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The Infusion of Interactive Digital Media With Self-Help and Stuttering Treatment

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Abstract

Limitations in the science of stuttering and stuttering therapy result in a failure to eradicate the stuttering phenomenon in clients with persistent developmental stuttering. Subsequently, many clients who stutter continue to live with the negative social consequences of stuttered speech, which include the potential for social marginalization and a reduction in quality of life. Consequently, current stuttering treatments, as well as a grass-roots self-help movement, have evolved to address these challenges faced by the stuttering population. This paper discusses the application of self-help styled interactive content over a digital media, in the form of audio and video podcasting, in stuttering support and treatment.

Introduction: What is StutterTalk?

StutterTalk is a self-help styled podcast available at www.StutterTalk.com and is hosted by three people who stutter who are all in the field of speech-language pathology (SLP). Audio and video podcasts are similar to archived radio or television programs and are easily and instantly accessed from the Internet. Episodes are played from the Internet or downloaded onto personal computers or other media devices such as portable media players (i.e., iPods), “smart” cell phones (i.e., iPhones, Blackberries), and other electronic devices. The purpose of this paper is to present the relevancy of self-help relative to clients who stutter and to detail the application of digital self-help media, such as StutterTalk podcasts, by discussing (a) the limitations of the science of stuttering and stuttering therapy, (b) the use of self-help to accompany and compensate for the limitations in the current stuttering treatment paradigm, (c) the infusion of self-help with the emergence of a digital culture, and (d) the StutterTalk podcast.

Science of Stuttering and Stuttering Treatment

While there has been significant neurological and genetic stuttering research published in recent years, the field of speech-language pathology has yet to definitively define the nature or etiology of the stuttering phenomenon (Bloodstein & Ratner, 2007). Unfortunately, a commonly recognized, yet generally uncited, reality known among stuttering researchers and therapists is that the field of speech-language pathology has not successfully identified an accurate or precise definition of the stuttering phenomenon. Professionals in the field are in

disagreement as to how best to conceive of the stuttering pathology. One such example may be best exemplified by the writings of world-renowned stuttering researchers, who attempted to clarify the stuttering phenomenon by writing

It is our position that, whatever else the clinical disorder of stuttering entails, there seems to be relatively little disagreement that the term *stuttering* refers to the domain of motor speech production and its disruption by speech disfluencies. Physical, physiological, cognitive, and emotional components, regardless of how frequent or intense they might be, would not be labeled as *stuttering* if they did not accompany a speaker's disfluent speech. (Yairi & Ambrose, 2005, p. 19)

Yairi and Ambrose (2005) further simplify their position by stating that stuttering "is first and foremost a disorder of speech" (p. 84). While this definition of stuttering certainly has face validity and is widely accepted by the field of speech-language pathology, this prevailing belief is in stark contrast to decades of stuttering research strongly suggesting that the stuttering phenomenon exists well beyond the realm of disordered speech. Stuttering-like behaviors have been reported in modalities beyond speech, such as signing, penmanship, Morse code, and the performance of various musical instruments (Backus, 1938; Harms & Malone, 1939; Liles, Lerman, Christensen, St. Ledger, 1992; Montgomery & Fitch, 1988; Meltzer, 1992; Roman, 1959; Saltuklaroglu, Robbins, Kalinowski, Guntupalli & Nanjundeswaran, 2005; Scripture, 1909; Silverman & Bohlman, 1988; Silverman & Silverman, 1971; Snyder, 2006; Voelker & Voelker, 1937; Whitebread, 2004; Wingate, 1970).

It remains unknown whether the reality of the stuttering phenomenon (i.e., a pathology revealed in expressive communication) lies beyond the contextual boundaries of how the field of speech-language pathology generally perceives and attempts to define the pathology (i.e., solely a disorder of speech). In fact, it sometimes appears as if the field is either ignoring or ignorant of the vast research which suggests that stuttering is much more than simple interruptions of motor speech (Snyder, 2006) and, as a result, remains baffled by the stuttering phenomenon and the cause of the pathology. Consequently, the effectiveness of stuttering treatment to eradicate stuttering is limited to the extent of our scientific clarity of the stuttering phenomenon. In essence, the absence of an accurate and precise definition of the stuttering phenomenon and the etiology of the pathology influences the current treatment of stuttering in at least two ways: (a) current stuttering therapy targets the distal symptoms of the pathology, as the core etiology remains unknown and (b) current stuttering therapy often clinically redefines the pathology (i.e., problems associated with stuttering) into variables that are within the therapeutic influence of SLP. Consequently, SLPs often focus on behavioral and affective therapeutic long-term objectives because eradication of the pathology is not a realistic or valid therapy objective at this time (Reitzes & Snyder, 2006). As a result, many feel that appropriate long term objectives for stuttering therapy revolve around the client's quality of life (QOL), such as (a) the ability to effectively communicate with anyone at any time in any environment, regardless of stuttering frequency, without shame, guilt, or fear (Hood, 2001); and (b) other holistic therapy objectives that are designed to improve the clients' QOL (Reitzes & Snyder, 2006). While traditional behavioral therapies may, and often do, alleviate some of the overt behavioral symptoms of stuttering in many stuttering clients (Starkweather & Givens-Ackerman, 1997), the field of speech-language pathology remains challenged with the task of identifying, defining, and quantifying the variables associated with improving client QOL (Ryff, 1995; Ryff & Keyes, 1995).

Social Marginalization

While existing stuttering therapy can be quite effective at improving the communication and QOL of clients who stutter (Reitzes & Snyder, 2006), many with persistent developmental stuttering (PDS) continue to live with the real-life consequences. While detailing the social consequences of living with stuttering is well beyond the scope of this manuscript, it could be

succinctly suggested that the consequences of stuttered speech result in the potential of social marginalization for many of clients with PDS. Social marginalization is defined as the process of relegating or confining a person (or subpopulation) into a lower social standing, often resulting in a reduction in life choices and opportunities (Leslie, Leslie, & Murphy, 2003; Mullaly, 2007; Yee, 2005). The manifestation of social marginalization is well documented as it pertains to the stuttering population, such as the widespread acceptance of an unfounded negative stuttering prejudice and stereotypes (Crowe & Cooper, 1977; Doody, Kalinowski, Armson, & Stuart, 1993; Fowle & Cooper, 1978; Leahy, 1994; McGee, Kalinowski, & Stuart, 1996; Snyder, 2001; Woods & Williams, 1976), as well as a potential hindrance of social, educational, and vocational opportunities and performance (Klein & Hood 2004; Klompas & Ross 2004). As a result, it has been suggested that an integral part of the therapeutic process for many clients with PDS includes management of the overt behavioral symptoms of stuttering as effectively as possible. Equally important are the intrinsic variables associated with successfully transcending the challenges and documented social marginalization relative to living with stuttered speech (Schneider, 2006).

The Role of Self-Help

Currently, we do not have a truly comprehensive understanding of the nature of stuttering and its etiology. The prevailing stuttering therapy models may leave some clients with PDS with challenges relative to how best effectively deal with the social marginalization of stuttered speech and ultimately QOL. Research suggests that self-acceptance remains the single biggest factor of QOL in those living in western cultures (Ryff, 1995; Ryff & Keyes, 1995). The lack of self-acceptance may play a significant role in impeding a client's ability to productively manage and cope with stuttering and stuttering-related social marginalization (Manning, 2000). Subsequently, the health-care community, which includes some speech-language pathologists (SLPs), has noticed the therapeutic efficacy of patient self-acceptance (Reardon & Reeves, 2002; Yaruss et al., 2002). Research reveals that programs aimed at increasing acceptance of self and one's medical condition improves the patients' quality of life (Clement & Tharyan, 2004).

The use of self-help groups is one avenue in which clients who stutter and their families seek to improve their QOL through increased self-acceptance (Kurtz, 1997), mentorship (Reardon & Reeves, 2002), peer support (Reitzes, 2006a), increased self-image (Yaruss et al., 2002), and facing stuttering in non-avoidant ways (Bloodstein & Ratner, 2007). Manning (2003) noted, "The support of others who stutter is essential, and the value of support groups cannot be emphasized enough" (p. 120). Support and self-help is, for many, a fundamental component of recovery and coping with stuttering (Starkweather & Givens-Ackerman, 1997). In discussing research by Kyrouz and Humphries (2002), Yaruss, Quesal, and Reeves (2007) explain

Self-help group participation can include: better short-term and long-term success with treatment goals, both in and out of treatment; enhanced ability to maintain goals across environments; increases in social attachment and interpersonal skills; benefits in general health, emotional well-being, adjustment, and self-confidence; enhanced understanding of the condition faced by self-help participants; and improvements in several other variables directly related to treatment outcomes and quality of life. (pp. 259-260)

In addition, self-help groups provide role models (Reardon, 2000; Reardon & Reeves, 2002; Reitzes, 2006a; St. Louis, 2001), and members provide one another support, respect, and information about the disorder (Plexico, Manning, & DiLollo, 2005). Cochrane (2004) explained that self-help participants "share and profit from a commonality of experiences. They are able to offer one another...differing perspectives on beliefs, feelings and therapeutic issues, and are able to, as a group, challenge negative thoughts" (par. 3). John Ahlback (1998), co-founder of Friends: The National Association of Young People Who Stutter (FRIENDS) stated,

“We want the young people themselves to reach out and share their struggles with each other, eventually making themselves teachers rather than victims.” Starkweather and Givens-Ackerman (1997) explained

[The] appeal [of self-help] to people who stutter rests on the fact that the pain these people feel can be alleviated through the support of others with the same problem. When people who stutter talk to each other, they do not feel the judgment and criticism that they feel when talking in the everyday world; instead, they feel an atmosphere of acceptance. The point is that, in an atmosphere where they do not feel such a strong need to struggle with stuttering, they can “let it go.” When they do this, the stuttering itself is often powerfully alleviated. Theories need to be aware of this force, and clinicians need to make use of it...stuttering treatment combines the powerful forces of the self-help movement, selected psychological therapies, and elements of tried-and-true speech therapy techniques. (p. 3)

As Starkweather and Givens-Ackerman (1997) noted, self-help is increasingly becoming integrated into the larger, overall therapy and recovery process (Reitzes, 2006b; Reardon & Reeves, 2002; Yaruss, Quesal, Reeves, et al. 2002). Supportive groups may focus on aspects of stuttering that are not included in some, if not many, treatment and therapy approaches (Bradberry, 1997). David M. Luterman (2008), an audiologist, speech-language pathologist and esteemed expert on counseling, has stated that he “can’t conceive of a [therapy] program” that exists without a support group component. In addition, speech therapy provides different uses, benefits and levels of success for different people (Yaruss, Quesal, & Reeves, 2007). Self-help satisfies the needs of many who may not be completely fulfilled just receiving speech therapy.

A survey study conducted of adults who stutter by the National Stuttering Association (NSA) found that a majority of respondents felt that their SLPs should be involved with or attend self-help meetings (Yaruss, Quesal, Reeves, et al. 2002). Many adults in this study reported that attending self-help meetings had positively raised their opinions of SLPs and positively affected their self-image and ability to accept stuttering. In a survey consisting of several hundred members of the NSA, the researchers found that this selective group of people who stutter reported that the NSA (a self-help organization) was their most valuable resource before SLPs, ASHA, the Internet, and other resources (Yaruss, Quesal, & Murphy, 2002). While the population in this survey (i.e., NSA members) is certainly not representative of the entire stuttering population, it does represent a strong indicator that for many, self-help is the most important resource in both managing and facing stuttering.

Why Self-Help?

One of the major reasons that self-help is sought out by people who stutter is because of the common experience of growing up feeling isolated and alone with their disorder (Manning, 2000; Reardon & Reeves, 2002; Guitar & Reville, 2003). In an essay titled, “Am I the Only One?” a teenager explains

[Am I the only one?] That is the question I ask over and over in my head every day at school. You look around and you see handicapped people in wheelchairs, people who are blind and deaf, and of course, people with braces. You never see a kid who stutters. (Cochran, 1998, p. 33)

Such feelings of isolation are common among people who stutter who often enter into adulthood without ever having met another person who stutters (Zebrowski, 2003). For example, Taro Alexander, the founder of the Our Time Theatre Company wrote, “I grew up feeling trapped, alone and isolated. I did not meet another person who stuttered until I was twenty-six years old. For a long time I thought of myself, and all people who stutter as freaks” (Our Time Theatre Company; par. 3). Guitar and Reville (2003) noted that group experiences for people who stutter may significantly reduce feelings of isolation and loneliness. For

example, after attending the 2002 FRIENDS annual convention, a teen said, “Every year I look forward to [the] FRIENDS [convention] and it's so sad when it's over. . . I have learned that I am not the only one who stutters and that there are people out there who are just like me” (see Reitzes, 2006b, pp. 25-26).

Self-help has also been credited with helping participants face stuttering in non-avoidant and open ways (Bloodstein & Ratner, 2007; Starkweather & Givens-Ackerman, 1997). For example, after attending a self-help convention, a mother wrote

As a parent attending the NSA conventions, I felt nothing but enthusiasm...Today Cate [her daughter] and I talk freely about stuttering and I talk freely about it to others. I have watched Cate transform over the past several months. Her self-confidence has gone way up, and she is learning how to deal with teasing. (Roman, 1999, p. 93)

Support from other people who stutter is available in several different in-person or “face to face” ways including self-help meetings and conventions, group speech therapy (Murphy, 1999; Murphy & Quesal, 2002; Ramig, 2003; Ramig & Bennet, 1995, 1997; Reitzes 2006b; Sisskin, 2002; Van Riper, 1973; Williams & Dugan, 2002), theatre groups (Alexander, 2002; 2004) and camps (Bennett & Batik, 1998; Blom, 2000; Kawaski, 2000; Sable, 2000). Self-help groups (Ramig, 1993; St. Louis, 2001; Yaruss, Quesal, & Murphy, 2002) and services continue to increase their role in providing opportunities and support for people who stutter. However, there is still a significant shortage of self-help resources (Bloodstein & Ratner, 2007; Caggiano, 2000; Daniels & Gabel, 2004; Snyder, Reitzes, & Jackson, 2008).

Limited Self-Help Resources

Self-help organizations such as the NSA and FRIENDS evolved from the needs of the stuttering population and subsequently support many people who stutter (Reitzes, 2006a). However, recognition of the importance of self-help often remains overlooked, and access to self-help groups is limited due to cost of travel, local availability, family demands, language differences, and the comfort level of people who stutter and their families. For example, many listeners have written StutterTalk to share that there are no self-help chapters or meetings in their area. Because of such self-help shortages and because of the advent of the Internet, additional supportive resources have emerged including emailing groups and electronic (internet) discussion forums for people who stutter (Reitzes, 2006b; Shields & Kuster, 2003; Starkweather & Givens-Ackerman, 1997) supportive videos (Reitzes, 2005), blogs (personal Web pages) and Social Networking groups available at sites such as FaceBook.com and MySpace.com and podcasts (Snyder et al., 2008).

Self-Help in the Digital Age

When the two authors of this paper were in speech therapy as teenagers and adults, they both benefitted from self-help resources, as well as speech therapy, as catalysts for positive change. For example, both authors benefited from media such as “Self-Therapy for the Stutterer” by Malcolm Fraser (2002) and “The Treatment of Stuttering” by Charles Van Riper (1973). While these books discussed speech management strategies and tools, they also spoke about stuttering from the perspective of people who stutter. For many, such books provided the first (albeit very limited) “stuttering friend” or first step into the self-help world.

Fortunately, the digitization of technology has had a profound impact on modern culture. The historical barriers of content creation and media distribution (i.e., the cost of production and distribution) have been essentially removed. As a result, smaller populations, such as niche markets like the stuttering self-help community, are enjoying the emergence of easily accessible high quality digital content created by professionals and members of the general public.

Since the historical barriers relative to content and media no longer exist, there has been an explosion of professional and consumer content creation over the digital media. Moreover, this professional and consumer created content is often very topic specific, and targets specific niche audiences. As a result, millions of people all over the world are trending toward the integration of immediately accessible very specific niche content into their daily lives. The practical application of these cultural changes is that even the smallest sub-population has instant access to digitized content that directly serves their interests and needs.

As an immediate response to the digitization of content and media, numerous online support options, such as e-mail groups and electronic forums, were created. While Internet self-help support options such as email groups and blogs offer a basic level of support to anyone who can afford an Internet connection, typically this support is provided via asynchronous typed communication. In response to the limitations of existing Internet self-help support-group options, the podcast “StutterTalk” was created to serve people who stutter on a global scale at little or no cost to listeners. StutterTalk is a self-help podcast created by people who stutter for people who stutter, their families, SLPs, and students. StutterTalk offers audio and video podcasts so that people who stutter can hear and see other people stutter openly and talk about stuttering from healthy and honest perspectives. StutterTalk podcasts are also a natural link or step between the typed, online support of email groups and the face-to-face support offered by self-help organizations such as the NSA and FRIENDS.

StutterTalk generally publishes one or more audio or video podcasts a week. StutterTalk episodes are listened to or watched by people who stutter and their relatives and friends, speech-language pathologists, graduate students, as well as other people identifying with the concept of social marginalization. For example, a regular listener who has Tourette’s Syndrome recently e-mailed the show to share how he can relate to so many of the topics discussed on the show, such as dating and interviewing for jobs, because people who stutter and people with Tourette’s share many similar communicative challenges. A listener from Sweden e-mails and calls the show often with questions because she is a psychologist who wants to better understand and serve her clients who stutter. Several parents have written and called to say they listen with their teenage children and several spouses have emailed the show saying that they tune in to better understand what their husbands or wives are going through.

StutterTalk podcasts are an interactive media and often include responses to e-mails, online comments, and telephone calls on air. For example, a woman from Maryland wanted to know, “Did you ever not vote because you were scared they would ask you your name?” After voting, this same woman wrote back to share that she was upset at herself for letting her mother speak for her to election officials on election day (see episode 73). Another listener from Washington State wrote

When I stutter my co-workers look away and in one case during a meeting someone gave me a piece of paper and a pen so I could write down my thoughts. I have reached a point where I don't know what to do. I am tired of being excluded and treated as inferior. I think a show on this topic would be helpful to me.

StutterTalk is a global self-help resource, as episodes are downloaded throughout the world from the United States and Canada to Britain, Sudan, Israel, Germany, China, and many other countries. StutterTalk has hosted audio and video podcasts in Hindi (the most common language spoken in India) and have plans to publish podcasts in Italian, Hebrew and other languages. Episodes have focused on various aspects of stuttering such as talking openly about stuttering, voluntary stuttering, going on job interviews, dating, speech tools from different therapy approaches, self-help events and organizations, covert stuttering, talking with family members, recovering from shame, faith and stuttering, the history of altered speech feedback and much more. StutterTalk has recorded numerous shows from live events including the 2008 Stuttering Foundation workshop reunion at the annual ASHA convention, the 2008 National Stuttering Association annual convention, a Manhattan screening of the stuttering

related film “Rocket Science” and several Our Time Theatre Company (an artistic home for children who stutter) live performances.

StutterTalk has interviewed dozens of people who stutter, parents of children who stutter and many researchers and specialists including David M. Luterman, Ed.D., CCC-SLP (episode 76) on counseling persons with communication disorders and their families, Phillip Schneider, Ed.D., CCC-SLP (37, 38, 74, and 83) on his film *Transcending Stuttering: The Inside Story* and the body and soul of speech therapy, Catherine Montgomery, MA CCC-SLP (episode 50) on the American Institute for Stuttering, Gerald Maguire, MD, (episode 51) on the history of pharmaceutical treatment options, Nina Reeves, MA CCC-SLP (episode 81) on speech therapy for children who stutter, Taro Alexander (episode 12) about the Our Time Theatre Company and Camp Our Time, Kristin Chemla, MA CCC-SLP (episode 31) on shame and healing, Ronald Webster, PhD (episode 69) on fluency shaping, Lee Caggiano, CCC-SLP and Joseph Donaher PhD, CCC-SLP (episode 44) on self-help, Dennis Drayna, PhD (episode 18) on the genetics of stuttering, Nan Bernstein Ratner, PhD, CCC-SLP (episode 55) on stuttering and language and Ken St. Louis, PhD, CCC-SLP (episode 19) on cluttering and person-first language. StutterTalk welcomes and regularly airs public service announcements from non-profits including the Stuttering Foundation, The NSA, FRIENDS, the British Stammering Association and the Indian Stammering Association.

While the three StutterTalk co-hosts have been managing stuttering and participating in self-help for years, some guests on the program are relatively new to self-help and offer listeners the perspectives, insights, and experiences of those who are still struggling and grappling with stuttering and acceptance (see episodes 7, 58, 60, and 67). Due to the success of StutterTalk and an expressed desire by many people who stutter and professionals to acquire basic information about the disorder (Reitzes, 2006b), a second podcast has been created entitled *Stuttering101* (available at www.Stuttering101.com). While StutterTalk podcasts average about an hour in length and feature conversations between several hosts and guests, *Stuttering101* episodes are much shorter, about 8-10 minutes, and focus on more lecture-like and factually oriented features such as *Stuttering and Breathing* (episode 1), *Prosthetic Stuttering Management Devices* (episode 4), speaking strategies such as self-advertising, cancellations and voluntary stuttering (episodes 2, 4, 5, 6, 7, and 8) and the *Role of Genetics in Stuttering* (episode 9).

Summary, Discussion and Conclusions

The limitations in the science of stuttering and stuttering therapy leave clients with PDS susceptible to social marginalization second to living with stuttered speech. To address this shortcoming, many within the field of SLP have evolved stuttering therapy to directly address the clients' QOL. The self-help movement, as employed by people with PDS or as an adjunct to formal stuttering therapy, is one avenue towards improving the QOL in people living with PDS. While the self-help movement is becoming more effective at reaching out and serving people who stutter, their families, and professionals, self-help resources are still often unrecognized or inaccessible to many. However, the digitization of content and media has removed many of the barriers toward self-help resources and provided new and exciting interactive media opportunities, such as audio and video podcasts. StutterTalk and *Stuttering101* are two examples of the emerging digital stuttering self-help resources specifically designed for people interested and associated with PDS. In the future, StutterTalk looks to expand stuttering self-help related content in other languages as well as additional digital social networking platforms such as Twitter (www.Twitter.com/StutterTalk).

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