“Not Unless It’s a Life or Death Thing”: A Qualitative Study of the Health Care Experiences of Adults Who Stutter

Hector R. Perez, MD¹, Camilo Doig-Acuña, BSc², and Joanna L. Starrels, MD, MS³

¹Primary Care Research Fellow, New York University School of Medicine, New York, NY, USA; ²New York University School of Medicine, New York, NY, USA; ³Division of General Internal Medicine, Albert Einstein College of Medicine and Montefiore Medical Center, Bronx, NY, USA.

BACKGROUND: For adults who stutter, communication difficulties can impact many spheres of life. Previous studies have not examined how stuttering might impact patient’s experiences with the medical system.

OBJECTIVE: Our objective was to understand the range and depth of experiences with the medical system among adults who stutter.

DESIGN: This was a qualitative study using age-stratified focus groups.

PARTICIPANTS: Sixteen adults who stutter were recruited at a national conference about stuttering.

APPROACH: We conducted three focus groups. Participants also completed a written questionnaire about sociodemographic characteristics, health status, and the impact of stuttering on their life [using the St. Louis Inventory of Life Perspectives Scale (SL-ILP-S) Total Effect Score]. We analyzed data using an iterative, thematic analysis, with an inductive approach, at a semantic level.

KEY RESULTS: Participants were mostly (75 %) male and resided throughout the United States. The mean SL-ILP-S Total Effect Score was 27.3, indicating that stuttering caused minimal concern in participants’ lives. Despite this, we identified five themes that characterize ways in which stuttering affects interactions with the medical system. Participants described (1) discomfort speaking with office staff and physicians, which resulted in (2) avoiding health care interactions because of stuttering, and (3) relying on a third party to navigate the medical system. During visits with physicians, participants felt that (4) discussing stuttering with physicians required trust and rapport, and (5) speaking assertively with physicians required self-acceptance of their stuttering.

CONCLUSIONS: We identified ways in which stuttering affects medical interactions. These results highlight the need for increased awareness and training for medical staff and physicians when caring for persons who stutter. Future studies among diverse samples of stutters can determine the effects of stuttering on medical interactions, and inform the development of interventions to provide high quality health care for adults who stutter.

KEY WORDS: health care systems; communication; communication disorders; stuttering; health disparities; disabilities; qualitative research; access to care.

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INTRODUCTION

Stuttering is characterized by disruptions in verbal fluency, typified by frequent, non-controllable audible or silent repetitions or prolongations of speech.¹ Data on the prevalence of stuttering are limited, but one study of 12,000 Australian individuals of all ages found a prevalence of 0.72 %, which is comparable to estimates of the prevalence of blindness or rheumatoid arthritis.^{2–4} Stuttering frequency and severity are often increased in situations of high stress, when talking on the telephone, or when talking with authority figures like police officers or physicians.⁵ Discomfort about speaking can lead to prominent avoidance behaviors, such as opting out of social or workplace obligations.^{6,7} Adults who stutter report lower quality of life, poorer social and emotional functioning, and poorer self-perceived mental health compared to adults who do not stutter.^{8,9}

Interacting with the medical system presents a challenging set of scenarios for the adult who stutters. Scheduling appointments, interacting with busy office staff, and other tasks that are necessary to access and to navigate the medical system can be particularly difficult for people with disabilities.¹⁰ Moreover, the medical encounter itself may be challenging for the person who stutters because of time constraints, difficulty talking to authority figures, or difficulty talking about sensitive issues. The extent to which these challenges exist for persons who stutter is unknown, and no previous studies have focused on stutters’ experiences interacting with the medical system. Therefore, we conducted a qualitative study of adults who stutter in order to begin to understand the range and depth of their experiences with the medical system.

METHODS

Setting and Participants

We conducted a qualitative study utilizing focus groups to capitalize on participants’ shared medical experiences.

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Because this is a population that is difficult to identify, for example, through medical record review of ICD-9 codes, we recruited a convenience sample of adults who stutter from among attendees of the National Stuttering Association conference in St. Petersburg, Florida in July 2012. Participants were recruited through fliers announcing the study at a table near the conference registration site. In order to be eligible for the study, participants had to self-identify as a person who stutters, be at least 18 years old, and speak English. Written informed consent was obtained from all focus group participants by H.R.P., a physician who stutters, at the time of recruitment. The Albert Einstein College of Medicine Institutional Review Board and the National Stuttering Association Research Committee approved the study.

Data Collection

Each participant completed a questionnaire to collect data about sociodemographic characteristics, health status, and the impact of stuttering on their life. Sociodemographic variables included age category (18–35, 36–49, 50+ years), current employment status, and geographic region of residence. Self-reported health status was measured using a one question screen adapted from the Behavioral Risk Factor Surveillance System (BRFSS) survey: “Would you say in general your health is—?” with five response options ranging from excellent to poor.¹¹ We also asked participants whether they had one or more physicians they considered their primary care doctor. We assessed the impact of stuttering in our participants’ lives using the St. Louis Inventory of Life Perspectives (SL-ILP-S) Total Effect Score, a summed score based on responses to eight items along a nine-point Likert-type scale.¹² The SL-ILP-S asks participants to assign self-ratings of disability related to speech. Similar to a previous study, each participant was classified into one of five categories based on the SL-ILP-S Total Effect Score: no concern about the impact of stuttering on their life (score 0–15), minimal concern (16–31), moderate concern (32–55), substantial concern (56–71), and extreme concern (72).

We grouped participants into three focus groups based on age category (18–30, 30–49, 50+ years) with the goal of enhancing participants’ comfort discussing health-related information. All focus groups were conducted by H.R.P., a physician who stutters, during the NSA conference, and lasted 45–60 min. Focus group questions were open-ended and aimed to understand participants’ experiences with health care before, during, and after medical encounters. Example questions included: “Do you believe your stuttering limited your ability to communicate with your doctor in any way? If so, how?” Focus groups were audio-recorded and professionally transcribed. While individual speakers could be identified in the transcripts, questionnaires were completed anonymously due to concerns about privacy, so these could not be linked to individuals in the transcripts.

Data Analysis

To describe participant characteristics, we determined the proportion of participants in each category of gender, age, geographic region, occupation, relationship with a primary care provider, and health status. In addition, we determined the proportion of participants in each SL-ILP-S Total Effect Score category, and we calculated the mean SL-ILP-S Total Effect Score of our sample.

For qualitative analysis of participant transcripts, we used an iterative, inductive thematic analysis approach to identify themes about stuttering and medical experiences. First, H.R.P. created an initial codebook based on semantic analysis of all focus group transcripts. The initial codebook was refined through iterative review of transcript data by two authors (H.R.P. and J.L.S.). Members of the interdisciplinary qualitative research group in the Einstein and Montefiore Division of General Internal Medicine (four physician-investigators and general internists, a psychologist, and two public health researchers) assisted with selective review of codes and transcript data during two qualitative workshops. Using the final coding scheme, two independent reviewers (H.R.P. and C.D.A.) coded all transcripts using NVivo software (QSR International Pty Ltd. Version 10, 2012). Discrepancies in coding were resolved by consensus. All study team members except H.R.P. are non-stutterers. We applied the constant comparative method^{13,14} to categorize and arrange codes to identify important themes and to understand how the themes related to each other.

RESULTS

Sixteen adults who stutter participated in the study (See Table 1 for participant characteristics). Most were male (75 %),

Table 1. Characteristics of Focus Group Participants (N=16)

Characteristic	N (%)	Characteristic	N (%)
Male	12 (75)	Health status	
		Excellent	6 (38)
Age		Very Good	6 (38)
18–35	6 (38)	Good	2 (13)
36–50	5 (31)	Fair	2 (13)
50–75	4 (25)	Poor	0 (0)
75+	1 (6)	Have one or more	14 (88)
		Primary Care	
Geographic Region		Physicians (PCP)?	
Northeast	5 (31)	Last visit to PCP	
South	4 (25)	Within past year	12 (75)
Midwest	1 (6)	Within past 2 years	2 (13)
West	6 (38)	Within past 5 Years	1 (6)
Occupation		5 or more years ago	1 (6)
Employed	14 (88)	Stuttering total effect*	
Unemployed	1 (6)	No concern	5 (31)
Retired	1 (6)	Minimal concern	7 (44)
		Moderate concern	3 (19)
		Substantial concern	1 (6)
		Extreme concern	0 (0)

*Total Effect Score as measured by the St. Louis Inventory of Life Perspectives (SL-ILP-S). This produces a score that purports to measure the sum total effects of stuttering on the life of the participant

employed (88 %), and described their health as “excellent” or “very good” (75 %) and described the impact of stuttering on their life as of “no” or “minimal” concern (75 %). The mean SL-ILP-S Total Effect Score was 27.3 out of a maximum of 72 (range 10–59, SD 14.5), indicating that on average, stuttering was considered to be of “Minimal Concern” in participants’ lives.

Qualitative analysis revealed five specific ways in which stuttering affects interactions with the medical system. Participants described (1) discomfort speaking with office staff and physicians, which resulted in (2) avoiding health care interactions because of stuttering, and (3) relying on a third party to navigate the medical system. During visits with physicians, participants felt that (4) discussing stuttering with physicians required trust and rapport, and (5) speaking assertively with physicians required self-acceptance of their stuttering. Below, we describe each of these themes and provide exemplary quotes.

Discomfort Speaking with Office Staff and Physicians.

Participants described discomfort with speaking, particularly with office staff and less notably with physicians. Communicating with office staff over the telephone was a particular cause of discomfort. For example, one participant said, “I’m calling [the office] back, and it’s like more talking... I just don’t want to deal with the anxiety surrounding that.” Another participant said, “They just assume that no one’s on the phone. They say ‘hello?, hello?, hello?’, and then just hang up, because I think they’re just very impatient... Calling on the phone to make an appointment, I think that’s harder than talking to your doctor.” Similarly, many participants felt uncomfortable speaking with office staff when arriving for an appointment because of perceived time pressures. One participant said, “They [office staff] want you to hurry up and say [your name and reason for being there]. It’s just harder for us because we stutter.” Another participant said, “When I go in and tell the receptionist my name, I feel nervous and I feel rushed and... I can’t get my name out... so I’m forced to spell out my own name.”

Conversely, most participants reported less discomfort speaking with their physicians, particularly when relationships were longstanding, but still cited instances when speaking was uncomfortable. One participant said, “I don’t feel rushed. I feel like if I need to talk to him [my physician] about this or that, I can.” One participant reported that discussing certain topics was difficult: “The stuttering is never a problem because I know [my physician] very well... However, when I am not doing what she says to do, then the anxiety [about speaking] does set in.” While some patients did not cite specific problems with communication with their physicians, many used language that reflected the importance of a physician becoming accustomed to their manner of speaking: “I’ve been going to the doctor for about 10 years now, so he’s more used to my speech.”

Avoiding Health Care Interactions Because of Stuttering.

Chronic discomfort with speaking caused some participants

to selectively avoid speaking, which sometimes prevented them from seeking or obtaining medical care. One participant said that during times when his stuttering is very bad, he “just want[s] to stay inside all day and send emails and text messages.” For some participants, this tendency to avoid speaking may impact healthcare seeking. One participant said about missing a telephone call from a physician’s office to schedule an appointment, “I don’t call back, because I don’t want to state why I called or my name or why I need to go... There are times where I have an appointment... but I don’t go because I missed their call.” That same participant reported that her avoidance was not limited to speaking over the telephone: “I don’t go in unless I need to—unless it’s like a life-or-death thing... because I don’t want to talk and explain in great detail what’s going on.” Others recalled times in their lives when their stuttering may have impacted their desire to seek medical care. For example, “I may have avoided seeking routine medical care when I could have because I didn’t want that interaction... I just didn’t want to expose myself as a person who stutters.”

Participants described changes in other health related behaviors as well. A participant said she had difficulty getting medications because she avoided making phone calls: “Having to get refills, you have to leave a message for the nurse. Quite often I end up waiting until it’s almost too late.” During medical visits, one participant said she avoided discussing certain topics: “There have been small things here or there that I would like to bring up and check on but I didn’t bring them up because I couldn’t say them.”

Relying on a Third Party to Navigate the Medical System.

Participants described how they relied on close family or friends to speak for them when interacting with the medical system. Many were explicit about how involving a third party relieved some of their discomfort with speaking. One participant said, “I’ll ask my mom or my grandmother to call in because I just don’t feel like going through all of that anxiety.” Likewise, a young participant reflected on when her mother could speak for her during doctor’s visits, reporting that she felt daunted by the transition from adolescent clinic: “I spoke with [my mother] at home about what was going on. Once we got to the doctor... things were fixed right then. But now since it is just me, I don’t key in on things unless I need to.” For older participants, speaking through others during visits was less common. Nonetheless, some participants reported using significant others or secretaries as proxies, particularly when making telephone appointments: “Making an appointment is hard [because of my stuttering]... I have my secretary call.”

Discussing Stuttering with Physicians Requires Trust and Rapport. Some participants resisted or avoided discussing stuttering with their physicians, even when stuttering caused negative health consequences, because they did not trust that

their physicians could provide help or because they lacked rapport with their physicians. Conversely, some participants described instances when discussing stuttering with physicians helped to build rapport and to increase trust.

Several participants did not see value in discussing stuttering with their physicians, because they did not trust that their doctors would understand their concerns or provide them any help. One participant said, "I certainly never would have told [my old doctor] that I stuttered. She would probably say 'maybe you should slow down' or 'maybe you should think about what you want to say,' [or] 'I don't hear you stuttering.'" Likewise, another respondent said, "What I don't appreciate is when a doctor pretends they know how to treat you for stuttering... [I would like them] to be mindful of where their competence lies." Some participants bemoaned the lack of medical education about stuttering, and one participant who is a physician noted, "When I was in medical school, they didn't focus on stuttering." Another participant added, "[Physicians] should be trained to recognize stuttering and then suggest programs or good speech therapists they could refer you to."

Because stuttering was uncomfortable and sometimes embarrassing to participants, good rapport between patient and physician was essential before discussing stuttering. For instance, one participant said that he was "taken aback" when his doctor asked about his stuttering. That participant recounted: "I saw this doctor and he said, 'I do notice that you have a stutter,' and it was very strange. I got kind of upset." He reported he felt unable to connect to that physician for the remainder of their visit: "He didn't have much tact. If he would ease into the question then I wouldn't be so offended." Another participant reported that one doctor she visited offered her what she thought were inappropriate medications without any sensitivity about her stuttering: "[He] has never brought [my stuttering] up, other than noticing I was nervous talking to him and [asking if] I want any kind of tranquilizer." Some participants tried to hide their stuttering and related struggles from their physicians. One participant said, "I was covert [about my stuttering] for many, many years... I wasn't interested in opening up to her about it. I put up a pretty thick wall." For this participant, she not only resisted speaking about her stuttering, which was causing her a great deal of stress and anxiety at work, but actively hid it from her physician. She continued, "I was having really bad panic attacks at work... I was worried that I was not able to function."

Still, other participants described examples of how discussing stuttering with their physicians was meaningful and allowed them to better discuss topics of importance to them. This relied on trust and rapport between patient and physician. One participant recounted her feelings about how her long-time physician had handled a life-changing event. She said, "Right after my dad had passed away, I was having a whole lot more difficulty talking. [My physician] asked, 'why are you stuttering so much more?'... She was always able to

bring it up [with me]." The participant above who described disabling panic attacks at work stated: "When I did start telling [my doctor] about my stuttering... it opened up a whole new world for me. I really was grateful that I was able to talk to her about my panic attacks and my speech and how it's affecting my life." Other participants related the need to share their stuttering challenges with their physicians: "It's important to tell your doctor about your stuttering, so when it crops up, he's already well aware of what's going on with you."

Speaking Assertively with Physicians Requires Self-Acceptance of Stuttering.

Participants described how they became more assertive while speaking in medical interactions. For participants, speaking assertively was an outgrowth of accepting themselves as stutterers. One participant said: "As we age, I think we all become more secure about who we are. And there comes a point in our lives when you say, 'this is as good as it is going to get, and that's okay.'" Another older participant said: "Now I'm at a point where my stuttering doesn't bother me because I think I've advanced to the point where I don't care what the other person thinks most of the time." In the midst of time pressure in the medical office, one participant related how he couldn't let that affect him: "I understand a lot of people are walking into the office, but then I can't let their pressure become my pressure... I have to say what I need to say in the time I need to say it. You're going to have to wait because I can't do anything else about it." Another participant said: "At this point, if I'm taking half of a day [from work] to go to the doctor's office... I'm definitely going to ask everything I want." One participant acknowledged that the assertiveness expressed by participants may reflect the study sample, stating, "I think you're talking to a group who are above the normal problems that the average person who stutters has... Probably if you'd ask other people who have less confidence in their stuttering, they may have more problems with it than us."

DISCUSSION

To our knowledge, this is the first qualitative study to describe the health care experiences of persons who stutter. We found that, even among this group of participants who reported minimal concern about their stuttering, there were communication barriers with office staff and physicians both during and outside of visits that could impact health and health care. Specifically, we found that participants' discomfort with speaking may lead to avoidance of health care interactions and reliance on third parties for help. Further, participants' comfort discussing stuttering with their physicians, even when stuttering caused negative consequences, was variable and depended on trust and rapport. Together, our findings call attention to an overlooked vulnerable population in health care and raise important questions for further research about health

access, health outcomes, and interventions for individuals who stutter.

Discomfort with and avoidance of speaking among stutterers has been reported in previous studies,^{6,7,15} but ours is the first to explore its role specifically in health communication. Discomfort may be heightened in situations that rely particularly on verbal communication, such as speaking on the telephone.^{6,7,15} In this study, we found that participants' discomfort speaking on the telephone and in person with office staff and with physicians sometimes led them to avoid using the telephone or going to appointments altogether. Other times, they relied on others' help in making phone calls or expressing themselves during medical visits. Reliance on others could hinder frank discussions with physicians about sensitive topics, and although it can provide momentary relief from speaking, relying on others' to speak on one's behalf could lead to low self-esteem and greater discomfort with speaking.^{6,7,16,17} Further, reliance on third parties may not be feasible for persons who lack social support.

We found that participants sometimes were reluctant to discuss their stuttering with their physicians, even when stuttering had negative health consequences. In fact, there is robust evidence that stuttering has health consequences that could be important to address during medical visits. Stuttering has been associated with personality disorders,¹⁸ mood disorders,¹⁹ generalized anxiety, and social anxiety disorders,^{20,21} which are believed to result from the cumulative negative social effects of stuttering.^{20,22} Speech-focused cognitive behavioral therapy has been shown to decrease social anxiety and psychological distress in adults who stutter.²³ Our finding that patients may be hesitant to discuss or even disclose their stuttering to physicians raises concerns about missed opportunities to diagnose and treat mental health problems associated with stuttering. Fortunately, we found that a trusting relationship between patient and physician can allow patients the latitude to discuss their stuttering and how it might affect their lives.

Among this cohort, assertive speaking in the medical office was an outgrowth of self-acceptance. Because persons who stutter often perceive stuttering as an undesirable attribute that is bothersome to the listener, feelings of shame and regret are common.¹⁶ We believe this may be responsible for the discomfort associated with speaking that we identified in this study. Increased self-acceptance of stuttering, conversely, leads to a reduced discomfort associated with stuttering.¹⁷ Some methods to increase self-acceptance of stuttering include joining self-help support groups, such as the National Stuttering Association, and behavioral therapeutic techniques, such as cognitive restructuring and planning ahead.^{17,24} In addition, as adults who stutter get older, they tend to view their stuttering more objectively as they become more knowledgeable about the condition. This leads them to increased levels of self-acceptance, and decreased discomfort and shame.¹⁷

Communicating with medical office staff was troublesome for many participants, who perceived that they lacked

patience. Addressing these issues may require a critical examination of current training standards for medical staff members in dealing with patients with disabilities.^{25,26} Promotion of "disability literacy" for all medical staff, which includes mandatory training and professional development activities on topics relevant to the health care needs of patients with disabilities, has been proposed as one solution.^{27,28} Still, as this study highlights, any training program that focuses on health care needs of patients with disabilities must incorporate ample sensitivity training for all staff, including non-professionals. Interventions available right now such as patient portals and secure patient messaging do not require speaking and may help ease the burden of patients who stutter when managing common health tasks. However, evidence about the effectiveness of such non-verbal health communication tools in this population or in other patients with disabilities is limited.²⁹ Moreover, whether non-verbal communication tools are empowering to patients or serve as another form of avoidance is unclear, and further research is needed to explore this complex area.

Helping a patient who stutters feel comfortable speaking through building trust and rapport is paramount for the physician. There are steps that providers can take to create a more comfortable, patient-centered atmosphere for persons who stutter. Physicians should be aware that persons who stutter may avoid discussing sensitive or difficult issues, and allow patients sufficient time and space to speak their mind. Because of the stigma associated with stuttering, many patients may feel uncomfortable discussing their stuttering on their initial visit. We recommend respectfully bringing it up in future visits, particularly by asking if and how it affects their life. When patients who stutter speak, they may manifest uncontrollable secondary symptoms, such as twitching or facial contortions, during stuttering episodes. Maintaining eye contact during these periods is imperative, as adults who stutter may be overly sensitive to negative non-verbal cues during speech production.³⁰

This study has several limitations. Participants were recruited as a convenience sample from a national conference devoted to helping persons who stutter. This cohort may have greater self-acceptance or be more assertive speaking than the general population of adults who stutter; indeed participants rated their stuttering as of minimal concern in their lives. In addition, our participants had the health and financial means to attend a national conference. As a result, our findings may not represent the experiences or attitudes of adults in the general population who stutter; however, it is likely that similar or greater challenges exist for other stutterers. Lastly, because of privacy concerns, we did not link individual assessments of stuttering impact to transcripts, which limits what we could conclude about the effects of stuttering impact on primary care experiences. Despite these limitations, given the dearth of existing data about the experiences with the medical system among people who stutter, our study is an important contribution to this nascent field of research, and raises

questions that warrant further study in more diverse populations of individuals who stutter.

This qualitative study of adults who stutter is a first step towards understanding how stuttering affects medical interactions. These findings will help to call attention to an overlooked population that might be receiving a lower quality of care. In addition, these results highlight the need for increased awareness and training for medical staff and physicians when caring for persons who stutter. Future studies among diverse samples of persons who stutter can help to determine the effect of stuttering on health access and health outcomes, and can inform the development of interventions to provide high quality health care for this population.

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Conflict of Interest: The authors declare that they do not have a conflict of interest.

Corresponding Author: Hector R. Perez, MD; Primary Care Research Fellow, New York University School of Medicine, 227 East 30th Street, 6th Floor, New York, NY 10016, USA (e-mail: hector.perez@post.harvard.edu).

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