



Contents lists available at ScienceDirect

Journal of Fluency Disorders

journal homepage: www.elsevier.com/locate/jfludis

Toward a better understanding of the process of disclosure events among people who stutter

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ARTICLE INFO

Keywords:
Stuttering
Disclosure
Openness
Concealment

ABSTRACT

Purpose: The purpose of this study was to identify components of disclosure events among people who stutter, and identify possible relations between these components in order to understand how disclosure events unfold.

Method: Twelve adults who stutter participated in semi-structured interviews focused on disclosure of stuttering. Participants were purposefully selected due to their self-reported history of disclosing stuttering. Qualitative content analysis using a grounded theory approach helped to identify relevant themes and subthemes related to the process of disclosure of stuttering.

Results: The findings describe the complex process of disclosure as being comprised of antecedents (including considerations about when and why to disclose), the disclosure event itself (including the content and form of the disclosure, most and least helpful methods of disclosure, as well as immediate listener reactions), and the perceived outcomes of the disclosure at individual, dyadic, and societal/contextual levels. These components of the process are linked and affect one another, resulting in a feedback loop. Disclosure methods are context-dependent and not mutually exclusive within individuals who stutter.

Conclusion: Professionals and advocates gaining a more nuanced understanding of the process of disclosure events can increase their ability to help people who stutter make optimal decisions about disclosure. Making good disclosure decisions can help PWS improve their quality of life and reduce a variety of environmental communicative barriers.

1. Introduction

Disclosure occurs when an individual shares personal information with other people that would have otherwise remained hidden or concealed. Although the term disclosure has most traditionally been thought of as being relevant mostly to hidden conditions or experiences, the disclosure process also seems to be quite relevant for individuals who stutter. Even though stuttering is not a totally concealable disorder for many people who stutter (PWS), there are several aspects of the condition that make disclosure of it important to consider. In addition, despite the idea that disclosure or openness about stuttering is not new in the stuttering literature, our field has lacked an understanding of the complexities and components of this process. This introduction will review (a) background literature on disclosure in general, (b) why disclosure is relevant to stuttering and PWS, (c) research on the correlates, consequences, and critical elements of disclosure for PWS, and (d) a justification for the current study and a description of goals and

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<https://doi.org/10.1016/j.jfludis.2020.105746>

Received 23 August 2019; Received in revised form 3 January 2020; Accepted 6 January 2020
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research questions.

1.1. Understanding disclosure

Disclosure is a process of sharing something personal with another person or people (Chaudoir & Fisher, 2010). This term has normally been thought of as being most relevant to concealable or hidden stigmatized identities that would not have been otherwise identified had the person not verbally disclosed (e.g., LGBTQ status, HIV/AIDS, mental illness, eating disorders, anxiety, post-traumatic stress disorder, traumatic brain injury) (Evans, 2019; Riley & Hagger, 2015). However, there appears to be some ambiguity in the literature regarding a precise operational definition of self-disclosure. For example, Chaudoir and Fisher (2010) define self-disclosure as the sharing of personal information with others through verbal communication. Quinn et al. (2014) describe disclosure more generally as a person's level of "outness" about a social identity that is stigmatized. They further described disclosure and "outness" as the extent to which other people in the environment know about stigmatized identity possessed by the individual. Similarly, Evans (2019) reviewed literature describing disclosure as a way of "coming out" about a discredited identity. In other words, disclosure can be thought of as a conscious decision to make a discredited, or stigmatized identity, visible (Goffman, 1963). Therefore, in planning this study, we utilized a working definition of disclosure that included the common elements of these various conceptualizations. Our view of disclosure then, was that it is the sharing of, or making visible, personal information that links a person to the identity of someone who stutters. Note that this definition did not make restrictions on how this identity is shared because a goal of the current study was to discover the various ways that this sharing could be accomplished.

Disclosure events can be viewed as aspects of stigma management for individuals with concealable stigmatized conditions (Chaudoir & Fisher, 2010). There have been various types of disclosure strategies that have been defined for a variety of conditions. For example, Corrigan (2005) described how disclosure of a mental illness is not an "all or nothing" construct, but rather one that varies on a continuum of "outness" ranging from less to more open including social avoidance, secrecy, selective disclosure, indiscriminant disclosure, and broadcasting. These different types of disclosures can be conceptualized as strategies or approaches pertaining to actual disclosure events, but they can also be viewed as a range for how "open" people are about their condition (i.e., a characteristic of a person) (Chaudoir & Fisher, 2010; Quinn et al., 2014). Evans (2019), however, discussed how these different types of disclosures are not linear in process nor are they mutually exclusive. She described how context-dependent the different types of disclosures can be. Evans described various types of disclosures including apologetic, pragmatic, and validating, which illustrates that the intent behind disclosures varies widely across individuals.

Positive correlates of disclosure have been found in several different populations and include increased empowerment, happiness, family support, and self-esteem (Caron & Ulin, 1997; Kadushin, 2000; Riley & Hagger, 2015), as well as reduced stigma, stress, anxiety and depression (Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003). Disclosure of a stigmatized condition is not without its risks however, and can lead to job and housing discrimination, social devaluation, stigma, risk for victimization, and increased depression if the confidant responds negatively (Haines et al., 2006; Halpin & Allen, 2004; Kalichman et al., 2003; Kosciw, Palmer, & Kull, 2015). These discrepant findings highlight the potential importance of making sure that early disclosure experiences are positive rather than negative (Chaudoir & Quinn, 2010).

Chaudoir and Fisher (2010) presented an in-depth model of the disclosure process that helped identify relevant components and complexities. Those authors discussed the importance of understanding when and why people choose to disclose, gaining deeper insight into the acts of disclosure themselves, and understanding why disclosure leads to positive or negative outcomes. They raised the possibility that the intent behind one's disclosure may impact how one actually discloses and the results obtained from that disclosure. They also discussed the potential of a feedback loop in the disclosure process in which positive experiences with disclosure engender continued openness, whereas negative experiences and listener reactions can lead to increased concealment. Some data suggest that positive first disclosure experiences lead to reduced chronic fear of disclosure (Chaudoir & Quinn, 2010). In the area of stuttering, it would be helpful to investigate the process of disclosure (i.e., components of the process that occur before, during, and after the disclosure event) following Chaudoir and Fisher (2010) conceptualization, to gain a more nuanced understanding of this issue for PWS.

1.2. The relevance of disclosure to a stuttering disorder

The notion of disclosure, or making the identity of a PWS known to other people, is not a novel idea in the stuttering literature. Some of the pioneers in the field discussed being open about the identity of a PWS and the idea of approaching or embracing stuttering (e.g., Sheehan, 1970; Van Riper, 1973). There also seems to be a renewed interest in disclosure among current researchers (Boyle, Milewski, & Beita-Ell, 2018; Byrd, Croft, Gkalitsiou, & Hampton, 2017; McGill, Siegel, Nguyen, & Rodriguez, 2018). It is important to state explicitly at this point how disclosure is relevant to stuttering. After all, stuttering is not a completely concealable condition for many PWS and therefore direct verbal disclosure (i.e., telling the listener specifically that they stutter) is likely unnecessary for many listeners to know that the speaker stutters, or at least has communication difficulty. Still, there are a variety of reasons why it is relevant to discuss disclosure as it pertains to PWS. First, it is possible for some PWS to be covert (i.e., successfully hide their stuttering) in particular situations, or "pass as fluent" with the goal of totally concealing their identity as a PWS from others (Constantino, Manning, & Nordstrom, 2017). Furthermore, even if total concealment is not possible, it is widely known and reported that many PWS at least try to minimize their stuttering when speaking to others (Boyle, 2018; Plexico, Manning, & Levitt, 2009), and rarely discuss it with others (Blood, Blood, Tellis, & Gabel, 2003; Erickson & Block, 2013). Incidentally, concealment strategies (e.g., avoidance and circumlocution) intended to minimize stuttering may actually lead to more negative perceptions on the part of the

listener (Von Tiling, 2011). Finally, stuttering as a disorder is highly intermittent and variable in its expression, which leads to inconsistency in how one presents oneself (Constantino, Leslie, Quesal, & Yaruss, 2016). The high variability inherent in the disorder, and the fact that stuttering remains misunderstood in society, make it likely that disclosure will be an ongoing process throughout the lives of PWS. In summary, there appear to be a wide variety of ways in which PWS can make decisions about passing as fluent, consciously minimizing or concealing their disfluencies, or deciding to be open about their stuttering.

1.3. Correlates, consequences, and critical elements of disclosure of stuttering for PWS

Most research on the topic of stuttering disclosure to date has been focused on understanding how listener perceptions of PWS may be impacted by verbal disclosure from PWS (Collins & Blood, 1990; Boyle, Dioguardi, & Pate, 2017; Byrd et al., 2017; Healey, Gabel, Daniels, & Kawai, 2007; Lee & Manning, 2010). Overall, studies have found that verbal disclosure of stuttering is more helpful in improving listener attitudes when it comes at the beginning of a message rather than the end (Healey et al., 2007), and when the wording of the disclosure is non-apologetic in nature (Byrd et al., 2017). Boyle et al. (2017) analyzed effective elements of a lengthier (5 minute) disclosure of stuttering and found that the most important aspects according to listeners were that the speaker came across as positive and confident (and therefore contradicting the stereotypes of PWS as being weak and timid), described struggles in addition to successes and achievements (e.g., having a job that requires lots of talking), and provided an explicit goal statement for the disclosure (e.g., telling the listener what they should do when they talk to a PWS). In addition, Flynn and St. Louis (2011) found that a live presentation that involved a PWS being open about his stuttering was more effective than a professionally prepared video on stuttering for improving public attitudes about PWS.

Few studies have focused on the correlates, consequences, and perceived critical elements of disclosure as reported by PWS themselves. Recently, McGill et al. (2018) conducted a mixed-methods survey of 42 adults who stutter which explored how they phrase disclosure statements, and when they use them. The results demonstrated that there were apologetic, educational, and direct types of disclosure statements. These statements were most commonly direct in nature (e.g., "I stutter"), and used most often in job interviews in the beginning of the interaction. Results from a recent survey of 322 adults who stutter found that PWS reporting relatively low quality of life reported significantly lower levels of openness and disclosure of stuttering compared to participants reporting average to high quality of life (Boyle et al., 2018). In a qualitative study conducted by Plexico, Manning, and Levitt (2009), PWS with a more approach-focused coping style (which included being more open about stuttering) tended to be more self-accepting of their stuttering. Participants in that study also described that being more open about stuttering had the effects of reducing time-pressure in communication, and allowing them to connect with similar others to enhance social support. Mancinelli (2019) recently reported results of the first experiment to our knowledge that manipulated disclosure in PWS during a conversational task and evaluated the impacts reported by PWS. Although slight benefits were reported by PWS after disclosure compared to non-disclosure, no significant differences in any of the psychosocial or speech-related variables measured were found. It is important to note that experimentally manipulated disclosure is not the same as a person's self-perceived level of openness, and that it lacks generalizability to everyday-life situations in which people makes decisions to disclose based on personal motives. It will be important to disentangle the constructs of disclosure as representing a general level of openness (i.e., being more willing to disclose as a personal trait) and disclosure as an event in research moving forward.

1.4. Purpose of the current study

Based on the review above, it is clear that although some correlates, consequences, and key elements of disclosure (measured in terms of disclosure events and the degree of openness that a PWS demonstrates) have been documented, our field is still lacking a nuanced understanding of the process of disclosure from the perspective of PWS themselves. This lack of understanding represents a barrier to service delivery for PWS because without a clear knowledge of the complexities involved in disclosure, it is questionable that clinicians can help clients make optimal decisions about it. Helping PWS make optimal decisions through a deeper understanding of this process may lead to enhanced outcomes for those individuals. This study therefore focused on developing a better understanding of the process of disclosure events of stuttering among PWS, including identification of different components of the process, and how those different components may relate to one another. To achieve these goals, a qualitative investigation using a grounded theory framework was utilized. Based on Chaudoir and Fisher (2010) disclosure processes model, we were guided by the following questions: (1) what are the components of the disclosure process and how can they be described? (2) how might the various components in the disclosure process be related to one another?

2. Method

Approval for this study was obtained by the Institutional Review Board of the first author's institution.

2.1. Recruitment and participants

Participants were recruited in a variety of ways. Recruitment e-mails were sent from the National Stuttering Association (NSA) executive office to NSA members. Announcements about the study were also posted to various social media sites (e.g., facebook groups) for PWS. Also, personal contacts were made to individuals who the authors knew of personally as being active in the stuttering self-help/support community. To be included, participants needed to indicate that they were PWS and that they were open

Table 1
Demographic details of participants.

Pseudonym	Age	Gender	Ethnicity	Highest degree	Occupation
John	38	Male	White, non-Hispanic	Bachelor's	Financial manager
Bill	70	Male	White, non-Hispanic	Bachelor's	Retired
Caitlin	27	Female	White, non-Hispanic	Master's	Speech-Language Pathologist
Chelsea	31	Female	Jewish	Master's	Speech-Language Pathologist
Matthew	26	Male	White, non-Hispanic	Master's	Speech-Language Pathologist
Rachel	30	Female	White, non-Hispanic	Master's	Nurse practitioner
Joane	30	Female	White, non-Hispanic	High School	Teacher's Aide
Rudy	67	Male	White, non-Hispanic	Bachelor's	Retired
Roger	30	Male	Jewish	Doctorate	Aerospace Engineer
Tori	29	Female	White, non-Hispanic	Master's	Speech-Language Pathologist
Audrey	55	Female	White, non-Hispanic	Bachelor's	Human Resources
Joe	28	Male	White, non-Hispanic	Bachelor's	Forensic Science

about their stuttering and disclosed it to others, in at least some life situations. Also, because we wanted to conduct face-to-face interviews, participants needed to be able to meet with the researchers in person. We used a purposeful sampling strategy that is common in qualitative research (Patton, 1990). That is, because the topic of this research project was to better understand stuttering disclosure, we were particularly interested in recruiting PWS who had experience in this area and who could discuss it with us, rather than attempting to obtain a random or representative sample of PWS overall. The type of purposeful sampling utilized did not try to represent the overall population of PWS through probability sampling, but instead sought people who were anticipated to be uniquely informative given their considerable experience with self-disclosure of stuttering. These participants were therefore judged to be particularly helpful in developing a theory about disclosure events that could then be tested for generalizability in future studies. Therefore, individuals who were active in self-help for stuttering, including speech-language pathologists who stutter, could theoretically provide rich and detailed information on this topic and represent an “ideal type” of a PWS who utilizes disclosure (Maxwell, 2005, p. 115).

Interested participants contacted the authors via e-mail and then a phone call was scheduled so that it could be confirmed that the individual was 18 years or older, and that they in fact stuttered (although in some cases, the individuals were already known to us and verification of stuttering status was not necessary). During those phone calls, it was also determined if participants could meet in person, and plans were made for conducting the interview. It was anticipated that around 10 participants would be included in the study, although that number was flexible and dependent on whether or not saturation was achieved. Ultimately, 12 participants agreed to volunteer for the study and so 12 interviews were conducted and analyzed. Demographic information for all participants is presented in Table 1, and pseudonyms are used throughout the paper. As can be seen from the Table 1, participants were equally divided in number of males and females, with ages ranging from 20 to 70. Participants represented various occupational sectors including business, health care, education, science, and engineering. In addition, four of the participants were speech-language pathologists. Most of the participants identified as being white, non-Hispanic. Participants were each given a \$25 Amazon gift card for their involvement in the study.

2.2. Interviews

In-person interviews were conducted with each participant. Many of the participants were interviewed in private hotel rooms during an annual conference of the NSA (the largest gathering of PWS in the world each year). These interviews had all been arranged prior to the conference. Some participants were interviewed in private offices in the geographic location near where the participants lived. An interview guide was created by the authors and a semi-structured interview approach was utilized for all interviews. This means that the main topics and issues were specified in advance, however the interviewer decided the sequences and wording of the questions within the interview. In addition, there were times when new questions emerged from the context of the interview without predetermination, as well as follow-up probes and questions with no predetermined wording. To establish a context for a discussion about disclosure of stuttering, participants were asked general questions about their stuttering such as how they would describe it, and how it has impacted their lives. Then, more specific questions about disclosure were asked. They were asked about a wide range of topics related to disclosure such as what it means to them, their goals for disclosing, why they do it, when it is most useful to them, benefits and drawbacks to disclosure, how disclosure is done most effectively, and what they believe the effects of disclosure are. Participants were asked other questions such as how they evolved in their level of disclosure over the course of their lives, how participating in therapy and self-help/support groups helped facilitate disclosure, and general advice they would give to PWS who are considering disclosure. However, this analysis was focused on the process of disclosure events themselves, and therefore information obtained relating to the topics in the preceding sentence are not included in this report. Interviews lasted from 40–75 min depending on the depth that the participants went into on the topics discussed. All interviews were audio recorded and transcribed verbatim.

2.3. Data analysis

Qualitative content analysis was conducted on the interview transcripts. A grounded theory approach was taken in this study. The

goal of such an approach is to develop a theory based on inductive reasoning that is grounded in the data collected (Bogdan & Biklen, 2007). Specifically, this type of approach is interested in proposing relationships between constructs to generate theory or explain certain processes (Maxwell, 2005). In this case, the type of results we were interested in were a description of the psychological and behavioral process of the experience of disclosing stuttering as a PWS. The focus was on the process of a disclosure event, its components and stages, and potential relationships between its components. There was no interest in calculating how frequently different answers appeared or comparing frequency of different types of answers. We focused on extracting data from the interviews that were perceived as relevant to the aim of this particular study and did not attempt to address other issues that may have been present in the data.

The analysis followed steps described by Graneheim and Lundman (2004). Interview transcripts were read several times to obtain a sense of the whole. Meaning units were then identified and open coding of those units was conducted. After open coding, axial coding within and across transcripts was conducted in order to generate categories and themes that would best cover the data. Interpretation of the data focused on judging the latent content underlying participant responses in relation to the topic areas of interest as well as previous research. The authors coded the interviews to generate themes. The authors then compared their codes, and any disagreements were resolved through discussion. The authors reflected on the analysis to ensure themes were coherent and adequately grounded in the data collected. Ultimately, agreement on all of the themes and subthemes presented in this paper was established between the researchers.

It was important to ensure maximum credibility of the findings. This was achieved by purposeful selection of a variety of participants with various backgrounds and experiences who could shed light on the topic of interest, collecting data through interviews, and using a grounded theory approach which was described earlier as an appropriate method for exploring this topic. In addition, the credibility of findings also deals with how well the themes cover the data collected (Graneheim & Lundman, 2004). The authors' discussion of the themes during the data analysis process was one means of establishing credibility.

Additionally, agreement on themes was analyzed with a group of 40 PWS at an annual stuttering conference. Those in attendance did not include any of the participants in the current sample. Key themes discussed in this paper were shared with the group, and none of the group members objected to the themes that had been identified or considered them implausible. Member checks of the analyzed data were also conducted with participants included in this study. These checks occurred approximately one year after the original interviews, after the data had been analyzed. Participants were given a summary of the findings and the authors' interpretations. Participants were instructed to read the summary, and comment on anything that they did not agree with, anything they would like to add, and whether anything presented in the summary particularly resonated or conflicted with their prior knowledge or experiences. Seven participants provided written feedback and none of them had any objections to how the data had been interpreted. They agreed that the analysis was a thorough description of the process of disclosure among PWS. These member checks, along with verification of results with a large independent group of PWS, support the credibility of the findings. It is important to note that although making claims of external generalizability of the findings was not a primary concern in this project, we believe that the steps discussed above enhance the credibility for external generalizations of the results to be made.

3. Results

Throughout the results section, transcript data is presented to illustrate the participants' perceptions. It should be noted that stuttering-like disfluencies are not documented in the transcript as they were not the focus of the research. The disclosure process of stuttering among PWS can be described by the following themes: antecedents of the disclosure event (including sub-themes of considerations of when and why to disclose), the disclosure event itself (including sub-themes of form of disclosure, most and least helpful aspects of disclosure events, and immediate reactions of the listener), and outcomes of disclosure (including sub-themes of individual, dyadic, and societal/contextual outcomes). See Table 2 for a summary of themes, subthemes, and examples of the various subthemes from the qualitative analysis.

3.1. Theme: Antecedents of the disclosure event

The data indicated that PWS have reasons for their disclosure and that disclosure is more likely to be used in certain circumstances. Therefore, the main theme of antecedents of the disclosure event represents the considerations PWS make before actually making the disclosure of stuttering. These considerations include when to disclose, and why to disclose. This can also be thought of as the goals that PWS have for disclosure (or the purpose in disclosure), and consideration of when, or in what particular circumstances, disclosure will be useful.

3.1.1. Subtheme: why to disclose stuttering

Participants reported a variety of purposes of disclosure including asking for increased understanding from the listener and "taking control of the circumstance that would possibly become threatening" (Chelsea). Roger stated that "I really just wanted to make sure my audience was not confused at what was happening". Although this could be pre-emptive, this request for increased understanding could occur following a negative listener reaction. As Roger described, "I need to explain to you that no, I did not forget my own name, even though it is the funniest thing in the world – that is not what just happened." Another potential goal of disclosure could be receiving certain benefits or allowances because of a disabled status. Caitlin described that people like to root for an "underdog" and described how people she knew had gotten out of speeding tickets, or received free meals after disclosing that they stuttered. Another reason to disclose was to validate one's identity as a PWS. These validating approaches appeared to serve several

Table 2
Summary of themes and subthemes from qualitative analysis.

Themes	Subthemes	Examples
Antecedents of the disclosure event	Why to disclose stuttering	Wanting to take control; wanting to feel better; wanting to be authentic; pre-empting listener confusion; receiving support or accommodations; weeding people out and identifying allies; improve communication; staying in the present moment; changing society and educating others about stuttering
	When to disclose stuttering	Professional settings; job interviews; high-stakes or consequential situations; in response to negative/confused listener reactions; with someone new that will stay in your life; when speech is (or is expected to be difficult)
The disclosure event itself	The form and content of stuttering disclosure	Simply talking and stuttering openly (not trying to conceal stuttering); voluntary stuttering; verbal disclosure before stuttering; commenting on stuttering after the fact; responding to negative listener reactions/educating others; telling the listener how they should respond
	Most helpful methods of disclosure	Direct without much elaboration and moving on to other content; educational (letting listeners know what it looks/sounds like, providing a rationale for the explanation, and letting them know they can ask questions); voluntary stuttering and referencing it; social media posts; sometimes there is no planned approach and depends on situation
	Least helpful methods of disclosure	Disclosing verbally with no follow-up educational statement; voluntary stuttering with no verbal disclosure; using confessional/apologetic wording; using poor body language; being “forced” into doing it; too much elaboration (making too big a deal out of it)
	Immediate reactions of the listener	No reaction/neutral response; gratitude that the information was shared; compassion; asking questions about stuttering; overly simplistic advice; downplaying or minimizing stuttering; silence; changing topics; social devaluation (e.g., laughter, rude comments)
Outcomes of disclosure	Individual benefits	Reduces inhibition, worry, and fear; increases authenticity; more presence in the moment; improved speaking/communicating; increased sense of dignity and self-respect
	Dyadic benefits	Opens up stuttering for conversation; listener less worried about stuttering and can better focus on message; courage impresses listeners; increases trust in a relationship; others become more open about themselves; connections with other people grow stronger; weeds out negative people
	Societal/contextual benefits	Involvement in stuttering community; helping other PWS; acting on behalf of other PWS; changing the world’s perceptions of stuttering/educating others
	Risks and potential costs of disclosure	Feeling awkward; feeling bad emotionally if listener response is negative; it can feel inconvenient; feeling that one must work extra hard to prove oneself; people perceiving the speaker as “different”; people giving unsolicited advice; people doubting that the speaker stutters; people making snap judgments about the speaker; people might discriminate against the speaker (e.g., not hiring them for a job, not promoting them at work); there is a stigma in the label or diagnosis of stuttering and risk of being stereotyped

functions including allowing PWS to be their authentic selves, weeding out negative people and identifying allies, sharing one’s experiences, and identifying with the disability community. Chelsea commented:

I think once you’re your authentic self and you know that you’ve put that out there then when it’s accepted you feel fully accepted and when it’s rejected then you, I think there’s still maybe there’s sadness ‘cause you’re human. But there’s a joy in knowing that you presented yourself and if that wasn’t what was wanted then you’re glad, you know, because you wouldn’t have wanted them. Be it a job, be it a relationship, be it, uh you know whatever it is. So being accepted for who you are because or with stuttering not in spite of it.

The issue of disclosure allowing one to be more authentic was also reflected in the observation that disclosure reduces cognitive load so that the communication interaction can be more fully focused on. Matthew remarked:

But I do think that it helps build a connection that makes my experience in the conversation more fulfilling, um, and I can just focus on the content much more than I could if I am kind of juggling content with thinking about stuttering too much... And I think that could be as simple as, you know, I could just more effectively be me. Um, focus on things that I value and communication which is connecting to my audience, which is eye contact which is being, um, you know, showing off whatever demand of that situation I can show up to more. So, it’s kind of a general goal but I do think in some ways that’s really what it comes down to is that I want to show up 100 % and in a way if I don’t disclose for the most part I’m not doing that.

From these findings, there appear to be several different reasons for disclosing including seeking increased understanding of the listener, accessing accommodations or differential treatment, validating one’s identity as PWS, and being more present and engaged during communication. These intentions and motivations for disclosure then impact the actual disclosure event itself regarding the form it takes. It should be noted that these intentions or goals are not necessarily mutually exclusive and an individual could use different types of approaches depending on the situation. Caitlin, who reported a previous history of covert stuttering noted that she believed disclosure is harder for covert PWS because in many relationships, others did not know that she stuttered. Disclosure was therefore perceived as more challenging because not only did stuttering have to be explained, but an explanation also had to be provided about why stuttering was concealed previously.

3.1.2. Subtheme: when to disclose stuttering

There were a variety of situations in which disclosure was perceived as being most beneficial. Some participants felt that disclosure was particularly useful in professional settings, or other high-stakes situations in which they felt like they were being judged, such as job interviews (although some participants noted that there can be costs associated with this as well), or giving a big presentation. These were situations in which participants mentioned that first impressions were important. As Roger stated, “I think it depends on what level of authority I have and how deeply I’m being judged by – my whole character is being judged.” Caitlin recounted her experience of working as a hostess and having to answer the telephone frequently:

... I had it really, really difficult on the phone and if I had concealed it, what would I do about that? Like, I might’ve gotten fired because, not because of my stuttering but because of, like, my avoidance of the phone, right? If I didn’t pick up the phone, that’s a problem.

Participants also mentioned that they disclose in response to negative or confused listener reaction. As Rachel explained, “Or, I stutter and they have some kind of reaction and then I just say “oh, I stutter.” Disclosure was also reported to be beneficial with someone new who is expected to be in the person’s life for a while to come, such as meeting other professionals, new clients, or family members of personal friends. It was not considered as important or likely to occur during brief and relatively inconsequential interactions with a person who was not going to remain in the person’s life. For example, Joe explained:

With that said, like if I meet someone for five seconds I don’t say, “my name is Joe I stutter.” I just say, “I’m Joe.” If I stutter, then whatever... But usually if I’ll be working with a group for long periods of time then I’ll say, “hey I’m Joe I stutter.” If I’m just like meeting a friend’s friend and the odds of me seeing them again are slim I’ll just say, “hey I’m Joe nice to meet you.” Need to move on with my life... Calling Domino’s for pizza I just I don’t say “hey I stutter.” I just kinda go with it and if I have to repeat I’ll repeat no big deal... So mainly if I’m going to be with you for a long period of time “hey this is what’s up.”

Disclosure was also perceived as helpful when speech was or was expected to be difficult. As Bill said, “During a day where speech is struggled and you acknowledge the difficulty ‘I’m struggling a little bit today.’” Others commented that the type of disclosure used depends on the situation and that there is no one way to disclose across all situations. Still, some participants felt that as they were learning how to disclose it was useful to have a relatively standard script about what to say. Matthew remarked:

It used to be a pre-made statement in all situations as I was starting advertising. Now I don’t do that as much because I’m more desensitized. I think um, when I first started disclosing I think it was no matter what at the beginning of no matter what. And I think now it really depends on kind of checking in with myself and saying to myself like do I feel that not sharing this would hinder me in expressing myself completely. So, for example if I’m ever in a position where I have to speak in front of a group. Typically, I’ll put that into my introduction before any stuttering even really happens.

Bill also discussed how as he has gotten older, he very rarely verbally discloses anymore except for right before giving a talk to a group of people. Finally, several participants mentioned that they experienced uncertainty about when to disclose, or whether they should disclose in certain situations. John described his questioning himself about why he had verbally disclosed in certain job interviews but not in others, stating “So, I actually personally find that very interesting as to the why I did for the first one but not the second one and it’s for the same, uh, company as well.” Roger also illustrated the internal dialogue about when and if to disclose during a job talk, saying:

I was like, “should I say something?”, do I need to say something or do I just get up and present well and stutter through what I need to stutter through because I know I can communicate what I need to communicate?

Tori discussed the fluidity and variability of disclosure in different situations and across different contexts:

I guess that a lot of my disclosure is also situational, so it definitely depends on who the audience is. I am doing a presentation to the board of education, I’ll choose not to disclose right off the bat sometimes, well it is a higher stakes situation, and sometimes, I’ll just hope to be a more fluent version, and if a stuttering moment comes up I may acknowledge it or I may not, depending on the reaction of the listener. It is very situational. But, I’m with my family I don’t, I am not open with my stutter. I mean there are areas that are still hard, like my family, but like the areas that are hard are usually areas that I’m not opening my stuttering.

From these findings it appears that there are a variety of perceptions about when disclosure is most beneficial and these can vary, between and within individuals who stutter. It seems that many PWS disclose in certain situations and not in others, depending on the anticipated consequences of their disclosure, or lack of disclosure. It does appear that the process of disclosure includes a planning stage of when and where to disclose, and continued monitoring of when disclosure might be needed as the communicative interaction unfolds.

3.2. Theme: the disclosure event itself

Following the antecedents described in the previous section, the disclosure event itself takes place. Participants provided information that helped to describe the actual form and content of the disclosure event, as well as most and least helpful aspects of disclosure, and the immediate reactions of the listener. The immediate listener reactions are considered a part of the disclosure event because disclosure is a communicative event involving the one who discloses and the person or people being disclosed to. The listeners’ response can also have an effect on the course of the disclosure (e.g., whether or not the PWS will continue talking about

stuttering, etc.). Therefore, the following sub-themes will detail what the disclosure event actually looks like, and how its various manifestations are experienced by PWS.

3.2.1. Subtheme: the form and content of stuttering disclosure

It was of interest to get a sense of what disclosure actually means to PWS, and how they would describe it. In that sense, the form and content of the disclosure was beneficial to probe. Participants described disclosure as taking many forms including simply talking and stuttering openly (not trying to conceal but rather focusing on communication), stuttering voluntarily, letting listeners know that they stutter before stuttering is observable (e.g., “I just want to let you know that I stutter”), commenting on stuttering after it has occurred (e.g., “You might have noticed I stutter”), responding to negative listener reactions, educating people about stuttering, and telling listeners how they should respond to stuttering (e.g., Rudy commented, “I would say ‘please give me a moment um for me to finish my sentence because I am a person who stutters’”). Disclosure was also thought of as just being open about stuttering and being willing to talk about it with other people. Stuttering can be disclosed in face-to-face interactions or on the telephone. Stuttering can also be disclosed more indirectly on social media (e.g., by liking or commenting on articles about stuttering on Facebook, etc.). Other strategies included wearing t-shirts about stuttering, and attending support groups or other gatherings of PWS. More specific examples of the form and content of disclosure events will be discussed in the next two sub-themes describing most and least helpful aspects of disclosure.

3.2.2. Subtheme: most helpful methods of disclosure

Many ideas for helpful disclosures were provided by the participants including being direct and brief in a casual or neutral manner either before or after a moment of stuttering. Bill mentioned his approach before giving a long presentation at work:

... I'd say, “Welcome, my name is Bill, and, uh, I have a little stutter when I talk but you'll get used to that.” And then boom, then I would just be off, off and running. I wouldn't say any more, any less. I thought, at least in my mind, it was a great approach. It was a little kind of a sharp jab and not, “Hi, I stutter and I'm sorry...”

Caitlin, on the other hand, preferred a bit more elaboration in her disclosures which included educating the listener about what stuttering looks and sounds like, why she wanted the listener to know about stuttering, and also letting the listener know that they can ask questions about it. She stated:

I've actually played around with, like, disclosing and then ending with like, “So, if you have any questions, let me know.” Um, I think that's always, like, a little bit more effective. Sometimes people ask questions, sometimes they don't. Um, because sometimes if I just say, “Hey, I'm a person who stutters,” um, or no, I would say something like, um, “Hey, I just wanted to let you know that I stutter.” Like, the other person just doesn't know what to say. Like, “okay, that's fine.”

Other helpful methods of disclosure included using humor, stuttering voluntarily and referencing it, or using social media to post or discuss stuttering-related issues. Talking about one's involvement in the stuttering community may also be a more indirect way of letting the topic come up naturally (e.g., discussing events or fundraising opportunities for PWS, or for four of the participants, discussing their jobs as speech-language pathologists). Rachel made the point that talking about stuttering, voluntary stuttering, or discussing the identity of a PWS is easier for her than to actually let herself stutter in front of other people and be vulnerable in that way. Even though she thought that just openly stuttering in front of others was more difficult, she believed it was a very powerful option for disclosure, stating:

I think the openly stuttering part that I feel is a way of disclosure. I know not everybody feels that way. Um, that's the hardest one. It's like a lot easier to be like, “I have ownership of this and um, I stutter and it's cool, I'm confident.” But to actually let yourself like lose control in front of another person is harder... But I am very aware when I'm letting myself stutter in front of another person. Like I'm very aware like “ok, I'm doing this right now, I'm not going to try and like rush through this stutter or this block, I'm just gonna do it”, um, and like look em' in the eye and be very there. Um, that's kind of my way of showing them that I speak differently.

Use of social media seemed to be particularly helpful to some PWS who may want to disclose to larger numbers of people at the same time. Caitlin mentioned that she wrote a blog about her therapy experiences and described that this type of disclosure “may be a cop out but I think it's easier than disclosing in person, because I'm able to explain everything and carefully craft it.” In addition, disclosing through social media may help reduce some of the awkwardness around raising the issue of stuttering to people who may not identify the individual as a PWS. This method may therefore be particularly beneficial for PWS who have previously passed as fluent speakers.

Other participants mentioned that they had no pre-planned approach that was consistently helpful, but rather that it depended on the situation. As Matthew noted, in a brief and inconsequential interaction (e.g., ordering a coffee) perhaps just voluntary stuttering may suffice to normalize stuttering without getting into an educational explanation. He elaborated that there is a lot of trial and error involved and that “It's been a lot of moments where I've like... I think a lot of the time when you wait for this perfect advertising response, you'll be waiting forever 'cause there's always will be kind of that voice saying you don't have to do this.” Some participants did not have any planned approach for disclosure in social situations, but rather felt more comfortable having the topic of stuttering come up more indirectly after getting to know someone. Rachel explained:

Socially, um, I think socially I don't have any planned approach. It's more just like people getting to know me, um, and then it

comes up that I went to this conference or that my boyfriend stutters. Or something like that. Or, I stutter and they have some kind of reaction and then I just say “oh, I stutter.” Again I just say, “oh, I stutter” I don’t like add a lot. Um, unless they really don’t seem to get what that means.

Tori described that the manner in which a person discloses and the tone they have is very important, stating:

...if I like advertise and I stutter more openly like having easier repetitions or even just like making eye contact or just like showing in my body and my face that I am like confident and comfortable, I think they’re so much more likely, it seems like they are so much more likely to just listen to me and be interested and ask me question, especially if we have conversations.

Similarly, Roger emphasized the importance of how the disclosure is made, concluding:

...when you can get to a place when you believe that confidence and effective communication is not simultaneously hand-in-hand linked with fluency of your speech, you can disclose in a much more powerful way. I think if you’re doing it in an assertive, confident, informational-based way—it’s much more helpful, its perceived much better than if you’re doing it in an apologetic way. But you’ve got to get to a place where you’re not sorry yourself.

Regardless of the approach used, it is clear from the responses that it is common for PWS spend considerable time thinking and reflecting on how to disclose in order to have maximum beneficial impact on themselves and their listeners.

3.2.3. Subtheme: Least helpful methods of disclosure

Participants also identified ways of disclosing stuttering that were not as helpful. Not all participants agreed on what is most and least helpful, but there were some trends observed regarding less helpful features. It was described that the use of voluntary stuttering, or simply stuttering openly without a follow-up verbal disclosure statement, or with a pause afterward that is not filled, can be awkward and less than optimal. Caitlin mentioned:

...sometimes I’ll consciously change the way I stutter [prolongs “s”], like that, just to let more sound out. Um, so I’ve done that before and so if I stutter openly and if that’s essentially a form of disclosure, I don’t think it’s a very effective one. Because you’re still not talking about it. And people, like, are still wondering, okay, are you nervous? Like, people just don’t know.

Participants like Caitlin also described potential downsides to social media posts that are more indirect and impersonal as a method of disclosure, stating:

For me in person there’s like a sense of relief where I feel like there’s... if for some reason I’m sensing the person is not really processing or still has a lot of judgment about stuttering there’s a conversation that could be had to share, to talk more, to have that human to human connection. And online it felt very threatening in that now the person can take that piece of information... pass judgments and kind of make a sweeping judgment about me, and I have no way to, uh, save myself [laughing]. So for me that disclosure was much more frightening.

The common thread running through the examples given is that there is a lack of interaction, or opportunity for clarification or back and forth dialogue between speaker and listener in disclosures that seem less helpful. The result is that the confusion around stuttering, or observed stuttering behavior, remains unclarified for the listener. Participants acknowledged that disclosure felt less helpful when it was apologetic or confessional in nature (i.e., feeling like they had to disclose out of necessity, feeling as if they were forced into it, or asking for patience or help). Matthew described:

I think times when I’ve found it to be less helpful or less effective is when I’m doing it out of obligation or out of like being pushed or apology and I think even the way that I frame it of like, you know, “please give me a second” or like “please bear with me” or “please be patient”. And I kind, I think in a lot of ways I don’t find that to be as fruitful... Um, and I think it kinds of colors how the other person views you know. When it happens throughout the rest of our conversation, like how uncomfortable they feel when it’s happening cause they might not feel that it’s appropriate to bring up because I’m not comfortable with it.

Body language was also relevant for unhelpful disclosures, particularly when body language and tone does not match the verbal content of the disclosure. Chelsea commented:

...voluntary stuttering and looking down or disclosing and apologizing, or um, disclosing but the way that my body posture, my body language is saying a very, telling a different story. Ok, so you might be saying “oh yeah I stutter,” but everything in me is screaming “I don’t want to be saying this right now.” So there’s like a disconnect between me being willing to say the words but I clearly didn’t integrate this as something I truly accept and I think the listener can see that so. That’s big, yeah.

Rachel remarked that too much elaboration or focus on stuttering seemed to make too big of a deal out of stuttering, stating:

...but I like doing it in a functional way like that as opposed to like asking for patience or like making a joke about it or something. Because I feel like that’s a little too much, you’re attaching way too much baggage onto it... so I was never really comfortable with, uh, stuttering and then stopping and like making a little joke about it or something I didn’t really know how to do that, it didn’t come naturally to me.

She also commented that voluntary stuttering, although a popular therapy technique in certain programs, was very difficult to do in everyday life and questioned its utility as a disclosure strategy. Finally, some participants noted that verbally disclosing identity of

a person who stutters during fluent speech production can be difficult and that it can feel easier to comment on genuine or purposeful moments of stuttering.

3.2.4. Subtheme: Immediate reactions of the listener

Most participants mentioned that likely the most common response they received from disclosing stuttering was the lack of a discernable reaction, a very neutral response (e.g., “cool,” “okay,” “oh”), or that the disclosure was received positively. Some listeners respond with compassion and appeared grateful that the information was shared. Others may have asked questions about stuttering to learn more about it. Stuttering openly, however, can lead to some unhelpful reactions including the listener(s) offering overly simplistic advice (e.g., “Just take your time”), or downplaying the stuttering (e.g., “You don’t really stutter” or “I would have never noticed”). Less frequently, open stuttering resulted in negative responses such as laughter, rude comments or jokes, or other types of social devaluation like not being deemed appropriate for certain jobs. For example, Joane and Bill mentioned instances of being laughed at when ordering food at restaurants. Audrey recounted people making jokes when she blocked on the name of her employer when answering the phone (e.g. “Did you forget where you work?”). Caitlin and Rachel both commented that potential employers had told them that they did not think it was possible for them to have certain jobs if they stuttered. However, according to the participants, more blatant negative reactions like laughter or joke making rarely occurred when stuttering was accompanied by a verbal disclosure statement that mentioned stuttering specifically. Matthew remarked:

Very rarely have I gotten a negative response from that advertising. I feel that for the most part people understand to a degree where they know that it’s not something they, you know, should laugh about or should smile about. It’s, you know, once they understand it’s part of how I speak. They’re more engaged with me as a person than as this oddity.

This suggests that verbal disclosure about stuttering can be helpful in improving overt listener reactions. It also supports the notion, described previously, that simply voluntary stuttering, or stuttering openly, without a verbal acknowledgment might leave too much up to listener interpretation. What also seems clear is that compared to participants’ interactions in which they did not openly disclose stuttering, situations in which they were more open and willing to talk about stuttering resulted in much better listener responses. Matthew described the difference in detail when he stated:

I think once I was able to start disclosing, people had a name for it. People understood that it was not something that they had to wonder about. I think people, again, if the emotion I transferred when I disclosed was, you know, just addressing what was in the room, they didn’t have to. And they didn’t have to feel that discomfort because I wasn’t giving it to them to feel. I think people, I think the conversations I have now, especially when I meet new people or friends of friends or experiences like that, I’m much more myself and I can just get to know people much more quickly.

Rachel echoed this sentiment by recounting various internship experiences she had, emphasizing the benefits that being more open about stuttering had in terms of better listener reactions:

The strongest comparison I can make is I did an internship as a student when I was 20 or maybe 19 and, um, I was concealing my stuttering as best I could. And it was just not a good experience. Like I could tell that they weren’t very fond of me. I wasn’t really totally engaged there I was very anxious about how I was being perceived and what I was doing. Um, they didn’t ask me back like to work there or anything like that. Um, and then the next summer I started being open about it and, um, like I had a lot more success in internships with jobs.

3.3. Theme: outcomes of disclosure

Participants described several different types of perceived outcomes resulting from disclosure of stuttering which can be categorized at the individual, dyadic, and societal/contextual levels. Participants described the benefits of disclosure, as well as potential challenges associated with it. These different types of outcomes will be described in the following sections.

3.3.1. Subtheme: individual benefits

One primary benefit of being open noted among participants at an individual level was a sense of reduced worry or anxiety. Disclosure can reduce fear, burden, and struggle, and help a person feel more at ease. Disclosure can increase a person’s confidence and comfort, and may actually result in reduced stuttering. As Bill Mentioned:

...after that I wouldn’t stutter for the rest of the four hours, but I just was just- it was just like taking a weight off your shoulders to just acknowledge it in one way or another so that was- that’s really helped me a lot about just acknowledging it.

It was also noted that disclosure can help increase feelings of authenticity, dignity, and self-respect. As Chelsea mentioned, “The first and foremost benefit is being able to be your authentic self. So to be able to show up fully in this world with all parts of yourself being equally valued. So that’s the biggest thing.” Audrey also described the issue of authenticity, stating:

...I began to actually recognize that I had an authentic self and began to like, um, allow let that authentic self out and, um, embraced that um the advantage was that this person – part of that fragmented self who thought she was voiceless and unworthy of being heard was and did have a voice that deserved to be heard. That it had been there all along; I just hadn’t given it license or permission to, um, come out.

In addition, disclosing can help with feeling more present during communication, possibly because the cognitive load associated with worrying about what listeners are thinking can be reduced after disclosure. Matthew commented:

I kind of see disclosure first and foremost as a tool that I use to fully engage in a conversation to fully be present cause there is you know there's always that background noise that is still there that says to me sometimes you know, "you don't have to talk, you don't have to introduce yourself, maybe you don't have to say this word." And I kind of have found disclosure to make the environment just safer to stutter. Then I don't have to feel as much of an urge to hide it or play that game where I'm trying to convince someone that I'm fluent. I can just kind of put it in its place and not try to make it into anything that it's not.

3.3.2. Subtheme: dyadic benefits

There were several benefits mentioned by participants that also have a positive impact on the listener and the communicative interaction overall. By addressing stuttering, a PWS can address listener curiosity about why their speech is produced differently. The listener can therefore pay more attention to the content of what is being said, rather than using cognitive resources to figure out what is happening. Disclosure can dispel misinterpretations from other people. Caitlin described:

Because I have blocks, I have to clarify. People either think that, like, I forgot my name, or forgot something or I'm having a seizure or I'm really nervous so disclosing, to me, means kinda clarifying that. And it also means that I'm opening up the doors to them so it's not this elephant in the room. Um, so that like if they wanna ask me a question or if they have, you know- some people just don't know whether they should finish my sentence or not, they know that like, okay, I've kind of opened up to them so they can ask any questions they may have.

Many participants also noted that they believe their connection with the listener is strengthened as a result of disclosure because other people are more willing to be vulnerable with them as well. Being open about a difficult condition that one is dealing with can break through a façade more quickly. As a result, interesting and honest conversations can be had. As Chelsea mentioned, "...the other thing is, side effect, is that other people have permission to be themselves. So it's kind of like a positive domino effect." Matthew reported:

... when I have been open there have been so many moments that my connection with other people have been strengthened because in a way, I think disclosure is vulnerability. It's making that decision to make yourself vulnerable and open up about something that might not be comfortable. And I think it's given people in my life, not everyone but a lot of people, have kind of responded with their own struggle and their own experiences that have kind of helped to bring us closer and have strengthened our connection.

3.3.3. Subtheme: Societal/contextual benefits

Other benefits of disclosure extended beyond either personal or dyadic outcomes into the realm of changing society. This could occur through a variety of mechanisms including educating the public about stuttering, or empowering other PWS and their family members to be active in the stuttering community. Matthew described clearly how educating other people about stuttering has an impact on how those individuals react to PWS in the future. He remarked:

I think a major advantage that I've found is that there's so much misinformation out there about stuttering and I think so many people that I've met when I've asked them and got into conversations – even some of my closest friends and family just had blatantly false assumptions about what stuttering was and I think by being open and by disclosing it – even if its someone that I've known forever by saying those words, it kind of opened the door for them to understand what this is. So, in my communication interactions with them I don't have to wonder what they're thinking 'cause they know. And as I've kind of worked on my stuttering for a good amount of years now I kind of see that now when they interact with another person who stutters they're not gonna have these assumptions anymore. That, you know, the person is not intelligent or they're really anxious or you know all these things that we know are false but just in our everyday experience and pop culture and the media is what we're fed. Um, so I think that's kind of a major one that I've seen.

Tori expressed a similar sentiment about finding purpose in educating society about stuttering so that environmental barriers might be reduced for other PWS. She concluded:

I think it's my mission to like, change the world. So that someone else doesn't have a bad reaction. So I'll just, explain to them, "oh you know, actually I do stutter, it actually doesn't have anything to do with anxiety or like, I'm not nervous, that's not why people stutter. It's something about, like, our brains work differently," you know, depending on their interest level, I'll educate them a lot.

Rachel illustrated how being open about stuttering can be difficult, but increased motivation to disclose can come from thinking about helping not only herself, but the stuttering community by being open about the condition. She reported:

...one of the biggest things for me about it is that when it's really hard for me to do and I don't want to do it, um, or I did it and it didn't go well and I feel still really embarrassed about it - Um, just thinking about other people who stutter and like, ok, I said something here however it went, um, there are other people who stutter and I'm also doing this on their behalf. That's like one of the, the self-respect and dignity thing and then that one are the two most powerful ones.

Audrey also mentioned that she has found value in giving back to the community of PWS, and helping them and their families

through self-help/support organizations. She noted:

...just like a whole new world and you know I um found myself um liking the National Stuttering Association and getting involved and got involved with the Friends community and realized that like wow, I could share my story with parents of kids who stutter, and that whole purpose thing just uh materialized, and yeah, it was kind of neat.

3.3.4. Subtheme: Risks and potential costs of disclosure

Participants reported that disclosure of stuttering came with certain risks or potential costs, in addition to the many benefits it yields. These potential negative outcomes included the fact that it can feel awkward, and a PWS might feel bad emotionally if a positive response from the listener is not received. In addition, negative or less than helpful responses can be received (e.g., downplaying the stuttering, or being given overly simplistic advice). For example Caitlin described, "...sometimes if I disclose in the times that I am more fluent, people are like, 'No, you don't stutter!' or 'No, you don't stutter that much, it's fine.' And that always makes me have a lot of shame..." Some participants noted that they can feel judged from people who are misinformed about stuttering and worry about being judged negatively from those types of people. This worry is especially apparent in situations in which snap judgments can occur when trying to establish a potentially meaningful and long-term relationship, including job interviews or online dating. Caitlin made the following comment about the difficulty with snap judgments that can come from the label of "stuttering":

We were talking about disclosing through dating apps and I didn't disclose through, um, the dating app that I was on because I wanted to clarify it in person. So, I felt like, if I had put, "I'm a person who stutters" on the app, then the person might not swipe for me because they might have their own, kind of, stigma and stereotypes, um, attached to that word. And I wanted to go in there and kind of clarify it for them.

Even for people like Chelsea and Rachel who have been very active in the self-help world, negative thoughts about being open about stuttering lingered. In addition, openly stuttering can be associated with feelings of discomfort or vulnerability, as well as physiological stress. Chelsea noted:

...to conceal this you might come across as wittier, smarter a lot of the, a lot of the a sort of a the stereotypes that we know some people might have or that the public might still have. Um, and it's sort of when you conceal it you bypass all of the having to be ... I made a conscious choice not use any strategies, no tricks and I actually let my stutter rip and that was a conscious choice and it was terrifying, and I came home after and I was like "you're crazy" and I got really emotional about it because it was, um, it was really scary so I think there's still an ongoing process that, until today that that I'm in.

Rachel also commented that sometimes she worries about how other people view her because of her stuttering. She noted:

I think it's scary for me to think about a little bit because we often don't know what people think of us. Um, and I think I tend to think nowadays that stuttering is not a big deal to anyone else. But I, if I really think about it hard I'm like I'm sure there are people or there are groups that sort of like... sometimes I worry like socially. Um, at work I have like, I feel like I fit in at work but there are sometimes when I'm like I wonder if like people see me as like someone else. Like a different type of person, um, because of this.

Stuttering openly can potentially have negative results at work settings, including being vulnerable to discrimination. Rachel described difficulties in previous job interviews, stating:

I've had a few experiences, like job interviews and stuff, um, where I was open about it, answered a bunch of questions about it and then was basically like told "wow, that's so impressive that you did all of that but we don't think we could have you at this job if you stutter."

Audrey, who reported stuttering covertly and passing as fluent when she was younger, described how her open stuttering at work led to her being fired from her job, noting:

Gradually, my strategies and tricks and tools began to erode and not work successfully. So, I began finding that I was uh suddenly stuttering openly at work, and I was actually fired from a job because of stuttering. I had had the job for twenty years. Yeah, it was a very difficult situation.

Tori mentioned how being open about stuttering can feel less convenient than avoiding, and that stuttering openly can be fatiguing and challenging. She commented:

It's just inconvenient. And that's the hard thing for me. Like I would love to just be like 100 % authentically stuttering, with my real voice and not avoid... it's just like I'm stuttering a lot. Especially for me, if I like, am totally open and totally myself and stutter, it would take forever.

Despite these challenges associated with disclosure, participants overall noted that the costs of continued concealment were much higher than the costs of disclosure. In other words, even though disclosure can come with benefits and challenges, the benefits were far greater in the long term. As Rachel stated, "I mean the worst thing is just stuttering and feeling terrible about it and not mentioning it." Caitlin also remarked, "Like, the act of avoiding stuttering was, like, a hundred times worse than the stuttering itself."

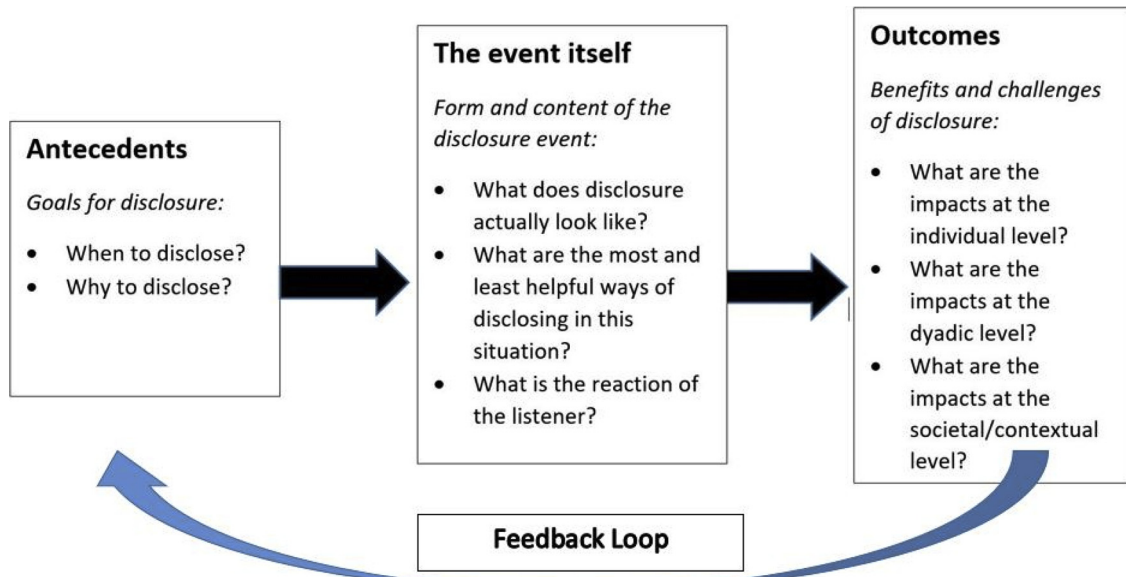


Fig. 1. A model of the process of disclosure events for stuttering. Adapted from Chaudoir and Quinn (2010).

4. Discussion

The hypothesis generated from this grounded theory analysis is that acts of disclosure among PWS have multiple components. The process of disclosure is comprised of antecedents (including considerations for when and why to disclose), the event itself (consisting of the actual form and content of the disclosure along with immediate listener reactions), and the outcomes of the disclosure at individual, dyadic, and social/contextual levels. Consistent with the data collected, and the prior theory of Chaudoir and Fisher (2010), we propose that these various components in this process are connected in various ways. Specifically, the goals for disclosure have an impact on the form and content of the disclosure event itself, which also has an impact on listener reactions. The person's goals for disclosing and how they disclosed also have an impact on the perceived outcomes of disclosure. This process creates a feedback loop in which the perceived outcomes of disclosure (either positive or negative) influence future decisions regarding when and why to disclose, and this process continues. See Fig. 1 for our proposed model of the disclosure process that displays its different components and how they are related.

It appears from the data that specific strategies used for disclosure can be context dependent and are not mutually exclusive. That is, any individual who stutters can exhibit different types of goals and methods for disclosure, depending on the situation they are in, rather than consistently exhibiting the same types of intentions and behaviors. This finding that disclosure methods are context dependent and that multiple types can be used simultaneously supports recent findings of Evans (2019). Even individuals who have ample experience in self-help, and are considered leaders in stuttering advocacy, have particular situations in which they grapple with whether they want other people to know that they stutter. It appears that PWS may be more or less comfortable with the identity of a PWS in different contexts, which supports previous literature describing that disclosure approaches are situationally-based (Corrigan, 2005). It is possible that the more consistently the PWS affirms the identity of a PWS across different situations, the less fragmented and more authentic they will feel.

We also propose that the goals that PWS have for disclosure can impact the nature of the disclosure event and its perceived outcomes. For example, people who want to avoid negative reactions from listeners may attempt to conceal their stuttering, and if they are successful in concealing and do not receive a negative listener response, they are more likely to conceal in a future situation. Or, a PWS may disclose only when asking someone for help. As a result, their disclosure may feel apologetic or confessional in nature which then may be reacted to more negatively by the listener, making it unlikely that the PWS will want to disclose again. In contrast, if someone has a disclosure goal of feeling authentic, or helping to reduce societal stigma, they may come across as more confident which may improve listener reaction and perceived outcomes, making it more likely the person will disclose in a similar way later on. In addition, goals for disclosure may impact how the PWS perceives listener reactions. For example, if a PWS has goals of being authentic, or to advocate for PWS, a negative listener reaction may not be perceived as negatively by that individual because they may be focused on the potential positive effects of what occurred, or their progress toward a desired goal. However, if a PWS has a goal of concealment or avoidance, a negative listener reaction could make them feel like a failure and reduce their disclosures in the future. Therefore, the intent behind the disclosure (i.e., avoiding an anticipated negative reaction compared to approaching a goal in a pragmatic or validating way) appears to be crucial for what follows in the disclosure process.

4.1. Theoretical and clinical applications

The current results support prior qualitative (Plexico et al., 2009b) and quantitative (Boyle et al., 2018) research in the area of stuttering that suggested positive links between being open about stuttering and enhanced communicative functioning and quality of life. The results of this study also support findings by McGill et al. (2018) which found a variety of different types of disclosure statements, however the current qualitative results add rich and nuanced information about when and why PWS disclose their stuttering, and illustrate a variety of approaches for that disclosure, beyond verbal statements. The current study also adds to knowledge about self-perceived outcomes of disclosure. Disclosure of stuttering can be thought of as an ongoing public relations decision-making process (Evans, 2019). Each disclosure event can be thought of therefore as an instance of stigma management (Goffman, 1963). Disclosure as an event is an important mechanism for managing one's identity in relation to disability (Chaudoir & Fisher, 2010). In essence, with each disclosure decision the person is asking themselves if they want to be known as a PWS in that situation. The current findings can add nuance to how disclosure is handled in clinical treatment of PWS. Rather than viewing the process of disclosure as consistent or static, it can be viewed as highly variable and dynamic. Speech-language pathologists could demonstrate their knowledge of the complexities of this issue by helping their clients who stutter come to their own decisions about disclosure through helping clients weigh the benefits and costs of disclosure across different situations with different people, brainstorming different ways of disclosing in various circumstances, and engaging in role play activities before using them in real life situations.

Another factor to consider clinically from the current results is that there may be important precursors to having successful disclosures in real life situations. Participants reported that disclosure was less effective when they felt forced into it. Instead, they felt that certain foundational experiences were important to consider. Therefore, it would appear to be very useful to screen new clients for high levels of avoidance. If a client reports high levels of avoidance of stuttering, or avoidance of speech situations, then approach-focused goals could be developed. These may include teaching the client effective communication skills, increasing coping skills for negative listener responses, improving client attitudes about stuttering, and desensitization to stuttering through stuttering modification and avoidance reduction approaches. Although it is most likely impossible for early disclosure experiences to be completely free of discomfort, it seems important to build a client's confidence, acceptance, and coping skills before expecting verbal disclosures in a variety of real-life situations. When verbal disclosures in real-life situations begin, they should move from less to more difficult situations to minimize negative listener reactions early in the process, or else the client may feel like disclosing less in the future (Chaudoir & Quinn, 2010).

4.2. Limitations and future directions

Despite the benefits of using purposeful sampling in this study, the sample obtained mostly identified as White, non-Hispanic, indicating a lack of ethnic diversity in the sample. Previous research by Daniels, Hagstrom, and Gabel (2006) demonstrated the complexities and importance of understanding how ethnicity and culture interact with identity management in stuttering. Therefore, future research should attempt to account for this cultural and ethnic diversity related to the disclosure processes of PWS. In addition, it will be important for future research to test the theory described in this study with a variety of samples of PWS in order to establish its external generalizability. Although establishing external generalizability of the findings through probability sampling was not an objective of this study (and therefore the recruitment of self-help activists and speech-language pathologists through purposeful sampling is viewed as a strength rather than limitation of the study), it will be important to utilize other samples that include a greater variety of PWS to answer other questions about disclosure. For example, how do personal variables such as age, gender, occupation, physical speech disruption severity, self-esteem, the ability to pass as fluent, and extraversion impact utilization of disclosure and how it is utilized? Future qualitative and quantitative research could address these questions going forward.

Also, this study focused on the process of disclosure events, rather than the longer-term process of alternating between concealment and openness over one's life. Data on the long-term change process was collected as a part of this project, however, the density of the data collected and our intent to focus on disclosure events themselves prevented us from reporting on this information in the current paper. A future report will expand on the change process over time, and specifically focus on life events and experiences (e.g., exposure to quality therapy or self-help/support opportunities) that cultivated a sense of increased openness about stuttering. It will also be important for future research to clarify an operational definition of disclosure in order to increase reliability of its measurement. For example, this study illustrates that self-disclosure can extend beyond verbal disclosure statements and can include various methods involving making stuttering more visible to other people. For this reason, it is suggested that an operational definition of disclosure as "making the identity of a person who stutters known and visible to other people" is general enough to capture the variability of how this identifying information is expressed and made visible to other people. This identifying information can be shared through verbal disclosure statements, but it can also be shared by letting others see and hear stuttering.

4.3. Conclusion

The ultimate goal of this research is to allow professionals and advocates to better help PWS in making optimal decisions about disclosure of stuttering. Gaining a better understanding of disclosure events among PWS will help to achieve that goal. Disclosure is a critical construct for PWS because it increases understanding of how one manages an identity related to stuttering. PWS making good decisions about disclosure can likely increase their quality of life through reduced internalized stigma, alleviation of inhibition, and increased social support. Therefore, acquiring a better understanding disclosure events and applying that knowledge to clinical

practice will likely result in enhanced communicative outcomes for individuals who stutter. Furthermore, effective disclosure of stuttering can have the additional positive impact of improving societal attitudes toward stuttering and therefore reducing environmental communicative barriers faced by PWS.

Acknowledgments

This project was partially funded by the Advancing Academic Research Careers (AARC) Award from the American Speech-Language-Hearing Association in the United States, awarded to the first author. Funding was also received from the National Stuttering Association Research Fund Award, which was awarded to both authors, from the National Stuttering Association in the United States.

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