a category with people who can't do anything about it. You can get control of it [stuttering]. I'm a firm believer in if you don't like something, change it. If you do enough research and you put the time in and whatever, eventually you'll find a solution to your stutter. ... That's why I no longer view my stutter as an obstacle but a goal.

Here, participants' understanding of disability resembled that of the medical model. First, Tom, like the two participants in the excerpts below, perceived disabled individuals as those persons with severe physical impairments:

Thabo: Well, what I think it is, it's a speech impediment. I don't think that it is a disability. ... Ja, [stuttering] because it's not like you can't talk. You can, but there's just a barrier to fluency, sometimes, but not all the time.

< Setter note the line space here >

Ayanda: I wouldn't define it [stuttering] as a disability as such. ... I'm trying to compare a disability like, let's say, someone who can't walk who is disabled. And someone who stutters, if I classify stuttering as a disability, no, I don't think it's that deep. I mean, it's something m-minor than a disability.

Furthermore, Tom believed that individuals are disabled by their physical impairment, and that they have little to no control over their impairment. This description was in contradiction to the perceived nature of stuttering. According to Tom and Eusibo (in the excerpts above), with concerted efforts, through speech therapy and self-help courses, control over speech can be restored and improved. In this way, the struggle with stuttering is overcome. It is important to note that Tom and Eusibo are graduates of a self-help programme specifically based on the medical model. It states that the aetiology of stuttering is due to the incorrect breathing of the person who stutters. On the course, individuals are taught different breathing techniques to combat their stutter. Individuals are encouraged not to regard stuttering as a disability. Rather, individuals are taught to understand stuttering as a challenge that can be controlled with the necessary hard work.

DISCUSSION AND CONCLUSIONS

It is significant that those who did see stuttering as a disability placed great emphasis on contextual factors affecting fluency and social inclusion, implicitly aligning themselves with approaches to disability which emphasize the role of social factors, such as the social model. Those who did not see stuttering as a disability seemed more aligned with the medical model in which the disability is seen to reside primarily in a physical impairment, specifically within individuals with a severe physical impairment. These individuals did not view stuttering as a 'real' disability. Similar to other individuals who stutter, there was a strong desire among participants to be sensitive to those individuals with 'real' or 'serious' disabilities, thus rejecting the idea of stuttering as a disability (Campbell et al. 2019; St. Pierre, 2012). These participants instead emphasized personal agency in overcoming the effects of this impairment, rather than emphasizing the need for social change and greater social inclusion.

These discussions relate to questions about stigma and its management in the context of stuttering. For example, among the group of men who viewed stuttering as a disability but did not view themselves as disabled, there were narratives of disablement and oppression. These men also described how their stutter frequently positioned them what Garland-Thomson (2011) termed as 'misfits' in response to their social environment. According to Garland-Thomson (2011), misfitting occurs when a disabled individual's bodily 'shape and function comes in conflict with the shape and stuff of the built world' (p. 594). Accordingly, men in this study described feeling

oppressed, disabled, vulnerable and struggling to navigate the working environment and spaces of higher learning they were exposed to as a result of their stutter. Yet, there was resistance to accepting the identity of a disabled individual because of the stigma associated with it. Therefore, men who did not define themselves as disabled chose to, what Goffman (1963) termed, 'pass as normal' and uphold the identity of an able-bodied individual. Likewise, men who stutter who did not define themselves as disabled also placed emphasis on the importance of fluency and performance of ableism in a work context. Campbell (2012) explains how social systems, such as neoliberalism, promote a hegemony of ableism. Accordingly, individuals are required to be productive and practice autonomy. Due to the dependency associated with being disabled, disabled individuals are commonly viewed as a weak and burdensome individual who is unable to meet societal expectations of normal (Campbell, 2012). Therefore, as in the case of the professional men who participated in this study, there was a resistance to assuming the identity of a disabled individual because of the stigma attached to it, and in some instances to advocating for reasonable accommodation for people who stutter in spaces of employment. This was in stark contrast to those participants who identified themselves as disabled. Among these participants there were definite patterns of infantilization and difficulty, as well as some engagement with the question of how social change might create more accommodation for men who stutter.

In addition to issues of stuttering and stigma, career success could also be used to explain the tension that existed between the group of young professional men and the group of university students with regards to their understanding of stuttering as a disability. It was evident that occupying a position of power and control was important for the group of professional men who participated in this study. For these men power and control was obtained through the exercise of adequate control over stuttering and through career success. While professional men in this research study, consistent with previous studies (Bricker-Katz et al., 2013; Butler, 2014), acknowledged that their stuttering has had a negative impact on the progression in their career, they had reported significant career success and improved speech. As a result, professional men in this study were able to successfully perform and uphold the identity of able-bodied individual, thus rejecting the identity of disabled man, which they associated with weakness and vulnerability. In stark contrast, the severity of stuttering positioned some university students in this study as weak and vulnerable. These men often reported feeling emasculated and being unsure about their future and career success as men who stutter. Thus, these

men may have identified with the identity of a disabled man because it echoed the disablement and oppression they experienced.

Finally, the tension in the data between beliefs about social barriers as a source of disablement and individual agency (or lack of it) as primarily responsible for disability does, of course, also mirror tensions between social and medical views of disability in general. With stuttering, however, as with other communication disorders and with many aspects of psychosocial disability, there is contestation not only about the role of social barriers in the process of disablement, but also about the nature of the impairment itself. Moralistic and individualized discourses about the need for people who stutter to overcome their impairment (and hence their disability) to an extent mirror such discussions about the need for people with psychosocial disabilities to 'pull themselves together' and to perform dominant social roles (Schomerus et al., 2009). A disability studies perspective on stuttering does not deny the role of agency in charge of speaking behaviour, but provides a context in which social conditions of enablement may operate alongside more traditional speech therapy approaches, with their emphasis on assisting individuals to cope with current social conditions. People who stutter may themselves play an important role in alerting others—including others who stutter—to the social barriers which may contribute to a disabling environment.

Clinical implications

A disability studies approach is also important for the practice of SLT. Campbell et al. (2019) argued that a disability studies approach will guide speech therapists to recognize the social and political aspects of stuttering, which is central to understanding and addressing the stigma and oppression encountered by people who stutter. As evidenced in the results, several men in this study attended speech therapy to gain control over their stuttering. For a number of participants in this study, speech therapy proved a valuable experience, while others saw speech therapy as being out of touch with their lived reality of stuttering. Professionals could empower clients by actively engaging in anti-stigma strategies and referring clients to relevant literature to provide them with a better understanding of stuttering and issues of disability (Boyle, 2019). We believe such strategies are important for challenging the stigmatized identity of stuttering and encouraging the formation of positive, affirmative identities consistent and accepting of disability and impairment (Swain & French, 2000).

Limitations of the study and direction for future studies

The analysis had several limitations. First, as mentioned above, while concerted efforts were made to recruit participants that adequately represent that the diverse socio-economic landscape of South Africa, only individuals from predominantly high education levels agreed to participate in the study. It is suggested that future studies broaden their recruitment strategy. In addition to the strategies used in this research study (i.e., poster advertisements, speech therapy services, universities and a programme for people who stutter), future studies are encouraged to recruit participants through social media in order to recruit them from diverse socio-economic backgrounds. This would allow for a more balanced and nuanced narrative of the disabling experiences of people who stutter, specifically in low- to middle-class countries such as South Africa.

Finally, since this paper forms part of a broader study that sought to examine the discourses of masculinities amongst men who stutter, only the disabling experiences of men who stutter were analysed. Future studies are encouraged to include the perspectives of women to gain a more balanced narrative of the disabling experiences of people who stutter. Presently, little is known about the stuttering experience of women (Isaacs & Swartz, 2020a).

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

REFERENCES

- Alqhazo, M., Blomgren, M., Roy, N. & Awwad, M.A. (2017) Discrimination and internalised feelings experienced by people who stutter in Jordan. *International Journal of Speech–Language Pathology*, 19(5), 519–528. <https://doi.org/10.1080/17549507.2016.1209561>
- Bailey, K., Harris, S. & Simpson, S. (2015) Stammering and the social model of disability: challenge and opportunity. *Procedia—Social and Behavioral Sciences*, 193, 13–24. <https://doi.org/10.1016/j.sbspro.2015.03.240>
- Bampi, L.N.S., Guilhem, D. & Alves, E.D. (2010) Social model: a new approach of the disability theme. *Revista Latino-Americana de Enfermagem*, 18(4), 816–823. <https://doi.org/10.1590/S0104-11692010000400022>
- Boyle, M.P., Daniels, D.E., Hughes, C.D. & Buhr, A.P. (2016) Considering disability culture for culturally competent interactions with individuals who stutter. *Contemporary Issues in Communication Science and Disorders*, 43, 11–22. https://doi.org/10.1044/cicsd_43_S_11
- Boyle, M.P. (2019) Making change happen: how can we work together to decrease stigma. In Campbell, P., Constantino, C., & Sampson, S. (Eds.) *Stammering pride and prejudice: Difference not defect*. Guildford: J&R Press, pp. 93–106.
- Bricker-Katz, G., Lincoln, M. & Cumming, S. (2013) Stuttering and work life: an interpretative phenomenological analysis. *Journal of Fluency Disorders*, 38(4), 342–355. <https://doi.org/10.1016/j.jfludis.2013.08.001>
- Butler, C. (2013) ‘University? ... Hell No!': stammering through education. *International Journal of Educational Research*, 59, 57–65. <https://doi.org/10.1016/j.ijer.2013.03.002>
- Butler, C. (2014) Wanted—straight talkers: stammering and aesthetic labour. *Work, Employment & Society*, 28(5), 718–734. <https://doi.org/10.1177/0950017013501956>
- Calderwood, K. & Degenhardt, J. (2010) Accommodating a social work student with a speech impairment: the shared experience of a student and instructor. *Journal of Social Work in Disability & Rehabilitation*, 9(4), 235–253. <https://doi.org/10.1080/1536710X.2010.523646>
- Campbell, F.K. (2012) Stalking ableism: using disability to expose ‘abled’ narcissism. In Goodley, D., Hughes, B., & Davis, L. (Eds.) *Disability and social theory: New developments and directions*. New York, NY: Palgrave MacMillan, pp. 212–232.
- Campbell, P., Constantino, C. & Simpson, S. (2019) *Stammering pride and prejudice: Difference not defect*. J&R Press.
- Connery, A., McCurtin, A. & Robinson, K. (2020) The lived experience of stuttering: a synthesis of qualitative studies with implications for rehabilitation. *Disability & Rehabilitation*, 42(16), 2232–2242. <https://doi.org/10.1080/09638288.2018.1555623>
- Cromby, J. (2011) Affecting qualitative health psychology. *Health Psychology Review*, 5(1), 79–96. <https://doi.org/10.1080/17437199.2010.544637>
- Daniels, D., Gabel, R. & Hughes, S. (2012) Recounting the K-12 school experiences of adults who stutter: a qualitative analysis. *Journal of Fluency Disorders*, 37(2), 71–82. <https://doi.org/10.1016/j.jfludis.2011.12.001>
- Ferguson, P. & Nusbaum, E. (2012) Disability studies: what is it and what difference does it make? *Research and Practice for Persons with Severe Disabilities*, 37(2), 70–80. <https://doi.org/10.1177/154079691203700202>
- Garland-Thomson, R. (2011) Misfits: a feminist materialist disability concept. *Hypatia*, 26(3), 591–609. <https://doi.org/10.1111/j.1527-2001.2011.01206.x>
- Gilman, J. (2012) Disability or identity?: stuttering, employment discrimination, and the right to speak differently at work. *Brooklyn Law Review*, 77(3), 1179–1216. <https://brooklynworks.brooklaw.edu/blr/vol77/iss3/7>
- Goffman, E. (1963) *Stigma: Notes on the management of spoiled identity*. New York: Penguin.
- Goodley, D., Liddiard, K. & Runswick-Cole, K. (2018) Feeling disability: theories of affect and critical disability studies. *Disability & Society*, 33(2), 197–217. <https://doi.org/10.1080/09687599.2017.1402752>
- Isaacs, D.H. (2021a) *Exploring discourses of masculinities amongst young adult men in the Western Cape who stutter* [Unpublished doctoral dissertation]. Stellenbosch University.
- Isaacs, D.H. (2021b) ‘Satan is holding your tongue back’: stuttering as moral failure. *African Journal of Disability*, 10, 1–7. <https://doi.org/10.4102/ajod.v10i0.773>

- Isaacs, D. & Swartz, L. (2020a) Lived experience of people who stutter: a descriptive review of qualitative studies from 1990–2017. *Disability & Society*, 36(1), 81–99. <https://doi.org/10.1080/09687599.2020.1735304>
- Isaacs, D. & Swartz, L. (2020b) Stammering less so that I can be more of a man': discourses of masculinities among young adult men in the Western Cape, South Africa, who stutter. *Psychology of Men & Masculinities*, 23(1), 74–85. <https://doi.org/10.1037/men0000302>
- Jackson, A.J. (2018) Models of disability and human rights: informing the improvement of built environment accessibility for people with disability at neighborhood scale? *Laws*, 7(1), 1–21. <https://doi.org/10.3390/laws7010010>
- McTigue, P. (2015) From *Navas to Kaltoft*: the European Court of Justice's evolving definition of disability and the implications for HIV-positive individuals. *International Journal of Discrimination and the Law*, 15(4), 241–255. <https://doi.org/10.1177/1358229115591653>
- Meredith, G. & Packman, A. (2015) The experiences of university students who stutter: a quantitative and qualitative study. *Procedia – Social and Behavioral Sciences*, 193, 318–319. <https://doi.org/10.1016/j.sbspro.2015.03.293>
- Pereira, H. (2012) Rigour in phenomenological research: reflections of a novice nurse researcher. *Nurse Researcher*, 19(3), 16–19. <https://doi.org/10.7748/nr2012.04.19.3.16.c9054>
- Ratief, M. & Letšosa, R. (2018) Models of disability: a brief overview. *Theological Studies*, 74(1), 1–8. Retrieved from <https://www.scielo.org.za/pdf/hts/v74n1/06.pdf>
- Schomerus, G., Matschinger, H. & Angermeyer, M.C. (2009) The stigma of psychiatric treatment and help-seeking intentions for depression. *European Archives of Psychiatry and Clinical Neuroscience*, 259(5), 298–306. <https://doi.org/10.1007/s00406-009-0870-y>
- St Pierre, J. (2012) The construction of the disabled speaker: locating stuttering in disability studies. *Canadian Journal of Disability Research*, 1(3), 1–21. <https://doi.org/10.15353/cjds.v1i3.54>
- St Pierre, J. (2017) Becoming dysfluent: fluency as biopolitics and hegemony. *Journal of Cultural and Literary Disability Studies*, 11(3), 339–356. <https://doi.org/10.3828/jlcds.2017.26>
- St Pierre, J. (2019) An introduction to stuttering and disability theory: misfits in meaning. In Campbell, P., Constantino, C., Sampson, S. (Eds.) *Stammering pride and prejudice: Difference not defect*. Guilford, NC: J&R Press, pp. 3–18
- St Pierre, J. & St Pierre, C. (2018) Governing the voice: a critical history of speech–language pathology. *Foucault Studies*, 24, 151–184. <https://doi.org/10.22439/fs.v0i24.5530>
- Swain, J. & French, S. (2000) Towards an affirmation model of disability. *Disability & Society*, 15(4), 569–582. <https://doi.org/10.1080/09687590050058189>
- Watermeyer, B. & Kathard, H. (2016) To be or not to be: stuttering and the human costs of being 'un-disabled'. *International Journal of Speech–Language Pathology*, 18(1), 11–19. <https://doi.org/10.3109/17549507.2015.1060528>

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