



## Self-help conferences for people who stutter: A qualitative investigation

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### ABSTRACT

Self-help activities for people who stutter (PWS) have been gaining in popularity; however, there is a scarcity of evidence to support their utility in stuttering management. The purpose of this investigation was to understand the lived experience of individuals who attended a self-help conference(s) for PWS from the perspective of a PWS to learn its potential utility in stuttering management. The investigator used Interpretive Phenomenological Analysis (IPA) to systematically collect authentic data of this social phenomenon. Twelve participants were recruited from a self-help conference and the self-help community of PWS. Semi-structured interviews were conducted 4–18 months after each participant's last conference. Interviews were transcribed and analyzed. Themes were explained in investigator narratives and illustrated through participants' quotes. Interpreted themes of the experience of having attended a self-help conference(s) for PWS included: *socializing opportunities with other PWS*, *affiliation*, *redefining oneself* and *post-conference disclosures*. A conclusion of the study was that the experience of having attended a self-help conference(s) for PWS helped to minimize negative impact that stuttering can have on daily functioning. It appears that self-help conferences were perceived as a safer or "stutter-friendly" environment and promoted social interaction, relationship building, and community building through planned and unplanned activities. Another conclusion was that the experience of having attended self-help conferences for PWS helped participants to communicate more easily. Reported increases in social activity and an "openness" about stuttering, suggest self-help conferences' utility in stuttering management. These findings are supported by other studies about successful stuttering management and self-help activities for PWS. They have helped attendees who stutter to communicate more easily and suggest a reduction in the negative impact that stuttering has on their lives.

**Educational objectives:** The reader will be able to: (1) describe recurring themes associated with the lived experience having attended a self-help conference(s) for people who stutter (PWS) from the perspective of a group of adults who stutter, and (2) describe the potential benefits of attending self-help conferences for PWS in order to make appropriate evidence-based referrals to self-help conferences for PWS.

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## 1. Introduction

Self-help conferences for PWS are 2 1/2 to 4-day events that are hosted by a self-help organization for PWS including the National Stuttering Association (NSA), Friends – The National Association of Young People Who Stutter (Friends), and Speak Easy International (Speak Easy) within the U.S. They are typically held annually with the site of the conference changing each year. The key elements of a self-help conference include: opening and closing ceremonies, keynote speeches, open microphone sessions in which people have the opportunity to speak to an audience, and regular sessions (also referred to as workshops) in which a speaker(s) discusses a specific stuttering related topic(s), planned social events (e.g., baseball game, dinner, and touring), and a banquet. During the evenings, conference participants typically partake in planned social outings or form or join in on a more spontaneous social gatherings, whether it is going out or utilizing the amenities of the hotel. However, research about self-help activities for PWS has been scarce.

Clinical research on stuttering has mainly focused on topics such as: traditional treatment programs/approaches, traditional treatment outcomes, stuttering measurements, chronicity prediction, relapse prevention, and clinical training. Evidence from studies about self-help have demonstrated that such activities benefit people from a wide variety of conditions (Borkman, 1999; Katz, 1993; Katz & Bender, 1976), including addiction, bereavement, cancer, chronic illness, diabetes, mental health conditions, and others. Studies that specifically relate to the potential role of self-help activities for PWS (Hunt, 1987; Krauss-Lehrman & Reeves, 1989; Plexico, Manning, & DiLollo, 2005; Ramig, 1993; Tetnowski & McClure, 2009; Trichon, Tetnowski, & Rentschler, 2007; Yaruss & Quesal, 2006; Yaruss, Quesal, & Murphy, 2002; Yaruss, Quesal, Reeves et al., 2002) have indicated some gains but also indicate a need for further investigation.

## 2. Method

An Interpretive Phenomenological Analysis (IPA) was used for this investigation to embrace the social complexity of the various meanings derived and verbalized by the participants in their experience of having attended a national self-help conference(s) for PWS. IPA aims to explore details of how people make sense of their personal and social worlds (Smith & Osborn, 2008), in this case, self-help conferences and post-conference experiences.

### 2.1. Participants

Twelve participants were included in this study. Inclusion criteria were that participants needed to (a) be at least 18 years old, (b) attend at least one self-help conference for PWS and (c) consider themselves to be a PWS. Ten participants were recruited from the 2007 NSA Conference in Atlanta, GA, while two others who fit the criteria, were recruited from the self-help community at large.

Participant pseudonyms along with the years they have participated in self-help conferences are summarized here: Alex (Male), mid 50s, 1 year; Bill (M), mid 30s, 1 year; Connor (M), early 40s, 1 year; Dylan (M), early 30s, 8 years; Evan (M), mid 30s, 1 year; Fred (M), early 70s, 12 years; Gilda (Female), early 30s, 2 years; Hayley (F), 7 years; Isabelle (F), mid 40s, 2 years; Jackie (F), mid 20s, 7 years; Ken (M), early 50s, 15 years; and Lynn (F), early 20s, 3 years.

### 2.2. Data collection

Semi-structured interviews were the chosen method of data collection. This allowed participant and investigator to engage in a dialogue that is loosely guided by a schedule of topics which include life as a person who stutters, history of therapy, first self-help conference, post-first conference, subsequent conferences, and future conferences. The investigator is able to modify questions to probe important or interesting topics that may not have been discussed if a structured interview format was used (Smith & Osborn, 2008).

### 2.3. Procedure

The primary investigator conducted face-to-face interviews with each participant without predetermined time constraints. Interviews were conducted 4–18 months post-conference based on participant availability and the need for long-term post-treatment data that includes intrinsic features of stuttering (Blomgren, Roy, Callister, & Merrill, 2005). Interviews were held at or near the participants' residence or work, in a quiet room for the purposes of sharing personal experiences and recording. Interview lengths averaged 87 min 20 s (SD = 25:43), with the median interview of 85 min 30 s and a range of 50–148 min. Interviews were recorded and transcribed verbatim before disfluencies and identifying information were removed or changed and italicized.

The recurring process of data collection, analysis, and interpretation helped to refine the findings to the most relevant data. This idea is similar to the constant comparative method originally used in grounded theory (Glaser & Strauss, 1967). Smith and Osborn's (2003) guidelines to data analysis in phenomenological studies were used with slight modifications because of the use of a qualitative software package, *Atlas.ti*, for efficient organization. Through these procedures the investigator was able to go from participant transcripts, to creating unique codes, to creating, refining, explaining, and supporting themes.

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