PERCEPTION AND PSYCHOSOCIAL OUTCOMES OF STUTTERING WITH AND WITHOUT SELF-HELP GROUP SUPPORT- GROUP COMPARISON

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Mysuru



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CERTIFICATE

This is to certify that this dissertation entitled "**Perception and Psycho-social Outcomes of Stuttering With and Without Self-Help Group Support- Group Comparison**" is a bonafide work submitted in part-fulfilment for degree of Master of Science (Speech Language Pathology) of the student with Registration Number: P01II21S0039. This has been carried out under the guidance of a faculty of this institute and has not been submitted earlier to any other University for the award of any other Diploma or Degree.

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CERTIFICATE

This is to certify that this dissertation entitled ""**Perception and Psycho-social Outcomes of Stuttering With and Without Self-Help Group Support- Group Comparison**" has been prepared under my supervision and guidance. It is also certified that this dissertation has not been submitted to any other University for the award of any other Diploma or Degree.

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DECLARATION

This is to certify that this dissertation entitled "**Perception and Psycho-social Outcomes of Stuttering With and Without Self-Help Group Support- Group Comparison**" is the result of my own study under the guidance of Dr Anjana B Ram, Assistant Professor in Speech Pathology, Department of Speech Language Pathology, All India Institute of Speech and Hearing, Mysuru, and has not been submitted earlier to any other University for the award of any Diploma or Degree.

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DEDICATED TO APPA, AMMA, SAHANA, KULLU, GUDDU

&

MY WELL-WISHERS.

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Chapter 1 INTRODUCTION

Stuttering is a speech disorder common in all age groups, seen majorly in males than females (males-0.89% and females -0.40%) (Sommer et al., 2021); it affects the person's normal fluency and time pattern of speech production. The prevalence of stuttering in India is 10% as compared to countries like Great Britain, Australia, and America, which have prevalence of 0.75–1% (Rout et al., 2014)

Studies have shown that adults with stuttering have a lower level of quality of life, social well-being, and mental health functioning (Craig et al., 2009); According to Boyle (2015), the experience of stuttering and social anxiety in Persons with stuttering (PWS) and can lead to severe avoidance behaviour; PWS may try to hide or hesitate to speak certain sounds or words in defined situations and with certain people. Many PWS experience different kinds of psycho-social problems in their life due to stuttering; this negative impact may affect their quality of life.

Along with traditional methods, there are several options available to address the psycho-social components of stuttering, and these measures help PWS achieve greater results (Ingham, 2012; O'Brain et al., 2012). Many researchers advocate employing a multi-modal approach to treat PWS (Yaruss, 2010: Guitar, 2013). These views were supported by the American Speech-Language-Hearing Association (ASHA, 2007), which said that improving a person's quality of life via removal of obstacles and limitations both within and outside of them is necessary for resolving communication disorders. As a result professionals could benefit from having access to a variety of techniques in the behavioral, cognitive, and affective domains in order to address the quality of life and well-being of clients who stutter (Craig et al., 2009; Plexico et al., 2009a; Tran et al., 2011; Yaruss, Coleman, & Quesal, 2012). There is evidence that stuttering treatment may be important in a multifaceted context. Many researchers agree that stuttering-related feelings and attitudes should be addressed in therapy (Yaruss et al., 2002), and that therapy that focuses solely on improving speech quality falls short in addressing speech-related anxieties both during and after treatment (Yaruss et al., 2002).

Speech-language pathologists (SLPs) must identify the stressors and try to minimize the negative effect/anxiety related to stuttering, they should also provide an alternative to reduce this anxiety and other thoughts and beliefs that have a negative impact (CASLPO, 2014). In addition to speech treatment, people with stuttering may attend self-help organizations to understand themselves better and realize that they are not alone. Participating in a self-help group (SHG) is another way of trying to reduce these negative attitudes and beliefs towards self and stuttering. Self-help groups have become increasingly significant in recent years. It is also becoming more common for SLPs to encourage their patients to join self-help groups. (Yaruss et al., 2002).

Self-help groups (SHG) are majorly trusted organizations which provide a forum where PWS can meet others with the same problem through face-to-face interactions or online meetings and can receive from or provide support to others with similar problem. The groups can be large, or can be split up to form small sub-groups. The PWS will be a group member where he/she can take up either an active or passive role in meetings and discussions. Furthermore, there are many self-help groups worldwide and in India too. There are nearly 50 self-help groups for persons with stuttering worldwide, according to study by Minnesota State University (2022).

The **National Stuttering Association** (NSA) developed by a National stuttering project, was established in California, United-States by Bob Goldman and Michael Sugarman in 1977. It raise awareness about stuttering, and also offers lectures and seminars to PWS, SLPs, and family members of persons with stuttering. The **British Stammering Association** (BAS) was founded in 1978 in London, United Kingdom, with the intention of eradicating stigma, false information, and prejudice faced by PWS.

Another nonprofit organization, the **International Stuttering Association** (ISA), works to provide stutterers throughout the world a voice. ISA collaborates with national and worldwide organizations for PWS including The **European League of Stuttering Associations** (ELSA) and The **International Fluency Association** (IFA) in order to educate the general public and PWS about the issue.

The Indian Stammering Association (TISA), a self-help organization foundation, was established in India on April 3, 2001 by Dr Satyendra K. Srivastava. This foundation is an organization of persons with stuttering from India that operates online.

Thus, the self-help groups support PWS by facilitating online or in-person interactions and assist them in understanding their problem; they inspire fellow PWS and lessen their social anxiety as well as their negative attitudes and beliefs about their problem. According to a research by Yaruss et al., (2002), 93% of PWS felt that attending self-help groups had a beneficial impact on their attitudes and emotions.

1.1 Need for the study

Research suggests that attending self-help groups has a significant advantage in managing anxiety and reducing negative behaviour of PWS, over attending speech therapy alone (Young, 2020). Thus there could be a difference in beliefs, attitudes, perception and acceptance towards stuttering and its associated psycho-social factors in PWS who attend self-help groups. However, there is less evidence available to claim that attending self -help groups will benefit PWS in managing stress and anxiety in Indian context. So there is a need to study and compare the psycho social outcomes of stuttering in PWS who are attending self -help groups alone verses speech therapy alone, in the Indian context.

1.2 Aim of the study

To compare and contrast perception and psycho-social outcomes of stuttering in PWS with and without self-help group support

1.3 Objective of the study

- > To study the organizational patterns of self-help groups for stuttering
- > To check the psycho-social well-being of PWS after participating in self-help groups
- To compare outcomes of stuttering management between PWS who are attending therapy alone versus those only in the self-help groups.

Chapter 2

Review of Literature

The phenomenon of stuttering is complex and intriguing in the world of speech disorders. This review of the research explores the effectiveness of stuttering therapy in persons with stuttering. It also covers the function of support groups in encouraging various approaches to stuttering management. This review seeks to give a thorough overview of stuttering-related therapies and the collaborative support systems that play a crucial role in increasing communication results and general well-being by combining the most recent findings.

In the study on the Meta -analysis of the effects of speech therapy, Andrews et al., (1980), gathered information from 42 studies which included a data related to 756 persons with stuttering. Here, the authors attempted to gather data on the effectiveness of speech therapy. Stuttering therapy was found to be more beneficial to stuttering patients than the other medical treatments. The authors also discovered that the techniques like prolonged speech, gentle onset, and air flow techniques, had a major effect on treating stuttering. The authors gathered information related to the treatment effectiveness from pre and post stuttering treatment measures. It was observed that, these techniques had positive effect on reducing stuttering in post treatment measures.

Annie Bradberry (1997), in her study on "The Role of Support Groups and Stuttering therapy", explained how speech therapists and clients can use support group as a supplementary way to work on fluency. In this study, author shared her working experience as a leader of a National support group. She highlighted the significance of self-help groups, which help to reduce negative feelings and stress and improve coping behaviours in clients with stuttering. The author also explained that where speech therapy focuses on goals to reduce stuttering and improve fluency; support groups or self-help groups on the other hand focus on improving a person's fluency in a real-world context. Also, these support groups help clinicians/ speech therapists work in different habitats where they can provide therapy more realistically. The author also addressed other benefits of attending stuttering support groups, including how they can assist people with stuttering to accept their condition, achieve self-esteem, cope with stress, and gain confidence as their speech gets more fluent.

Yaruss et al., (2002), conducted a study on Speech Treatment and Support Group Experiences of People Who Participated in the National Stuttering Association (NSA). The authors conducted a survey using two questionnaires to collect information about speech therapy and support group experiences. In this study a questionnaire was sent to 175 adults with stuttering through e-mail, where 71 adults with stuttering participated in the study. The questionnaire included 50 questions with multiple-choice options; the questions were related to the nature of therapy and their experience in speech therapy and support groups. Here the authors have probed into positive and negative experiences about speech treatment. Questions and targeted information were helpful for speech-language pathologists and NSA leaders to facilitate and enhance the support and treatment for PWS. Results showed that 52% of the participants were not able to maintain fluency outside the therapy setup, 32% of the participants were disappointed because of the, lack of attention given to the participants' feelings over their speech in speech therapy, 41% of the participants were dissatisfied about therapy because they were not prepared in advance for relapse of stuttering and 39% of the participants stated that the treatment did not address their fear, challenges related to stuttering and 30% of participants in the study who attended only fluency-shaping therapy, had experienced a relapse of stuttering in their lives after they stopped attending therapy. However 57% of the participants attending support groups had better life experiences, reduced fear of stuttering, and a better quality of life perspective. Among them, 36% of the participants indicated positive effect after joining support group in terms of their acceptance towards stuttering. This study suggests that the combination of speech therapy and support groups can synergistically enhance each other's effects, creating a complementary approach for individuals seeking to manage their stuttering.

Hayhow et al., (2002), in their study have tried to gather information related to stuttering and peoples' views about stuttering therapy. Here the authors collected data by sending the questionnaires through posts to the participants who were attending or had attended speech therapy before joining the support group (British Stammering Association). The questionnaire was made in such way that, it collects the information regarding the concerns related to stuttering, therapy impact on their lives and other methods which they have tried to reduce the stuttering. From the responses of 332 participants, it was found that, participants had both positive and negative reaction towards the speech therapy, 30% of the

participants suggested that, they gained slight control over their stuttering and 25% indicated that speech therapy increased their confidence and positive attitude towards stuttering. With regard to the impact of stuttering, 81% of the participants had negative experiences during their education, 52% indicated that stuttering had affected their choice of occupation, 24% revealed that, they had problem in making friends due to stuttering and 19% of the participants had problem in their relationship due to stuttering. As far as success with stuttering treatment was concerned, 25% of the participants indicated therapy was slow in producing results, and they were disappointed as they were not able to do anything about their stuttering, 24% stated that only techniques like prolonged speech and rate control were better in reducing the stuttering. Through these findings, it was concluded that no single speech therapy was helpful in reducing stuttering but a combination of intensive stuttering therapy and support group could be beneficial to the persons with stuttering.

In a study by O' Brain et al., (2003), the outcomes of prolonged speech in persons with chronic stuttering and effectiveness of the Camperdown program's therapy was the focus of research by the authors. The research included 16 participants, and these participants underwent pre therapy assessment before 2 weeks of the program and post therapy measures were also conducted at two different stages, first at 6 months after the therapy and second at 12 months after the therapy. It was found that participants showed minimal or no stuttering after enrolling in the program with relatively normal speech rate and speech naturalness. Along with the program effectiveness measure, authors also conducted self-report inventory measures to collect information related to daily stuttering severity, speech naturalness, satisfaction with their speech, their experience in learning prolonged speech, level of comfort or willingness in using prolonged speech outside the therapy setup, and how unnatural they sound when they are trying to control their stuttering. Results showed that, all the participants ie., 100% of the participants were unable to maintain fluency and control their stuttering outside the clinical setup, 10 participants said they felt uncomfortable using prolonged speech during therapy and even beyond clinical settings. 2 participants said it was very difficult to learn how to use prolonged speech technique, and seven others said it was difficult to use the technique outside of the therapy setting. Moreover, 55% of the participants stated that they prefer to stutter rather than using uncomfortable and unnatural speech outside the clinic.

Stewart and Richardson (2004) conducted a qualitative study on effectiveness of stuttering therapy from the perspective of persons with stuttering. Here the authors collected information from 13 adult persons with stuttering related to their experience of stuttering therapy. In this study authors have used a phenomenological qualitative approach along with the in-depth and semi structured interview. The information related to level of fluency, ability to maintain fluency in different situation, control over stuttering, speech therapy type, and satisfaction in life, improvement in fluency, self-esteem, and their view about feelings and attitudes after attending speech therapy was probed into, during the interview. The results showed that 7 out of 13 people indicated that attending speech therapy had a positive effect in reducing their sense of isolation, since after attending speech therapy they felt more fluent than before. Along with positive responses, participants also indicated that, they had problem with generalization of speech techniques outside the clinical setup. The participants revealed that their speech feels totally different outside the clinical setup and that there was no change in their life style even after attending speech therapy.

In a study done by Onslow and O'Brain (2012) related to management of childhood stuttering, authors stated that stuttering is more prevalent in children in the early years of language development. Stuttering at early age includes effortful speech production and rapid onset of the problem. If the problem is not rectified during early age it might affect the person psychologically and can also affect their education, social communication and there occupation too. So it is very important to address the problem as early as possible. Here the authors have done a meta-analysis, were they have collected 136 studies and gathered information related to early rehabilitation of stuttering and it was found that people/children who underwent treatment at an early age or during their pre-school age, had 7.7 more times of positive effect in reducing stuttering than compared to other groups who started speech treatment at later stages of their life.

Yaruss (2010), assessed the quality of life in persons with stuttering after attending the speech therapy. The authors found that, stuttering can impact a person's life, their satisfaction with life and these negative feelings can lead to reduced ability to achieve life goals. The aim of the study was to collect information related to impact of stuttering on client's quality of life and also to know how these negative reaction reduce after starting the treatment. The study included 173 participants who had been attending speech therapy. The author administered OASES- A on each of the participants, in this study. Only the fourth section of OASES-A ie. Quality of life was only considered. Results showed that 12% of the participants indicated that there quality of life was not at all affected by stuttering, 28% of the participants stated that stuttering had a negative effect on their quality of life. However, 38% indicated that stuttering didn't interfere in their communication satisfaction at home and working situations. 36% of the participants reveled that stuttering did not any effect on their relationship, whereas 14% of the participants indicated that stuttering had affected their relationship. 35% of the participants stated that stuttering is not affecting their employment but, 21% of the participants reveled that stuttering had a negative effect related to their job. Overall results from pre-test showed that 44% of the participants stated that stuttering has negatively impacted their quality of life, while the post treatment results showed that there was drop in these negative impact scores related to quality of life. The author concludes that speech therapy can reduce the impact of negative feelings related to stuttering, and OASES-A can be a good measuring tool to assess the life satisfaction in persons with stuttering.

In a study by Irani and Gabel et al., (2012), authors gathered information related to long term effectiveness of intensive stuttering therapy. The study aimed at collecting client's perception about effectiveness of intensive speech therapy program. Here the authors have used a phenomenological qualitative approach as method to analyses the data from semi structured interview. The interview questions were probed to gather information related to positive effect of nature and duration of therapy program, speech therapy techniques learned, activities related to transfer and desensitization of stuttering and also about attitudinal changes seen in participants after the therapy program. Results from the study showed that, participants indicated positive effect of nature and duration related to speech therapy, and they also stated that techniques like prolonged speech, pull-outs, easy onset were beneficial in reducing their stuttering. Participants also indicated that therapy and counselling had helped them in changing their attitudes towards stuttering, and activities which were carried out to transfer the fluency in outside clinical setup had a positive impact and they were able to maintain their fluency better. Further, authors concluded that intensive speech therapy is beneficial for bringing positive changes in behavioural measures and attitudinal changes in person with stuttering.

Boyle (2013) studied, psychological characteristics and perceptions of stuttering in adults who stutter with and without support group experience. According to the author, stuttering can have a psychological impact on PWS, and this can affect their quality of life and self-esteem. In this study, the author considered 279 adult participants (179- male, 97 females) with stuttering, and measured their self-esteem, self-efficacy, life satisfaction, selfstigma, perceived stuttering severity, and other stuttering related beliefs and compared between the people with and without support group experience by using the Rosenberg selfesteem scale (Rosenberg, 1989), The general self-efficacy scale (Schwarzer & Jerusalem, 1995), The Satisfaction with Life Scale (SWLS) (Diener et al., 1985) and The Self-Stigma of Stuttering Scale (4S) (Boyle, 2013). Perceived severity of stuttering was assessed using self-report which had eight different speaking situations. This survey was conducted online using Qualtrics Survey Research Suite Software Version 28,206 (Qualtrics Labs, Inc.). Results showed that those who participated in the support groups had higher levels of life satisfaction and self-esteem, compared to the PWS who did not attend support groups. This according to the author's opinion is because, support groups help them to accept the stuttering and bring cognitive changes in them, which leads to improvement in confidence, better coping with stuttering, reduced avoidance behaviour, and helps them to understand their problem better as they interact with other PWS. Additionally, self-help groups increase coping skills and the person's psychological well-being. It offers more advantages than just going to speech therapy alone. This study, thus supports the notion of attending support groups along with speech therapy.

Trichon and Tetnowski (2016) conducted a study titled, "Self-help conferences and change in the experience of stuttering: preliminary findings and implications for self-help activities". The authors highlighted the importance of attending self-help groups, conferences, and workshops, which have large benefits in reducing the fear of stuttering, and improving the quality of life of the PWS. In this study, the authors used widely accepted questionnaires to assess the relationship between attending self-help conferences and their impact on the experience of stuttering. To check this, they used questions like, "(i) Is there a difference between pre- and post-self-help conference (SHC) scores on the Overall Assessment of Speaker's Experience of Stuttering (OASES; Yaruss & Quesal, 2008) for people who stutter (PWS) that attend a self-help conference?", "(ii) Are there any differences between the preand post-SHC OASES scores for PWS who attended: (a) one conference, (b) a few conferences (2-4), (c) several conferences (5-8), or (d) many conferences (9+) ?", "(iii) Does the pre- and post-SHC OASES ratings based on conferences attended have a statistically significant interaction?". In this study, the authors considered 117 participants with stuttering and assessed OASES at the beginning of joining SHC and after attending SHC for 4-6 months. Results revealed a change in the overall experience of stuttering among participants, and large changes were seen in participants who were new to SHC or attending SHC for the first time. The result from the study supports the notion that attending self-help groups or conferences is vital in managing stuttering.

Medina et al., (2019) conducted a pilot study related to the Inspiration of Adult Stutterers to Attend Stuttering Support Groups. In this study, authors investigated persons with stuttering motivations for attending stuttering support groups on a regular basis. For this study, seven adults with stuttering who had participated in more than one support group were recruited. In order to allow participants and researchers to have a free-flowing discussion on the subjects of interest, the authors performed a semi-structured interview. Interview questions were aimed at eliciting information about participants stuttering and general experiences with support groups (such as opinions and perceived impacts of support groups). The interview was audio recorded and was 30-45 minutes in length, and participants also completed a case history questionnaire through email; the questions were regarding their stuttering history (which included questions like, age of onset, severity, and coping strategies) and social history (i.e., work background, perception of listener and self, and openness). The audio-recorded data was then transcribed for analysis. Thematic analysis was used to investigate descriptions of motivating factors in each participant's narrative. The findings from the research indicates that, support groups serves as a place to gain new perspectives by watching others who stutter, and it also creates a sense of not being "alone." It provides opportunities to speak and stutter easily. After attending support groups, participants reported improvements in their socialization and emotional well-being. Additionally, participants also stated that participating in support groups helped them to assist and learn from others. The study concluded that support groups improve social communication skills and help with socialization.

Gerlach and Holister (2019) conducted a study, on the Usefulness of Guidelines for Young People Who Stutter in Stuttering Support Organizations. Researchers studied the effects of regular participation in a stuttering support group on the mental and emotional development of young people who stutter. Twenty-two young people who stutter (age range 10-18) were recruited from a national association for young stutters called FRIENDS. The authors administered OASES in 3 phases before joining the support group, post support group joining, and three months after the support group joining. A semi-structured interview was conducted to collect brief information about participants and their experiences with stuttering. A mixed qualitative and quantitative study was conducted to analyze the data. The results of using OASES at three different time points revealed a significant improvement in self-acceptance, changes in cognitive and communicative functioning, normalization of stuttering, and a reduction in the negative effects of stuttering. This suggests that participating for several days in a stuttering support group organization is helpful in minimizing the negative effects of stuttering and that these support groups can also be used as an additional form of stuttering therapy. Young (2020) conducted a study on how participation in support groups impact psychosocial outcomes for people who stutter. In this, author compiled the studies related to the effect of stuttering support groups on the psycho-social outcomes of adolescents and adults who stutter. In this study, the author considered non-randomized between-group clinical trials, a within-group study, two single-group studies, and one qualitative research study. These articles were extracted from computerized databases like SCOPUS, PubMed, and Google Scholar. This critical review's results marginally indicated that joining a support group enhanced the psycho-social well-being of persons with stuttering.

Boyle and Gabe (2020) in there article titled, "Openness and progress with communication and confidence have all gone hand in hand: Reflections on the experience of transitioning between concealment and openness among adults who stutter", tried to explore how a person transforms their covert behaviour's (like holding onto some negative feelings, hiding their feelings, emotions and hiding their problem in front of others) into expressing themselves by stuttering without hesitation, openly talking about stuttering or beginning to stutter overtly. Participants in the study were recruited by sending an e-mail to the members of the National Stuttering Association. Also, individual e-mails were sent by the researcher to participants. Researchers specifically chose participants who could freely share their thoughts and experiences concerning stuttering and who were at least occasionally upfront about their stuttering. Face-to-face interviews were used to gather information from a total of 12 individuals, 6 male and 6 female, ranging in age from 26 to 70 years. All of the participants were graduates with jobs, and also they had been involved in NSA and had four years of experience in self-help groups. The interview was centred on the participants' impressions of their stuttering, their prior experiences with stuttering, and the influence that stuttering had on their lives and few spontaneous questions were based on the responses from the participants. Also, questions related to speech treatment or involvement in self-help groups or conferences that have changed them into being more open about stuttering were asked to the participants. The responses were audio recorded and transcribed. A phenomenological approach and thematic analysis were used to analyze the responses, and the authors concluded that PWS, who had been involved in the self-help/support community for a several years, generally had a positive transition from attempts at concealment to more openness over time.

Raj et al., (2023) conducted a study titled, Facebook groups for people who stutter: An extension of and supplement to in-person support groups. This study was related to the support groups available online. These online support group platforms have shown better results in psycho-social aspects and experiences of PWS. So, this study aims to check the usefulness of Facebook-based support groups in improving the psycho-social aspects of PWS. Seven participants were included in the study (6 persons with stuttering and 1 person without stuttering). One of the researchers was allowed by the founder of the Facebook support group page to observe the participants for three months. Meetings were held two times per month, and the duration of each meeting was about one hour to one and half hour. The authors conducted a qualitative study to explore the experience of participants and a semi-structured interview was carried out with the participants. This helped them to collect as much information as possible through interviews (information related to research questions, personal history, participants' knowledge about stuttering and Facebook based support group). The interview and response from the participants was audio recorded and transcribed for analysis. The outcome of this research was that these online platforms can instantly reach an incredible number of people. Additionally, technology enables PWS to easily share materials, and social networking sites appear to offer a perfect, collaborative setting for them to share ideas, emotions, experiences, and general knowledge. These platforms/ websites also help to gain more psycho-social support from other PWS by interacting with them through meetings and providing life-changing and beneficial experiences for PWS.

Chapter 3

Method

The purpose of the following research investigation was to compare the psycho-social effects related to stuttering in persons with stuttering (PWS) who are currently attending a self-help group (SHG) alone or stuttering therapy alone.

The study incorporated descriptive and standard group comparison study design.

Procedure:

Data collection was carried out in three phases. The researcher developed three sets of questionnaires, (i) Demographic details related to self-help group organization, (ii) Demographic details and Experience of those attending self-help group, (iii) Demographic details and Experience of those attending stuttering therapy. These questionnaires were validated by five experienced Speech Language Pathologists with at least five years of experience in stuttering assessment and management. Written consent of participants was taken for participating in this research study. The consent form was attached along with other questions in the Google form.

Participants:

Total 40 participants with stuttering in the age range of 18-33 years were included in the study. Out of them 20 PWS were attending SHG alone and the remaining 20 participants were attending only stuttering therapy. Participants with other concomitant speech and language problems were excluded from the study.

The study was carried out in three phases.

Phase 1: The demographic details related to the organizational setup of a self-help group for stuttering were collected through the Google form-based questionnaire prepared by the researcher. The information was collected by sending a google form link to the head of the Indian Stammering Association (TISA) group in Mumbai through e-mail. The questionnaire included 20 questions in total, some of which were of multiple choice questions and the others were short answer type (given in the Appendix).

Information such as requirements for formation of self-help group with inclusion/exclusion criteria, number of participants included in the setup, inclusion of rehabilitation professionals in the group, and frequency of meeting etc, were probed into.

Phase 2: The Psycho-social aspects of stuttering in PWS were assessed.

Participants' psycho-social aspects related to stuttering were assessed in both the groups (i.e., one group who attended speech therapy alone and the other group who attended only the self-help group). The Google form based questionnaire developed by the researcher was used to gather information related to their experience in speech therapy or self-help groups. Questions such as how long have they been attending speech therapy/self-help groups?, What type of therapy techniques they are using, the benefit of attending therapy or self-help groups and advantages and disadvantages of speech therapy/ self-help groups were probed.

The questionnaires to the two groups (given in the Appendix) were shared through email or Whatsapp, with multiple choices and short-answer type questions. After the completion of the questionnaire, OASES-A (Yaruss & Quesal, 2008) and UTBAS-6 (Iverach et al, 2016) were administered on each PWS in both groups to check for the attitudes and emotional behavior towards stuttering and coping strategies used to manage stuttering in both the groups. The tests were administered through Zoom and Whatsapp platforms.

Phase 3: Virtual Face to face interview was conducted to probe more into the severity of stuttering in the participants of the two groups.

SSI-4 was administered to collect information on quantitative measures of stuttering severity in the participants of both the groups.

Chapter 4 Results and Discussion

The aim of the study was to understand the organizational setup of a self-help group (SHG) and also to compare the psycho-social effects related to stuttering in persons with stuttering, attending stuttering therapy alone verses SHG alone. Data from the 3 phases was collected from the participants and statistical analysis was carried out using IBM SPSS software (version 26.0). Shapiro Wilks test of normality was first carried out, and as distribution of data showed both significant and non-significant result, Independent't' test and Mann Whitney 'U' test were used to further analyse the data.

The results are discussed under each objective as follows:

4.1. Organization setup of self-help group for stuttering

In the present study, only one self-help group ie., the Indian stammering association (TISA) was taken into consideration. The TISA management representative gave information about the formation of the self-help group. He stated that people discover about the self-help group or TISA through the internet, family or friends. The organization criterion into accepting clients for the SHG include individuals who have been stuttering for longer than three years. There were no restrictions on the number of individuals who were accepted to the group. According to the activities carried out, the self-help group participants were divided into sub-groups.

The TISA management also informed that there is no other professional engagement in the organization, and those who have been a part of the group for a long time assist other members in overcoming stuttering. A counsellor or researcher was occasionally invited to interact with members as part of some of TISA's targeted activities, so that participants could understand more about their issues and get any questions answered.

The Organization's goal was to increase stuttering acceptance rather than focusing on fluency. They employed more stuttering modification techniques like bouncing and voluntary stuttering in the SHG. Here, the participants additionally used prolongation technique as a fluency shaping strategy. The organization member reported that meetings in self-help group were held according to the group members' availability as majority of them were working or studying. Hence meetings were scheduled during their convenient time. The meetings were conducted sometimes once a month, sometimes twice a week, or every week depending upon the availability of participants. Calls or messages via Whatsapp were the primary communication methods used to inform participants about the meetings.

The organization received funding from the SHG members who were a part of the group through their voluntary donations. The organization management further stated that, they followed up with clients who had previously visited the setup in order to find out how well they were doing in managing their stuttering. Furthermore, the organization additionally provided SHG participants written guidelines on how to manage stuttering.

4.2. Comparing the psycho-social aspects of stuttering between PWS who are attending stuttering therapy and self-help groups.

4.2.1. Questionnaires given to Self-help group participants.

From the questionnaires handed out to people attending SHG, it was found that all had a prior knowledge about stuttering and most of them were aware of stuttering therapy. Around 60% of the participants were aware of presence of self-help groups for stuttering. The participants stated several valid reasons to attend self-help/ support groups. 11 out of 20 participants shared that support group helped them by improving their self-esteem and self-acceptance of stuttering and it showed them that, they are not the only individuals who are facing this problem. 9 out of 20 participants indicated that, they tried many speech therapy sessions but, couldn't find any satisfaction as they were not able to maintain fluency outside the clinic or therapy session. They claimed that support groups helped in reduction of fear (situation/person), boosting their confidence and helping them to talk in an easy manner.

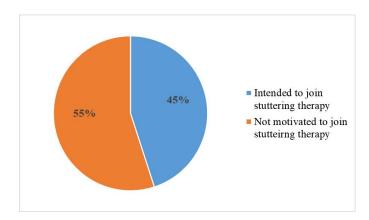
Majority of the participants were attending self-help group for more than 1year, which indicates that people benefit from SHG services for a long period of time. This is similar to the findings from Gerlach and Holister (2019), who found that attending a stuttering support group organization for longer duration is beneficial in reducing the negative impact of stuttering.

With respect to benefits from support group 19 out of 20 participants positively suggested that they are highly benefiting from support group involvement. This is in consensus with the study by Boyle (2013), who found that attending support groups benefits persons with stuttering by providing a supportive and understanding environment where they can share their experiences, learn coping strategies, and receive encouragement from others facing similar challenges. This approach has been shown to positively impact participants' self-confidence, communication skills, and overall well-being.

The participants were asked about their willingness to join speech therapy when they were involved in the self -help group. The results are as shown in the fig.1.

Figure 1

Pie Chart Depicting Percentage of Participants Motivated to Join Speech Therapy after Attending SHG



55% of the participants suggested that, they had no desire to pursue speech therapy, as shown in fig1, as they believed that SHG could help them manage their problem and felt that speech therapy is inadequate to address the emotional aspects of stuttering. However 45% of participants intended to join formal speech therapy after attending SHG.

Thus, SHG had almost 50% impact on motivating people to join speech therapy and seek more help with their stuttering. Ideally combination of both speech therapy and SHG would help in holistic management of stuttering. The results of this study are in agreement with the research conducted by Yaruss et al., (2002), who indicated that individuals frequently experienced a recurrence of stuttering when they stopped attending therapy. However, those who embraced a holistic approach, combining stuttering modification treatment with active involvement in support groups, reported enhanced and sustained positive life experiences.

In the present study, 95% of participants suggested that attending SHG has improved their self-image and acceptance of their problem. Annie Bradberry (1997) similarly discovered that stuttering support groups offer advantages by aiding individuals with stuttering to embrace their condition, foster better self-esteem and confidence and help manage stress related to stuttering.

In the present study when participants were asked about the speech therapy technique used in self-help group, 75% of the participants suggested using prolongation, slow speech and bouncing as effective speech therapy techniques to reduce stuttering. 100% of the participants agreed with advantages of enrolling in SHG such as meeting others persons with stuttering and encouragement from fellow persons with stuttering. They believed that, this platform helps them to exchange ideas, feelings and experiences with other PWS, it helps them gain more confidence while speaking in a large group, and aids in understanding stuttering and persons with stuttering better, and instills the feeling that they are not alone. This finding is similar to a study by Medina etal (2019), in which the author reported that participants indicated an improvement in their social skills and emotional well-being after joining the self-help group.

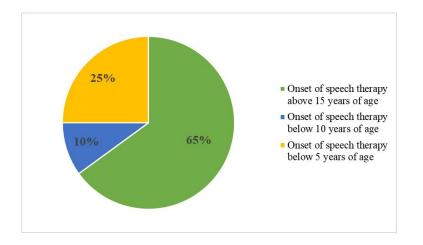
When the participants in the present study were asked if they would recommend selfhelp groups for other persons with stuttering, 100% of the participants highly recommend joining SHG for PWS. Thus this shows that SHG has positive impact on the rehabilitation of people with stuttering. This is similar to the findings reported by Trichon and Tetnowski (2016), and Boyle & Gabe (2020), who showed that participating in stuttering support groups, conferences, or virtual meetings can help reduce the negative effects of the condition.

4.2.2. Questionnaires given to participants attending speech therapy

The following results were obtained by the questionnaires handed out to the PWS who were attending speech therapy alone. Among them, 75% of the participants were aware of stuttering and had prior knowledge about speech therapy.

With respect to age of client at onset of therapy, participants' responses are shown in the fig 2.

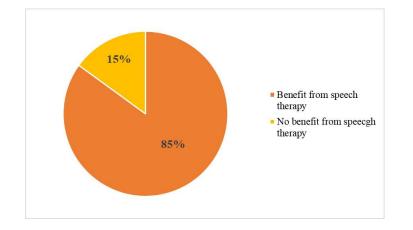
Figure 2



Pie Chart Depicting the Percentage of Age of Participants at the Onset of Therapy

From the fig 2, we can see that, 65% of participants started attending speech therapy above the age of 15 years, while 25% started intervention below the age of 5years and 10% started rehabilitation below 10years of age. This warrants the importance for increasing awareness about early rehabilitation for stuttering. Onslow & O'Brian (2012) in their study on Metaanalysis of rehabilitation of persons with stuttering revealed that the early rehabilitation in persons with stuttering increases the chance of overcoming stuttering. This emphasizes the need for early rehabilitation and management of stuttering for better prognosis. The answers to the question on benefit of attending speech therapy are as shown in the fig, 3.

Figure 3



Pie Chart Depicting Percentage of Participants Benefiting from Therapy

From fig 3, it can be clearly seen that, 85% of participants suggested that, they are benefiting from speech therapy. With respect to benefits from speech therapy, 8 participants stated that, the therapy helped in understanding of their problem better, 9 participants stated that it helped them learn techniques to control stuttering. 12 participants said that stuttering therapy helped them face situations with more confidence. Thus stuttering therapy has a positive effect on people in managing their stuttering, This is similar to studies conducted by Irani, Gabel et al., (2012) and Andrews et al., (1980), who found that stuttering therapy programs are beneficial for changing attitudes and behavioural measures of speech dysfluencies.

However as depicted in fig 3, it can also be seen that 15% of the participants suggested that they are not benefiting from the stuttering therapy as they are not able to use the therapy techniques because of the fear of stuttering, thus making therapy effectiveness not satisfactory. Hayhow et al., (2002), also found that no single therapeutic approach could be identified as particularly beneficial. In there study 25% of the participants indicated that therapy was slow in producing results, and they were disappointed as they were not able to do anything about their stuttering. In another study by O'Brian et al., (2003), adults with stuttering who had completed an extended speech therapy course were recruited to provide both objective and self-report data. On a nine-point scale, their subjects offered subjective

ratings of the numerous fluency-related indicators both before and after therapy with positive ratings at lower end of the scale, and negative ratings at the higher end. According to the findings, despite spending months in the therapy programme, majority of the participants lacked a sense of comfort and ease when using lengthy speech in social circumstances outside the clinic.

In the present study when participants were asked if they were able to maintain speech fluency outside the therapy situation, 65% of the participants reveled that they were able to maintain fluency outside therapy situation, while 35% of the participants were unable to maintain speech fluency and had difficulty in using speech therapy techniques outside. They also felt that modified speech seems unnatural beyond clinical setting. Hence, they failed at generalizing fluency in other situation. They also felt that little attention was paid to their feelings and they did not feel comfortable using modified speech.

Out of the 20 participants 13 reveled that, their fears and concerns were not discussed adequately. 12 of them believed that they were not given enough guidelines related to relapse and about the problems they might face in maintaining fluency after therapy. 3 participants also felt that they were not given practice materials for speech techniques that was practiced in therapy. Thus although stuttering therapy is beneficial, when it comes to generalization, people fail at sustaining their modified speech skills. These results are in consensuses with the study done by Yaruss et al., (2002), in which 52% of the participants claimed they were unable to achieve the same fluency in a real-life situation as they did in the "clinical setting" and among them, 60% of the individuals who underwent a variety of treatment methods were unable to maintain their fluency after the treatment regardless of the treatment approach. Further, Stewart and Richardson (2004), in their study, employed a qualitative technique to get information with regard to the stuttering therapeutic benefits. They discovered that treatment had not helped in the transfer of skills from the clinic to real-world situations.

4.2.3 Comparison of psycho-social aspects of stuttering between Self-help group and stuttering therapy group participants.

To assess psycho-social outcomes of stuttering, the researcher administered OASES-A (Yaruss & Quesal, 2008) and UTBAS-6 (Iverach et al., 2016) on the participants of the study. Sections in OASES like "**speaker's reaction to stuttering, "communication in daily life" and "quality of life**" were considered mainly to compare between groups. The overall impact score of OASES was also considered for the comparison between the two groups. In UTBAS-6 responses for all six questions were divided into three sections "**frequently having these thoughts**", "how much they believe these thoughts" and "how anxious these thoughts make them". A qualitative statistical analysis was carried out for each section of Likert scale questionnaire using IBM SPSS Software (version 26.0).

The descriptive statistics of sections of OASES-A and 3 sections of UTBAS are represented in table 1 and 2 respectively.

Table 1

Variables	Group	п	Mean	Std. Deviation	Median	Minimum	Maximum
Section_1	SHG	20	58.65	20.58	52.50	37.00	99.00
(reaction to stuttering)	Stuttering therapy	20	56.10	9.75	56.00	41.00	71.00
Section_2	SHG	20	47.05	11.12	42.50	32.00	74.00
(communication in daily life)	Stuttering therapy	20	43.85	7.90	44.00	27.00	59.00
Section_3	SHG	20	45.35	16.13	39.00	25.00	75.00
(quality of life)	Stuttering therapy	20	39.70	8.85	38.00	23.00	57.00

Descriptive Statistics of 3 sections of OASES-A

Note. SHG = Self-help group

OASES = Overall Assessment of the Speaker's Experience of Stuttering

Table 2

Variables	Group	п	Mean	Std.	Minimum	Maximum
				Deviation		
UTBAS_(how frequently I	SHG	20	12.10	4.61	6.00	25.00
have these thoughts)	Stuttering therapy	20	10.10	2.14	7.00	14.00
UTBAS_(how much I	SHG	20	12.35	4.29	6.00	24.00
believe these thoughts)	Stuttering therapy	20	10.50	2.43	7.00	15.00
UTBAS_(how anxious these	SHG	20	13.40	4.94	6.00	26.00
thoughts make).	Stuttering therapy	20	10.75	2.35	7.00	15.00

Descriptive Statistics of 3 sections of UTBAS.

Note. SHG = Self-help groups

UTBAS = Unhelpful Thoughts and Beliefs about Stuttering

On the Shapiro Wilks normality test only section 2 of OASES-A i.e. "communication in daily life", and all 3 sections of UTBAS i.e. "how frequently they have these thoughts", "how much they believe these thoughts" and "how anxious these thoughts make them", showed significance. Hence independent 't' test was carried out for all the above mentioned sections of OASES-A and UTBAS. The results as shown in the table 3.

Table 3

Variables	't' value	Sig. P value
OASES-Section_2 (Communication in daily life)	1.048	.301
UTBAS_ 1(frequent thoughts)	1.758	.087
UTBAS_2 (believe in thoughts)	1.675	.102
UTBAS_3 (anxiousness)	2.163	.037*

Independent 't' test to Compare between SHG and Stuttering Therapy Groups

Note. OASES = Overall Assessment of the Speaker's Experience of Stuttering UTBAS = Unhelpful Thoughts and Beliefs about Stuttering

As shown in the table 3, the results from the independent 't' test showed that there was no significance (p>0.05) in any of the sections of OASES-A between the two groups. However from the table 1, it can be seen that, difficulties with communication in daily life is slightly more in SHG than the stuttering therapy group. Thus, structured evidence based practice incorporated in stuttering therapy sessions may be slightly more beneficial in managing stuttering and helping with communication in daily life than the informal and indirect approach used in self-help groups.

With respect to three section of UTBAS pertaining the independent 't' test showed significance (p<0.05) between the two groups only for third section of UTBAS pertaining to "how anxious unhelpful thoughts related to stuttering make them feel". The remaining two sections pertaining to "how frequently they have these thoughts" and "how much they believe these thoughts" were not significant (p>0.05). However comparing the mean scores of all three sections of UTBAS from the table 2, it can be seen that self-help group participants had slightly more unhelpful thoughts compared to Stuttering therapy group. One possible reason for this could be that, in the present study that, the meeting at self-help group were not conducted as intensives as stuttering therapy sessions.

For the section of OASES-A which did not show normal distribution on Shapiro Wilks test Mann Whitney 'U' test was used. The results of the non- parametric test are as shown in the table below.

Table 4

Mann Whitney test to Compare Two sections of OASES-A between SHG and Stuttering Therapy Groups

Variables	Modulus (Z) value	Sig. P value	
Section_1 (reaction to stuttering)	352	.725	
Section_3 (quality of life)	501	.616	

From table 4, it can be seen that both the sections of OASES-A were not significant (p>0.05). However, people attending self-help group had slightly more negative reaction towards stuttering than compared to people attending stuttering therapy alone as shown in the table 1. Also, persons with stuttering attending stuttering therapy had better quality of life compared to people attending self-help group. Yaruss (2010) also found better quality of life scores in 173 individuals after attending stuttering treatment. One possible reason for increase in impact scores of OASES could be because, the self-help group taken in the study, was meeting depending on the availability of the participants. Hence, the participants were not getting help on a regular intensive basis. Ideally, combining both stuttering therapy and self-help support group would be helpful in reducing the unfavorable attitudes towards stuttering.

4.2.4. Comparing the overall impact rating of OASES-A in both the groups

All the four sections of OASES-A were considered in this section (ie. 'general knowledge', 'reaction to stuttering', 'communication in daily life', and 'quality of life') to find-out the overall impact rating between both the groups, the test result are as shown in the table below.

Table 5

Frequency and Percentage of Overall Impact Rating of OASES-A in Both Groups

Overall severity	SHG	Stuttering Therapy
Mild	2 (10%)	4 (20%)
Moderate	18 (90%)	16 (80%)

Note: SHG = Self-help group

From the table 5, it can be seen that, among the SHG participants OASES-A reveled that, 90% had moderate impact of stuttering, while 10% reported only mild impact. However among the stuttering group, 80% reported moderate impact while 20% reported mild impact of stuttering in their lives. Hence OASES-A showed slightly more impact on SHG compared to stuttering therapy group. These findings contradict with a study done by Gerlach and Holister (2019), authors found reduction in overall impact score of stuttering in PWS after the participation in self-help groups. One possible reason for increase in overall impact score in SHG group could be because, stuttering therapy was more intensive than compared to SHG, hence issues with stuttering were addressed better in stuttering therapy.

4.3 Comparison of quantitative outcomes of stuttering management between PWS and those attending self-help group.

An attempt was made to compare quantitative stuttering measures of PWS in both the groups. Participants were evaluated using SSI-4 by Riley (2009) and the results are shown in the following table 6,

Table 6

Frequency and Percentage Overall Stuttering Severity obtained by SSI-4 in Both Groups

Stuttering severity	SHG	Stuttering therapy	
Mild	8 (40%)	5 (25%)	
Moderate	12 (60%)	15 (75%)	

Note: SHG = Self-help group

From the table 6, it can be seen that 60% of the SHG participants showed moderated stuttering severity, while 40% had mild severity. Among those attending stuttering therapy alone 75% had moderate severity and 25% showed mild stuttering severity. Thus it can be seen that clients with more severity tend to prefer stuttering therapy over SHG. The self-help group had reduced stuttering severity compared to people attending stuttering therapy. This may be because of being amidst people who stutter, PWS felt more comfortable because of the reduced environmental demand.

Chapter 5 Summary and Conclusion

Based on the findings of the current study, it is evident that stuttering rehabilitation can be through formal, structured evidence based speech therapy, as well as through self-help group (SHG) support. The present study was mainly aimed at probing into the psycho-social outcomes in stuttering management between two groups of people with stuttering, one those attending speech therapy alone and the other attending SHG alone. Three questionnaires were developed in the study to gain information on, organization setup of SHG, demographic details and experiences related to participation in SHG (those attending SHG alone), demographic details and experiences pertaining to stuttering therapy (those attending stuttering therapy alone).

Total 40 persons with stuttering participated in the study, out of which 20 were attending self-help group and remaining were enrolled in stuttering therapy. Participants from only one SHG were taken for the present study, which had meetings based on the availability of the participants and no professional help was sought in the group. The aim of the SHG was to work on understanding and accepting stuttering rather than improving individual's fluency.

Probing into psycho-social factors of stuttering in both the groups, results reveled that, the people attending self-help groups had more impact of stuttering in their day to day life (as obtained in OASES-A) and more unhelpful thoughts (as obtained in UTBAS) compared to stuttering therapy group. Hence people with more negative feelings preferred to attend self-help groups over stuttering therapy. However, stuttering therapy group had more severity of stuttering than the self-help group which showed that people with increased severity of stuttering preferred to take more formal, structured speech therapy than attending self-help groups. Also, as stuttering therapy was more intensive than the self-help groups (which had meetings only based on availability of participants), PWS could address issues related to stuttering better. Hence for a holistic rehabilitation of stuttering, where both covert and overt

features can be tackled, a combination of both intensive stuttering therapy and regular selfhelp group support is warranted.

Compared to the West, India does not have regularly functioning stuttering self-help groups. As a future direction, the present study highlights the importance of formation of SHG's for persons with stuttering across the country. This would aid in sustained improvement in fluency and better management of negative feelings and unhelpful thoughts related to their speech, and also provide accessible platforms to share their experiences, learn from one another and complements the benefits of traditional stuttering therapy. Speech language pathologists should promote SHG along with the traditional speech therapy to ensure better rehabilitation of persons with stuttering.

References

American Speech-Language-Hearing Association. (2007). Scope of practice in speechlanguage pathology. (Scope of Practice).

- Andrews, G. Guitar, B. Howie, P (1980). Meta-analysis of effects of stuttering treatment, Journal of Speech and Hearing Disorders, pp. 287-307.
- Bradberry, A. (1997). The role of support groups and stuttering therapy, Journal of *Seminars in Speech and Language*, 14(4).
- Boyle M.P. (2013). Psychological characteristics and perceptions of stuttering of adults who stutter with and without support group experience, *Journal of Fluency Disorders*, 38, pp.368–381.
- Boyle, M. P. (2015). Relationships between psycho-social factors and quality of life for adults who stutter. *American Journal of Speech-Language Pathology*, 24(1), pp. 1–12.
- Boyle, M.P. Gabel, M.R. (2020). 'Openness and progress with communication and confidence have all gone hand in hand'': Reflections on the experience of transitioning between concealment and openness among adults who stutter. *Journal of Fluency Disorders*, 65, doi.org/10.1016/j.jfludis.2020.105781.
- College of Audiologists and Speech-Language Pathologists of Ontario (CASLPO). (2014). *Practice standards and guidelines for developmental stuttering*. Toronto.
- Craig, A., Blumgart, E., & Tran, Y. (2009). The impact of stuttering on the quality of life in adults who stutter. *Journal of Fluency Disorders*, 34, pp. 61–71.

Diener, E., Emmons, R. A., Larsen, R. J., & Griffifin, S. (1985). The Satisfaction with Life Scale. *Journal of Personality Assessment*, 49, pp. 71–75.

- Guitar, B. (2013). Stuttering: An integrated approach to its nature and treatment (4th ed.). Baltimore, MD: Lippincott Williams & Wilkins.
- Gerlach, H. Hollister, J. Caggiano, L. Zebrowski, M. P. (2019). The utility of stuttering support organization conventions for young people who stutter, *Journal of Fluency Disorders*, 62, doi.org/10.1016/j.jfludis.2019.105724.
- Hayhow, R. Cray, M. A. Ebderby, P. (2002). Stammering and therapy views of people who stammer, *Journal of Fluency Disorders*, 27, pp. 1-7.
- Ingham, R. J. (2012). Comments on recent developments in stuttering treatment maintenance research using the Camperdown Program. *Journal of Speech, Language, and Hearing Research, 55,* pp. 306–309.
- Irani, F. Gabel, R. Daneils, D. & Hughes, S. (2012). The long term effectiveness of intensive stuttering therapy: A mixed methods study, *Journal of Fluency Disorder*, 37, doi.org/10.1016/j.jflfludis.2012.04.002.
- O'Brain, S. Onslow, M. Cream, A. Packman, A (2003), The Camperdown Program: Outcomes of a New Prolonged Speech Treatment Model, Journal of Speech Language and Hearing Research, 46, pp.933-946.
- O'Brain, S. Packman, A. Onslow, M. & Menzies, R. (2012). Measuring outcomes following the Camperdown Program for stuttering: A response to Dr Ingham. *Journal of Speech, Language, and Hearing Research, 55, pp. 310–312.*
- Onslow, M. O'Brain, S. (2012). Management of childhood stuttering, *Journal of Pediatrics* and Child Health, 49, doi:10.1111/jpc.12034.
- Plexico, L. W. Manning, W. H. & Levitt, H. (2009a). Coping responses by adults who stutter:Part I. protecting the self and others. *Journal of Fluency Disorders*, *34*, pp. 87–107.

- Medina, M. A, Almedia, N. Amarante, L. Martinez, N. & Prezzemolo, M. (2019) Adults
 Who Stutter and Their Motivation for Attending Stuttering Support Groups: A Pilot
 Study, *Journal of American Speech-Language-Hearing Association*, 5, pp. 142-154,
 doi.org/10.1044/2019_PERSP-19-00049.
- Raj, E. X. Daniels, E. D. & Thomson, E. P. (2023), Facebook groups for people who stutter: An extension of and supplement to in-person support groups, Journal of Communication Disorders, 101, doi.org/10.1016/j.jcomdis.2022.106295.

Rosenberg, M. (1989). Society and the adolescent self-image (revised ed.). Middletown, CT: Wesleyan University Press.

- Rout, N. Kumar, S & Kumar, N. (2014) A Survey on Conceptions of Stuttering. Rehabilitation Process and Outcome, doi:10.4137/RPO.S12755. pp. 37-13.
- Schwarzer, R., & Jerusalem, M. (1995) Self-efficacy measurement and generalized selfefficacy scale. *Measures in Health Psychology: A User's Portfolio. Causal and Control Beliefs*, pp. 35-37.
- Sommer, M. Waltersbacher, A. Schlotmann, A. Schroder, H. (2021). Prevalence and Therapy Rates for Stuttering, Cluttering, and Developmental Disorders of Speech and Language: Evaluation of German Health Insurance Data. *Frontiers in human science* doi: 10.3389/fnhum.2021. pp. 292-645.
- Stewart, T. Richardson, G. (2004). A qualitative study of therapeutic effect from a user's perspective, *Journal of Fluency Disorders*, 29, pp. 95-108, doi:10.1016/j.jflfludis.2003.11.00.
- Trichon, M. & Tentowski, J. (2010), Self-help conferences for people who stutter: A qualitative investigation, Journal of Fluency Disorders, 36, doi:10.1016/j.jflfludis.2011.06.001.

- Tran, Y. Blumgart, E. & Craig, A. (2011). Subjective distress associated with chronic stuttering. *Journal of Fluency Disorders*, 36, pp. 17–26.
- Yaruss, J. S. Quesal, R. W. & Murphy, B. (2002). National Stuttering Association members' opinions about stuttering treatment. *Journal of Fluency Disorders*, 27, pp. 227–242.
- Yaruss, J. Quesal, R. W. Reeves, L. Molt, L. F. Kluetz, B. Caruso, A. J. & Lewis, F. (2002). Speech treatment and support group experiences of people who participate in the National Stuttering Association. *Journal of Fluency Disorders*, 27(2), pp. 115–134.
- Yaruss, J. S. (2010). Assessing quality of life in stuttering treatment outcomes research, *Journal of Fluency Disorders*, 35, pp. 190-202, doi:10.1016/j.jflfludis.2010.05.010.
- Yaruss, J. S. Coleman, C. E. & Quesal, R. W. (2012). Stuttering in school-age children: A comprehensive approach to treatment. Language, Speech, and Hearing Services in Schools, 43, pp. 536–548.
- Young H (2020). How does participation in support groups impact psycho social outcomes for people who stutter? *School of communication science and disorder*.

APPENDIX 1

Questionnaire on "Demographic Details of Organizational Setup"

1. Email * 2. Name *

3. Contact Number *

4. Founder of the Self-help group.*

5.	When	was	the	group	formed? *
<i>v</i> .		11 660	the care	Broup	Iomittee.

6. What is the need for organizing this setup/self-help group (SHG). *

7. Criteria used for accepting clients in the SHG? *

Clients who are attending speech therapy
 Clients who have attended speech therapy
 Clients who don't have exposure to speech therapy
 Clients who have been stuttering for more than 3 years
 Other:

8. Criteria used for not accepting clients in SHG?*

Clients with no stuttering

Clients recovered from stuttering

Clients who may have other communication disorders other than stuttering

Other:

9. How many clients are considered in SHG?*

10. Are participants divided into subgroups? If yes, please explain. *

11. Which of the following allied professionals are available in the setup? *

Speech	Therapist		
Psycho	logist		
Counse	ellor		
All of t	the above		
None o	of the above		
Other:			

12. Are any speech therapy techniques taught in the SHG centre? *.

Prolongation	
Slow rate of speech	
Air flow method	

13. If any other techniques or forms of therapy are used? Please explain. *

- 14. Do clients attending SHG have prior knowledge about SHG and Speech Therapy?
 - Yes
 - No
 - Maybe

15. How do clients get to know about your self-help groups ?

- Friends Family
- Website

Other:			
	<u></u>		

16. How often are the meetings conducted? *

Weekly once	
Once every fort night	
Once a month	
Once in 3 months	
Other:	

17. How is the group funded? *

Government
NGO
Non profit organization
Other:

- 18. What is the mode of communication used to inform the participants about the meetings?
 - Phone Email

19. Do you follow up with your clients who have come to your setup before ?

◯ Yes ◯ No

20. Do you provide the participants with written guidelines about stuttering management?



APPENDIX 2

Questionnaire on "Demographic details and Experience of those Attending Self-help group"

	1.	Email*	
	2.	Name *	
	3.	Contact Number *	
4.		oluntarily agree to participate in this research study. If you consent to participate * he study, please click " I agree" option below.] I agree] I disagree	-
5.		d you have any prior knowledge about the term "stuttering"? If yes, explain g., through Google, books, friends, family, Television etc.)	*
6.		d you have any prior knowledge about stuttering therapy? * Yes No	

- 7. Did you have any prior knowledge about the Self-help group ? *
 - Ves No
- 8. What made you attend self-help group/ Stuttering support group? Explain. *
- 9. Are you currently a member of a stuttering support group? *



- How did you know about the self-help group that you are attending now? Explain
- *

11. For how long have you been a member of a group?*

- <3 month</p>
- ── <6 month
- ── <1 year
- 1 year and above
- 12. How many members are there in your group *
 - 1-5 members
 - 6-10 members
 - 11-15 members
 - >15 members

*

- 13. According to you, what should be the ideal support group size?*
 - 1-3 members
 - 1-5 members
 - 5-10 members
 - 10-15 members
 - >15 members
- 14. Are you benefiting from the support group? *.
 - Yes, to a large extent
 - Somewhat
 - Not benefiting
 - 15. Has your involvement in self-help group encouraged/motivated you to join speech therapy?

\sim	400 X 2		225 B		13
()	Increased	VOIIT	desire to	pursue	therapy
-	Interensed	Jour	crebite to	pursue	unerup y

- Decreased your desire to pursue therapy
- Had no affect on my desire to join to speech therapy

Other		
Other:		

- 16. Were you in speech therapy before attending a support group? *
 - Yes No

- 17. Are you attending self-help group along with speech therapy? *
 - Ves No
- 18. How has your involvement with a support group affected your self-image or your acceptance of yourself as a person who stutters?
 - Very positively
 - Somewhat positively
 - O No effect
 - Somewhat negatively
 - Very negatively
 - Do you use specific speech techniques in self-help group to reduce the occurrence of stuttering? If yes, please explain.

20. Do you get any professional help during the session? *



No

*

*

21. From which experts do you receive assistance?*

	Speech language pathologist/ Speech therapists (SLP/ST)
	Psychologist
1	Counselor
	Other:

22. What role should an SLP have in the Support group movement? *

	Therapeutic role
	Counselor
	Participant
	Observer
	Referral source
Γ	Other:

23. How often are the meetings conducted ? *.

C		***	4 4	
C)	Wee	kly	once

- Once every fort night
- Once a month
- Once in 3 months
- 24. Do you think stuttering support groups should only allow people who stutter to * participate?
 - O No opinion
 - **Yes**
 - O NO
- 25. what are the advantages of enrolling in self-help group? *
 - Can meet other persons with stuttering
 - Encouragement from other person with stuttering
 - Helps to exchange ideas, feelings and experiences with other persons with stuttering
 - Helps to gain more confidence while speaking in a large group
 - Helps to understand stuttering and persons with stuttering better
 - Can gain a sense of feeling that you are not alone

26. Would you recommend self-help group for other persons with stuttering ?*



APPENDIX 3

Questionnaire on "Demographic details and Experience of those Attending Stuttering Therapy"

1. Email *

2. Name *

3. Contact Number *

I voluntarily agree to participate in this research study. If you consent to participate *
in the study, please click "I agree" option below.

I agree

🕖 I disagree

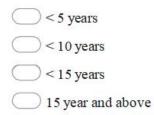
- 5. Did you have any prior knowledge about "Stuttering/ Stammering"? If yes, explain (e.g., through Google, books, friends, family, Television etc.)
- 6. Did you have any prior knowledge about Stuttering therapy/ Speech Therapy? *
 - Ves No

7. Who recommended you to attend speech therapy *

🔵 Family

Friends/ Colleagues

- Through internet
- 8. At what age did you start receiving speech therapy ? *



9. Are you attending speech therapy at present ?*



- 10. What type of schedule do your speech therapy sessions follow? *
 - 1 per week
 2 per week
 3 per week
 >5 per week
 Other:

- 11. Overall, how much time have you spent in speech therapy ?
 - 1 month
 - \bigcirc <3 months
 - \bigcirc < 6 months
 - < 1 year</pre>
- 12. Are you benefiting from attending Speech therapy? *
 - Ves No
- 13. If you are not benefiting from speech therapy , choose the reason below/ explain?
 - ◯ Not using speech therapy techniques
 - ◯ Not able to generalize the technique
 - Lack of motivation
 - Other:
- 14. If you benefiting from speech therapy, what aspects did you find beneficial? *
 - Learning/better understanding about the problem
 - Learning techniques to control stuttering
 - Learning to face different situation with more confidence

Other:

15. Can you maintain your fluency outside the therapy situation ?

C	Yes	
C	No	

 If you are unable to maintain speech fluency outside therapy, please explain why.

Lack of motivation	
--------------------	--

- Unable to generalize fluency in other setting/situation
- Seems unnatural to use technique in other situation
- Difficulty to use speech therapy technique

Other:	
	Other:

17. Considering all the speech therapy techniques you tried, what aspects were disappointing or troublesome?

Little attention was paid to my feelings

- I was asked to speak in a way which didn't feel comfortable
- Therapist did not have much experience
- I had difficulty in maintaining fluency outside therapy settingNot
- enough time was available for therapy

Other:

18. What were the factors overlooked in therapy ?*

- Guidance in dealing with relapse
- Discussion of your fear, concern and experiences
- Giving practice material for techniques used in therapy
- Discussion of obstacles in maintaining fluency after therapy

10000000	
Other:	
Ouler.	

19. Have you experienced any additional issues while in therapy? If yes, explain. *

20.	What other type of treatment have you tried for stuttering other than speech
	therapy?

	Psychological consultation
	Feedback devices (DAF, FAF, Masker or Fluency master)
Ľ	Motivational course
	Medication
	Hypnosis
	Audio therapy
	Virtual reality
	Other:

21. How has stuttering therapy helped you in your day to day life? *