Neurogenic Stuttering: Exploring Potential Emotional And Life Impact

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NEUROGENIC STUTTERING: EXPLORING POTENTIAL EMOTIONAL AND LIFE IMPACT

Natalie DeVries, M.A.

Western Michigan University, 2022

The purpose of the current study was to explore the potential emotional and life impact of living with neurogenic stuttering and how and when an impact develops, if present. The current diagnostic criteria for neurogenic stuttering includes no emotional impact (Canter, 1971). The literature is divided in supporting this criterion (Lebrun et al., 1990; Leder et al., 1996; Perino et al., 2000; Theys et al., 2008; Tani & Sakai, 2011; Ellis & Sheehy, 2013; Vanhoutte et al., 2014). The current study relied on qualitative interviewing which was analyzed using Reflexive Thematic Analysis to explore potential for emotional and life impact (Braun & Clarke, 2006). Qualitative data was supplemented with quantitative data (Overall Assessment of the Speaker's Experience of Stuttering - Adult; Yaruss & Quesal, 2006; Stuttering Severity Instrument – 4; Riley, 2009) to further explore the experience of living with neurogenic stuttering. Results indicate that the experience of neurogenic stuttering for the seven participants in the study was best described with four progressive themes – struggle, life changes, coping, and identity. The data from the current study suggests that a life and emotional impact was present for each of the participants with neurogenic stuttering.
NEUROGENIC STUTTERING: EXPLORING POTENTIAL EMOTIONAL AND LIFE IMPACT

by

Natalie DeVries

A thesis submitted to the Graduate College in partial fulfillment of the requirements for the degree of Master of Arts Speech-Language Pathology Western Michigan University April 2022

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Natalie DeVries
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CHAPTER 1

INTRODUCTION

Imagine waking up on a regular day. You get in your car to go to work. On the way, a car loses control and smashes into yours. The next thing you know, you wake up in the hospital and when you go to speak, you have difficulty stringing words together. When they ask your age, you start by stuttering, saying “tw-tw-tw-tw-tw,” and find that you can’t get the rest of the “twenty-two” out. It’s logical to think that suddenly acquiring a fluency disorder or stuttering could be associated with an adverse emotional or life impact. But the literature on the topic is limited, leaving treatment for the potential emotional impact unexplored. The current study focuses on the potential emotional and life impact of developing neurogenic stuttering to bridge this gap in the literature.

Stuttering is a fluency disorder, or variation in the forward flow of speech production, which is in need of further research. Stuttering is characterized by a loss of control while speaking, which can manifest in specific “stuttering-like” disfluencies, including sound/syllable repetitions, prolongations, and blocks (Yairi & Ambrose, 2013; Blomgren, 2013). A person who stutters may produce typical disfluencies along with the stuttering-like disfluencies. Typical disfluencies are produced in conversation by typically fluent speakers and are characterized by phrase repetitions (I want- I want a sandwich), revisions (I need – I want a sandwich), and interjections (I um want a sandwich) (Yaruss et al., 1999). Secondary characteristics (sometimes referred to as “associated behaviors”) may or may not accompany production of stuttering-like disfluencies and can be verbal or nonverbal in nature. Secondary characteristics may include, physical tension, eye blinking, tongue clicking, circumlocutions (talking around a word), and other reactions to a moment of stuttering. The secondary characteristics may be an indicator of
the cognitive and affective impact of stuttering the person who stutters may be experiencing (Blomgren, 2013).

Further complicating our understanding of fluency disorders in research and among the general public, “stuttering” is an umbrella term that encompasses multiple specific fluency disorders. The various types of stuttering are often broadly characterized as either developmental or acquired. Developmental stuttering - stuttering that emerges in the preschool years often between ages three and five and is neurodevelopmental in nature - is the most common type of stuttering and has received the most attention in research (Yairi & Ambrose, 2013). Other fluency disorders, such as acquired stuttering, may emerge after the developmental language period in the preschool years (Lundie et al., 2014).

According to Van Borsel (2014), acquired stuttering is defined as non-developmental in nature, meaning it begins after the period of language development in childhood often in the preschool years. Many terms have been used to describe the acquired nature of the disorder which has divided the literature on the correct term to use. Some researchers refer to the disorder as stuttering, while others choose to define it broadly as disfluency. Additionally, the terms non-developmental, adult-onset, late-onset stuttering, and lesion-based labels (e.g., stroke-associated stuttering; Van Borsel, 2014) have been used. The restrictive nature of more defined terms (e.g., adult-onset), negates the reality that acquired stuttering can onset in both childhood and adulthood. The term acquired stuttering is used broadly, and in the current study, to describe stuttering that onsets past the preschool years (Van Borsel, 2014).

There are two forms of acquired stuttering: psychogenic and neurogenic. Psychogenic stuttering has a psychological etiology, often onsetting after a significant emotional trauma (Van Borsel, 2014). Neurogenic stuttering has a neurological etiology, specifically in the central
nervous system (CNS), often caused by neurological injury such as a stroke or Traumatic Brain Injury (Canter, 1971). Neurogenic stuttering is the most common form of acquired stuttering in adulthood (Lundie et al., 2014).

There are documented differential diagnostic criteria to distinguish between the two forms of acquired stuttering. The criteria that have been established are used to distinguish the etiology and subsequent evidence-based treatment. For example, an individual who has had a stroke may begin to stutter due to the emotional distress of a new diagnosis (psychogenic), or as a result of a lesion in the brain associated with the stroke (neurogenic) (Van Borsel, 2014). The two types are distinguished mainly by the individual’s response to treatment. Psychogenic stuttering generally has a rapid response rate to behavioral treatment, with significant reduction in disfluencies within approximately two treatment sessions. Neurogenic stuttering may persist for longer and may not respond to behavioral treatment with significant increases in fluency (Lundgren, 2010). It is important to differentially diagnose between the two forms of acquired stuttering due to the differing treatment procedures and outcomes.

It is especially important to distinguish neurogenic stuttering from other fluency disorders, such as developmental and psychogenic stuttering, because the verbal symptoms are categorized in the same broad categories (repetitions, prolongations, blocks; Alm, 2004; Van Borsel & Taillieu, 2001). Due to the similar verbal output, when clinicians assessed the communication of people whose stuttering was developmental or neurogenic in a research setting, one-fourth of diagnoses were incorrectly distinguished as the opposite form of stuttering (Van Borsel & Taillieu, 2001).

Despite similarities between neurogenic stuttering and other forms of stuttering in terms of verbal output, there are distinct differences between the forms of stuttering, which may be
subtle but important to distinguish. The inability to distinguish neurogenic stuttering from other forms of stuttering may in part be due to less awareness of or research on neurogenic stuttering when compared to more common forms like developmental stuttering. Although researchers have previously called neurogenic stuttering ‘rare’ the lower rate of diagnosis may be related to less knowledge and awareness about the communication disorder overall (Van Borsel & Taillieu, 2001). Developmental stuttering is called a ‘common’ form of stuttering in research which contrasts the use of the term ‘rare’ with neurogenic stuttering (Perez & Stoeckle, 2016; Al-Dakrouy, 2020). The life and emotional impact of developmental stuttering has been widely researched; neurogenic stuttering has less robust research and the diagnostic criteria lead to the assumption that there is no emotional impact. There is a significant need to better understand the lived experiences of people with neurogenic stuttering. The potential for life impact as a result of living with neurogenic stuttering is particularly relevant given the “lack of emotional impact” used as a diagnostic indicator. The original source of the diagnostic criteria addressed the limited sample size used in the study and did not specifically state how the lack of emotional impact was assessed noting only that there were not learned reactions to stuttering (Canter, 1971). The topic of emotional impact among individuals with neurogenic stuttering has been largely unexplored in-depth with the participants’ perspective used for research. The disagreement in the literature and diagnostic criteria may lead to sweeping generalizations about the emotions associated with neurogenic stuttering which could in turn reduce the inclusion of adverse impact assessments.

The current qualitative study will investigate the following research questions:

1. What, if any, is the impact of living with long-term neurogenic stuttering (more than 6 months) in terms of emotions, thoughts, and social participation?
2. If there is a life impact associated with living with neurogenic stuttering, when and how do people who live with neurogenic stuttering perceive that it develops?
CHAPTER 2

REVIEW OF LITERATURE

The chapter is organized into nine sub-sections. The first four sub-sections focus on 1) prevalence, 2) etiologies of neurogenic stuttering, 3) neurogenic stuttering behaviors, and 4) diagnostic criteria. I will then review the literature for the 5) emotional and life impact associated with developmental stuttering, as well as 6) the emotional and life impact of living with neurogenic stuttering. Finally, I will 7) review studies suggesting no emotional or life impact associated with neurogenic stuttering, and 8) review contrasting studies indicating a potential for adverse emotional or life impact with neurogenic stuttering and include 9) the purpose of the current study.

2.1 Prevalence

Stuttering is a less common diagnosis than other speech and language disorders (e.g. articulation disorders). The lower incidence of stuttering diagnosis may be related to many factors including less clinician knowledge of fluency disorders compared to other communication disorders or avoiding use of the term ‘stuttering’ around children even though avoidance is no longer supported by research (Byrd et al., 2020). Neurogenic stuttering makes up a small part of the larger group of individuals with fluency disorders. The prevalence of developmental stuttering, the most common fluency disorder, is 5% with 1% incidence over the lifespan (Yairi & Ambrose, 1999; Yairi & Ambrose, 2013). Prevalence refers to the number of people who stutter at a given time, and incidence refers to the number of people who have ever stuttered. The decrease in prevalence versus incidence may be accounted for by spontaneous recovery in children which often occurs between ages two and four. Spontaneous recovery is when a person who stutters stops stuttering naturally without intervention (Yairi & Ambrose,
Approximately 2.4% of children will persist through adulthood in stuttering, rather than recovering through intervention or spontaneously during the developmental period. Persistence may account for the 1% incidence of developmental stuttering in the general population across the lifespan (De Nil & Theys, n.d.).

Less research has been completed on the incidence and prevalence of neurogenic stuttering (Lundie et al., 2014), but estimates suggest there is a 5.3% prevalence of neurogenic stuttering among stroke patients. The rate of stuttering persistence (or stuttering lasting for 6 months or longer) in individuals who develop neurogenic stuttering following a stroke is 2.5% (De Nil & Theys, n.d.). The estimates do not reflect the entire population of individuals who develop neurogenic stuttering, due to many different etiologies other than stroke, but serves as a starting point for quantifying the prevalence in the population in lieu of more extensive data. It is important to note the prevalence and persistence of neurogenic stuttering because it is a small proportion of an already small portion of the population who stutters overall. The small proportion of individuals who develop neurogenic stuttering does not make the experience of neurogenic stuttering any less important and may contribute to inadequate research on the topic. It is important to continue researching and understanding the experience of living with neurogenic stuttering especially when compared to the extensive research on developmental stuttering.

2.2 Etiologies of Neurogenic Stuttering and Lesion Sites

Neurogenic stuttering may develop following a number of neurological events. The most common causes are stroke and Traumatic Brain Injury (TBI), but neurological disorders such as Parkinson’s, brain tumors, as well as recreational drug overdose are also known causes of neurogenic stuttering (Canter, 1971; Ward, 2010; Lundgren et al., 2010). It is important to note
that some research suggests developmental stuttering may resurface following the onset of Parkinson’s disease which differs from neurogenic stuttering caused by Parkinson’s (Shahed & Jankovic, 2001). More rarely, neurogenic stuttering may occur following dialysis (the process of removing toxins from the blood due to reduced kidney function), dementia, seizures, and thalatomy - where a portion of the thalamus is removed (Ward, 2010; Lundgren et al., 2010; Andy & Bhatnagar, 1991). Neurogenic stuttering may also appear as an early diagnostic sign for larger neurological problems, such as dysarthria - a weakening in the facial muscles causing slurred speech (Silbergleit et al., 2009; Guitar, 2019).

Given the specific site of lesion associated with many neurological injuries, such as stroke and TBI, patients with neurogenic stuttering often have a distinguishable area affected in the brain (Lundgren et al., 2010). However the underlying areas of the brain associated with the onset of neurogenic stuttering are considered speculative due to the varying etiologies and symptoms overall (Lundgren et al., 2010). One theory of the cause of neurogenic stuttering across areas affected in the brain is disruption in cortico-basal ganglia function primarily in the left hemisphere (De Nil, 2019; Theys et al., 2013). Many stroke patients have been found to have lesions in the left hemisphere which coordinates communication between the cortex and basal ganglia (Theys et al., 2013). The basal ganglia specifically relate to speech behaviors in coordination and control of motor-speech movements, auditory monitoring of speech, internal timing, and executive functions (Theys et al., 2013; De Nil, 2019).

Another area that has been affected by stroke in people with neurogenic stuttering is the white matter tracts in the brain which coordinate communication between different brain regions; the coordination contributes to fluent speech (Theys et al., 2013). Along with the basal ganglia, damage to the thalamus and frontal lobe have been commonly associated with the development
of neurogenic stuttering. Overall, neurogenic stuttering has been associated with bilateral and unilateral damage in all lobes of the brain except the occipital lobe (Alm, 2004; Helm-Estabrooks, 1993). The diffuse sites of lesion indicate that there are many potential etiologies for neurogenic stuttering arising from neurological trauma or injury. Determining the primary diagnosis (such as stroke, TBI, Parkinson’s, etc.) and site of lesion can be helpful in determining the possible impact on fluency based on the speculative assumptions about the areas affected in the brain.

2.3 Neurogenic Stuttering Behaviors

The stuttering-like disfluencies associated with neurogenic stuttering are the core behaviors of stuttering: blocks, prolongations, and repetitions. The most frequent stuttering-like disfluencies associated with neurogenic stuttering are repetitions of sounds and syllables (e.g., “neur-neur-neurogenic”) and prolongations of sounds (e.g., “nmmneurogenic”). Blocks (“_____neurogenic”) may also occur but are less common when compared to developmental stuttering (Alm, 2004). The specific manifestation of the stuttering-like disfluencies may differ from person to person based on their specific diagnosis and individual factors. For example, neurogenic stuttering may include repetitions and blocks at the ends of words and phrases (e.g., “stutte-r-r-r” or “stutt__er”). The stuttering-like disfluencies at the end of a word are less common than the stuttering-like disfluencies at the beginning of the word often seen in developmental stuttering (e.g., “s-s-stutter,” Manning & DiLollo, 2018). In terms of the types of words individuals with neurogenic stuttering may produce disfluencies on, it is most often content words which are more meaningful. There may also be no pattern in the loci of stuttering, or position of stuttering within word type. Due to variability of neurogenic stuttering behaviors there is debate in the actual nature of neurogenic stuttering because it can ‘blur the lines’
between stuttering-like disfluencies and typical disfluencies experienced by all speakers (e.g., “um” or restarting a phrase; Guitar, 2019; Van Borsel, 2014).

Although there is variability in the stuttering-like disfluencies in each type of stuttering there are common speech characteristics which may occur with neurogenic stuttering. There have been reports of atypical pauses without tension in speech with neurogenic stuttering which is not a core behavior of stuttering. For some, but not all people with neurogenic stuttering, the frequency of stuttering may also be influenced by situations and communication partners. The same is true for spontaneous speech versus speech tasks; some individuals with neurogenic stuttering only stutter in certain speech contexts, while others stutter across speech contexts (De Nil, 2019; Theys et al., 2008). The differing characteristics of neurogenic stuttering-like disfluencies across individuals is consistent with the variable nature of other fluency disorders such as developmental stuttering. For a summary of differences in distinctive features between developmental and neurogenic stuttering, see Table 1.

Table 1

Distinctive Features of Developmental Versus Neurogenic Stuttering

<table>
<thead>
<tr>
<th>Feature</th>
<th>Developmental Stuttering</th>
<th>Neurogenic Stuttering</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(according to diagnostic criteria)</td>
<td></td>
</tr>
<tr>
<td>Age of onset</td>
<td>preschool years</td>
<td>after the preschool years</td>
</tr>
<tr>
<td>Affective/cognitive impact</td>
<td>common</td>
<td>uncommon</td>
</tr>
<tr>
<td>Secondary behaviors</td>
<td>common</td>
<td>uncommon</td>
</tr>
<tr>
<td>Loci of disfluencies</td>
<td>content and function words</td>
<td>content and function words</td>
</tr>
<tr>
<td>Word position</td>
<td>typically first syllable</td>
<td>all word positions</td>
</tr>
<tr>
<td>Site of Lesion</td>
<td>n/a</td>
<td>specified</td>
</tr>
<tr>
<td>Adaptation effect</td>
<td>common</td>
<td>uncommon</td>
</tr>
</tbody>
</table>

Note: features in this table were derived from work by Plexico, 2009; Richels at al., 2010; Krishnan & Tiwari, 2011; Perez & Stoeckle, 2016; Choi et al., 2020 on developmental stuttering and De Nil, 2019; Krishnan & Tiwari, 2011; Canter, 1971; Helm-Estabrooks, 1999 on neurogenic stuttering.
2.4 Diagnostic Criteria

Best practice for communication disorders is the use of evidence-based research for diagnosis and treatment. Evidence-based practice is defined in the American-Speech-Language Hearing association position statement as, “an approach in which current, high-quality research evidence is integrated with practitioner expertise and client preferences and values into the process of making clinical decisions.” (ASHA, 2005) There are three main considerations when choosing evidence to inform a therapy approach or diagnosis: research on the subject, clinician preference, and client perspective (ASHA, 2005; Cohen & Hula, 2020). The client’s perspective is as equally important as research and clinician judgement. Client perspective is considered extremely valuable because many aspects of fluency disorders are unobservable, so only clients know about the internal experience of their impairment (Cohen & Hula, 2020).

To determine the best evidence-based treatment for the type of stuttering a person has, it is important to differentially diagnose between the many forms of stuttering (e.g., developmental, neurogenic, psychogenic). Distinguishing the type is often done with diagnostic criteria. There are clinical diagnostic criteria for neurogenic stuttering, but they are not well-defined and the necessity of each for diagnosis often varies by source (De Nil, 2019; Lundgren et al., 2010). There are six or seven distinct criteria for diagnosing neurogenic stuttering based on the source (e.g., 7 criteria in Canter 1971; 6 criteria in Lundgren et al., 2010 & Manning & DiLollo, 2018; De Nil, 2019). For the purpose of the current study, all seven possible criteria will be considered which are 1) no reported history of fluency disorders, 2) sudden degradation of the Central Nervous System (CNS), 3) lack of fluency following fluency-enhancing techniques, 4) no adaptation effect when reading, 5) fluency does not increase during automatic speech tasks, 6) stuttering on medial and final syllables, 7) little variability in the individual’s disfluency across
contexts, and no secondary behaviors or emotional reactions to the sudden stuttering (Canter 1971). Individuals who develop neurogenic stuttering may have vastly different symptoms and experiences with disfluency.

There are specific procedures that can be used to assess neurogenic stuttering in a diagnostic evaluation. Fluency enhancing techniques are novel ways of speaking to increase fluency such as whispering or sing-song speech and may be used in diagnostic assessment. The diagnostic criteria of no change in stuttering with fluency enhancing techniques is assessed with activities such as singing and choral reading. Additionally, the adaptation effect may be assessed which is the tendency to stutter less with each oral reading of the same material and is assessed with subsequent reading passages. Lastly, automatic speech tasks may be assessed and are rote phrases which are memorized and can usually be stated without effort such as counting and stating the alphabet (Krishnan & Tiwari, 2013; Van Lancker Sidtis & Yang, 2017; Manning & DiLollo, 2018). The activities may be used in a diagnostic evaluation to assess the seven criteria for diagnosing neurogenic stuttering.

De Nil (2019) asserts that none of the diagnostic criteria are required for diagnosis, and the lack of any criteria does not exclude an individual from a diagnosis of neurogenic stuttering. De Nil (2019) also suggests that the diagnostic criteria be used as a ‘rule of thumb’ because each individual’s neurogenic stuttering may vary based on their primary neurological diagnosis. All or none of the seven diagnostic criteria may be present when a diagnosis is made. Lundgren et al. (2010) argued that all six criteria presented in their study need to be present along with an underlying neurological cause to be considered neurogenic stuttering. There is overall disagreement in the literature about which diagnostic criteria are necessary or unnecessary for diagnosis of neurogenic stuttering.
Along with the varying criteria to diagnose neurogenic stuttering, there is not always a primary diagnosis to distinguish neurogenic stuttering from other forms of stuttering. For example, neurogenic stuttering may occur following undocumented neurological damage, such as undiagnosed TBI. The type of stuttering is then difficult to categorize as neurogenic due to the lack of a primary diagnosis which is a part of the diagnostic criteria for some researchers. There are also times when symptoms are consistent with multiple types of stuttering (psychogenic, developmental, neurogenic) due to some crossover in the diagnostic criteria or the absence of a particular symptom. Other individuals may develop stuttering-like disfluencies which are actually part of a different speech and language diagnosis such as dysarthria or aphasia following a stroke or have comorbid neurogenic stuttering and an additional speech or language disorder (Theys et al., 2011). If a clinician is unable to differentially diagnose the cause of stuttering within an individual or distinguish between stuttering and other speech or language disorders, the person may receive inadequate treatment given that best practices vary by specific diagnosis (Lundie et al., 2014).

There are known emotional and life impacts of many speech and language disorders such as aphasia, which can accompany neurogenic stuttering. In aphasia following stroke, the life impact may include increased rates of depression for both the clients and family members, as well as feelings of anger, sadness, grief, and acceptance (Worrall et al., 2016; Sorin-Peters, 2003). In addition, fluency disorders such as developmental stuttering have well-documented emotional impact (Tichenor & Yaruss, 2020; Plexico, 2009). The research on the emotional and life impact of neurogenic stuttering, which are reviewed in subsequent sub-sections, is far less comprehensive.
2.5 Developmental Stuttering: Emotions and Life Impact

When diagnosing developmental stuttering, social, emotional, professional, and life impact may be used for diagnosis and justification of therapy provision with adults (Ingham et al., 2012; Sønsterud et al., 2020). The criteria for diagnosing neurogenic stuttering often include lack of emotional impact as cited in the literature (Canter, 1971; Manning & DiLollo, 2018). The overt speech characteristics of stuttering may be the most noticeable aspect of both neurogenic and developmental stuttering, but the severity of speech symptoms does not always reflect the underlying emotional and life impact (Manning & Beck, 2013). It is important to understand the emotions and life impact that effect the experience of living with stuttering for diagnosis and treatment.

Research in fluency disorders has primarily focused on developmental stuttering, including the possible adverse life impact that can accompany it. In Corcoran & Stewart’s qualitative study (1998) seven adults with developmental stuttering noted a negative impact of developmental stuttering related to feelings of helplessness, fear, shame, and avoidance, with a primary theme of suffering. In terms of helplessness, many of the participants noted feeling as if they had “no control” of their stuttering or their responses to it. A sense of shame was often linked to stuttering-related stigma both from internal and external sources. One participant noted feeling that when they spoke listeners discounted “everything positive” about them to focus on their stuttering. Others felt that they were to blame for their stuttering which caused negative feelings about themselves such as guilt and immaturity. Lastly, in terms of fear, many of the participants reported an intense fear of stuttering due to the negative emotions that arose when they stuttered. In response to negative emotions, all of the participants avoided or hid their stuttering to some extent, even though they also reported that hiding stuttering was emotionally
taxing in its own way. Avoidance also led to changes in the way that the participants lived their lives such as choice of careers, using the telephone, and talking with family members (Corcoran & Stewart, 1998). Boyle (2016) also reported the finding that not having an explanation for why stuttering developed can make it difficult for others to understand and process.

Plexico et al. (2009) also researched emotions in a qualitative interview study of nine people with developmental stuttering by examining coping responses to stuttering. Plexico et al. (2009) noted that coping styles are learned and occur in response to anticipation of stuttering. Anticipation of stuttering is the proprioceptive sense that a moment of stuttering is impending, which can contribute to anxiety and fear of speaking situations (Jackson et al., 2015). Adaptive coping may occur by reducing limitations, changing the environment, and managing negative life experiences; Less adaptive coping may occur when functional ways to adjust to ‘problems’ in life cannot be found. If coping is less adaptive it may lead to using escape and avoidance in speaking situations which was noted to cause feelings of isolation and frustration. Participants also described spending large amounts of time strategizing how to use tricks and techniques in conversation to avoid stuttering and experiencing the associated loss of control in public. Additionally, some participants noted feelings of fear, panic, hopelessness, frustration, anger, threat, and anxiety when in speaking situations, along with the desire to avoid uncomfortable or embarrassing reactions from the listener or themselves to their stuttering. To fend off negative feelings altogether, some participants discussed avoiding ‘normal’ activities, repression, self-distraction, and substance abuse to distance themselves from the ‘problem’ of stuttering (Plexico et al., 2009). Overall, there is a wide range of emotional coping strategies and experience among adults with developmental stuttering, which have been well documented (Craig et al., 2011; Butler, 2013; Blumgart et al., 2014).
More recently, Tichenor and Yaruss (2020) noted the adverse impact on adults with developmental stuttering and highlighted the stress and feelings of vulnerability that may lead to repetitive negative thinking about stuttering. Overall, they found that people who stutter may have an adverse impact related to stuttering in terms of participation limitations, anxiety, and negative thinking. Adverse impact can have both personal and physiological implications such as decreased life participation and emotions such as anxiety and fear (Tichenor & Yaruss, 2020). For example, some people who stutter may decrease communication with others due to negative social consequences associated with speaking such as poor listener reactions (Constantino et al., 2020). The adverse impact of stuttering can then lead to stigma applied to the self and the stuttering community, which can perpetuate negative feelings about oneself (Tichenor & Yaruss, 2020). Boyle & Fearon (2018) found that people who stutter that reported self-stigma or were aware of stigmas about stuttering had physiological reactions such as higher levels of stress and poorer health. The negative emotions noted by Tichenor & Yaruss (2020), are similar to the negative emotions discussed in other relevant studies of developmental stuttering (Plexico, 2009; Corcoran & Stewart, 1998).

In addition to the adverse impact of living with developmental stuttering, there are associated unique microaggressions experienced by people who stutter. In a qualitative study of seven adults with developmental stuttering, Coalson et al. (2022) described the microaggressions that an individual may experience. For the purpose of the study microaggressions were described as insults and invalidations that occurred due to the person’s association with a marginalized group - in the study being a person who stutters. The microaggressions experienced by the participants in the study were categorized into six overarching themes: patronization, second-class status, perceived helplessness, workplace microaggression, clinical microaggression and
denial of privacy. The dominant themes to describe the microaggressions experienced in the study included patronization, second-class status, and perceived helplessness. Patronization included experiences such as invalidation, and incidental strength – attributing other skills to the person who stutters to compensate for the ‘inability’ to speak fluently. Second-class status included avoidance by the listener, and desexualization of the participants due to their identity as a person who stutters. Perceived helplessness included perceived intellectual inferiority, and being treated like a child (Coalson et al., 2022). The negative emotional and social impact of developmental stuttering has been well-documented in both adults and children and may add to the understanding of the lived experience of developmental stuttering.

Although there are documented examples of negative impact of stuttering in the literature, Boyle et al. (2019) uniquely highlighted the ways in which developmental stuttering can also have a positive life impact. Boyle’s study was completed using a qualitative content analysis of five books about the lived experiences of stuttering. The positive life impact themes that emerged from the books were later assessed through a survey study of a large sample of people who stutter. Three major themes emerged: personal benefit, relationship benefit, and gained perspective. Within the personal benefit theme that emerged the subtheme benefits included, positive behavioral outcomes, cultivation of determination, feeling stronger, and emotional growth. The relationship benefits that emerged were social support access, deepening of relationships, and increased sensitivity to others. Lastly, in the gained perspective theme, there were subthemes of gained perspective about stuttering and life, a sense of appreciation, and finding positive meaning in challenges (Boyle et al., 2019). Although some studies have documented a negative impact of developmental stuttering, there may be recognized benefits to stuttering as well.
The negative and positive emotional impacts documented in research may relate to the potential life participation outcomes. The impact of stuttering on labor market participation was documented by Gerlach et al. (2018). The findings led researchers to report that people who stutter earn $7000 less annually and are less likely to be employed (males only), and are more likely to be underemployed (females only) (Gerlach et al., 2018). Similarly, Klein and Hood (2004) found that stuttering was perceived to impact job performance and the ability to find employment through overt and covert discrimination. Some participants in the study also reported stuttering to be a ‘handicap’ in the workplace. Those with a higher education level reported that stuttering had less of an adverse occupational impact (Klein & Hood, 2004). Yaruss (1998) described the handicap of stuttering as a disadvantage that limits an individual from performing a role that is ‘normal’ for them such as occupational role fulfillment, social participation, and self-sufficiency.

In developmental stuttering, the emotions and life impact, whether positive or negative, have been noted as important in the literature. The Overall Assessment of the Speaker’s Experience of Stuttering (OASES) (Yaruss & Quesal, 2006) was created to assess life impact in terms of the affective and cognitive nature of stuttering to supplement traditional fluency-based stuttering assessments. The OASES assesses four main sections: general information about stuttering, how speaker’s feel about their stuttering, communication across situations, and impact on quality of life. The participant fills out each question with a Likert rating scale of 1 to 5 (1= always, 5= never). The scores of each question are averaged to determine a severity score for each of the four sections. A higher score in any area indicates a greater negative impact, and the scores across all sections are averaged to produce one overall adverse impact score ranging from mild to severe (Yaruss & Quesal, 2006).
The OASES provides important information about the cognitive and affective impacts of developmental stuttering. The original study’s normative sample included only people with developmental stuttering (Yaruss & Quesal, 2006). The OASES has been converted to many other languages and normative samples were created in these populations. In the Dutch normative sample, the inclusion criteria did not include the type of stuttering that the participants exhibited (i.e., developmental, neurogenic, psychogenic, etc.) (Koedoot et al., 2011). Other normative samples such as the Blumgart et al. (2012) sample in Australia included explicit criteria excluding people with neurogenic stuttering from the normative sample, stating, “[A] lack of history of a physical or neurological disorder or condition that was independent of stuttering and which could dominate the impact of stuttering.” The norms of the OASES do not include the experience of individuals with neurogenic stuttering, but the OASES has been used in a research setting with a person with neurogenic stuttering to compare adverse impact over time (Ellis & Sheehy, 2013). Assessing the cognitive and affective impact of stuttering in individuals with neurogenic stuttering is potentially important to understand the lived experience.

2.6 Neurogenic Stuttering: Emotions and Life Impact

Compared to the research on developmental stuttering, research on the potential emotional and life impact of neurogenic stuttering is underrepresented. The limited research that exists consists primarily of case studies and small group studies. One benefit of case studies is that they provide more in-depth information to better understand individual cases within a larger issue that have not been well-researched, such as prevalence (Lundie et al., 2014). Although case studies provide detailed information about the subject, they only provide information about the experience of a single individual rather than group-level experiences. Another limitation may be that information cannot usually be generalized to the larger population without explicit planning.
of relation to widely accepted, established, underlying ideas or principles (Yin, 2013; Bengtsson & Hertting, 2014).

The limited research that does exist investigating the potential emotional and life impact of living with neurogenic stuttering is mixed. In the next section, I review the literature that did not find evidence of an emotional or life impact associated with living with neurogenic stuttering. Then, I explore contrastive findings from studies indicating the presence of emotional impact.

2.7 A Review of Evidence Suggesting No Emotional or Life Impact of Neurogenic Stuttering

Results from three studies in the literature suggest that there is insufficient evidence to assume that living with neurogenic stuttering is associated with adverse emotional or life impact. One such study is Leder et al.’s (1996) qualitative observation and interview case study that did not report an emotional impact for a 29-year-old male who developed neurogenic stuttering. The patient was initially diagnosed with psychogenic stuttering. The patient’s stuttering did not respond to typical therapy for psychogenic stuttering (i.e., there was not an immediate and dramatic reduction in disfluency), but his stuttering decreased when he began carbidopa-levodopa treatment which led to the diagnosis of Parkinson-like, extrapyramidal syndrome with associated neurogenic stuttering. One of the criteria originally used for diagnosis of psychogenic stuttering included no ‘avoidance,’ ‘specific word fears,’ or ‘situational fears’ due to his stuttering. The authors did not mention the specific means of determining the lack of avoidance, fears, and emotions made during the diagnosis. Contrary to the lack of emotions noted by the authors, the patient began attending psychiatric therapy after his correct diagnosis and reported, “positive psychological gains during this very upsetting time in his life.” The limitations of the study include the researchers not addressing whether the ‘upsetting time’ referred to the sudden
onset of stuttering, the incorrect diagnosis of psychogenic stuttering, the correct diagnosis of Parkinson-like syndrome, or something else. So, although the diagnostic criteria of no avoidance, word-specific fears, or situational fears of psychogenic stuttering were applied in Leder et al.’s findings (1996), there was vague mention of emotions without a specific cause documented. More importantly, the client’s emotions related to stuttering were not assessed despite beginning psychiatric therapy and reporting positive outcomes from the treatment.

The absence of reported participant emotions continues in Lebrun et al.’s case study (1990) which assessed a singular case of an individual with neurogenic stuttering. The patient was a bilingual French and Dutch male who began stuttering following a brain lesion from shrapnel in the right parietal lobe at age 23. The patient was in a coma for four weeks following the brain lesion and began stuttering in both French and Dutch when he regained consciousness. The patient’s stuttering was persistent over the course of 35 years from when the brain lesion occurred through documentation in the case study (Lebrun et al., 1990).

The patient exhibited mostly moderate blocking at the beginning of words and some repetitions of sounds and words, with involuntary eye blinking, closing of the eyes, and head bending. The researchers concluded that although the patient exhibited some secondary behaviors, they were not considered ‘reactive’ to stuttering due to the lack of language loss overall that may have led to an emotional response. The researchers also reported the patient’s awareness of his stuttering but described him as ‘not desperate’ when discussing his disfluent speech (Lebrun et al., 1990). There was no additional explanation of the lack of desperation, or other emotions. The findings came from the examination and were noted by the clinicians and the research does not indicate that the client was asked how he felt about stuttering. The lack of formal adverse impact testing or addressing emotions or life participation with the patient despite
prior recognition of a possible impact in the introductory section is insufficient for determining that no adverse impact was present. Overall, Lebrun et al. (1990) did not report an adverse impact based on their observation which aligns with the current diagnostic criteria for neurogenic stuttering of no emotional impact (Canter, 1971).

Perino et al.’s case study (2000), diverges from the lack of adverse impact noted in the previous studies because the participant completed emotional testing and did not report any negative emotions related to stuttering. The diagnostic criteria for both neurogenic and psychogenic stuttering were used for a singular case to differentially diagnose neurogenic stuttering using patient-reported outcomes. The patient was a 26-year-old woman who reported stuttering following headaches in the bilateral, frontal, and temporal lobes. The patient went to the emergency room due to a severe headache where she participated in a fluency evaluation which indicated severe stuttering. The client reported no situational fears during the time that she stuttered as well as no anxiety or depression based on analog scales related to the stuttering as exhibited in the fluency evaluation. The lack of anxiety or depression was used to make a differential diagnosis between psychogenic and neurogenic stuttering. The lack of emotional impact may be related to the fleeting nature of the patient’s stuttering which stopped after a sumatriptan injection (i.e., headache reducing medication) in the emergency room. Perino et al.’s (2000) study utilized differential diagnosis but did not specifically mention the use of ‘no emotional impact’ in the diagnostic criteria for neurogenic stuttering. The limited emotions reported in the study were based on patient report, unlike Leder (1996) and Lebrun et al.’s (1990) studies which largely based emotional impact on researcher report. Two of the three studies reviewed based emotional and life impact on the assumptions of the researchers and determined the findings were not pertinent to the diagnosis of neurogenic stuttering. By directly asking for
the input of the participant, Perino et al. (2000) could say no emotional impact was evident at the
time of the study, whereas the other studies did not consult the participants about emotions
directly.

2.8 Contrasting Evidence Indicating Potential for Adverse Emotional or Life Impact

Although the previous three case studies did not provide evidence suggesting an adverse
emotional or life impact of living with neurogenic stuttering, other more recent research indicates
that there is potential for an associated emotional impact. Theys et al. (2008) examined the
specific impact of neurogenic stuttering in terms of speech and non-speech characteristics
through phone surveying 98 speech language pathologists who had treated people with
neurogenic stuttering. Non-speech characteristics included emotions, and secondary behaviors
such as tension. Neurogenic stuttering was defined for the participating clinicians as an acquired
disorder characterized by atypically high rates of sound or syllable repetitions, prolongations, or
blocks. The survey addressed seven topics: personal and medical information prior to stuttering,
onset of neurogenic stuttering, cause of stuttering, lesion of the neurological event, stuttering-like
disfluencies, co-occurring disorders, and therapy type and outcome (Theys et al., 2008). There
was not a designated topic area which addressed emotions or life participation when beginning
the study, but the researchers indicated an emotional impact based on their interactions with
them.

The study included patients who developed neurogenic stuttering following stroke (n =
29), TBI (n = 11), neurodegenerative diseases (n = 9) and other neurological injuries (n = 9)
ranging from 36 to 93 years of age. The speech language pathologists reported some patients
exhibited emotional behaviors such as frustration, fear, irritation, crying, and anger in reaction to
their stuttering (Theys et al., 2008). The noted emotions were largely dependent on each
individual discussed in the study, but the actual reason or extent of each emotion was not documented. Theys et al.’s study (2008) indicated that the diagnostic criteria of no emotional impact could not be applied to all of the participants in the study because of the therapists’ report of participant emotions.

The non-speech characteristics of stuttering were similarly assessed in Ellis and Sheehy’s case study (2013) of one individual who developed neurogenic stuttering and showed signs of an emotional impact according to patient report, clinician report, and adverse impact testing (OASES-A & Modified Erickson S-24 Scale). The case study examined a 57-year-old man with Toxic Metabolic Encephalopathy (TME) which impairs arousal and awareness following respiratory distress. When the client began speaking following respiratory distress, he exhibited stuttering-like disfluencies. The patient attended therapy as he recovered from TME in a university speech and hearing clinic where he was assessed by researchers (Ellis & Sheehy, 2013).

The patient initially raised concerns about public speaking in his career as a lawyer because he found his stuttering “extremely troubling.” The researchers completed emotional impact testing to further understand the patient’s emotions. The patient’s behavioral stuttering severity was initially categorized as mild using the Stuttering Severity Instrument - Fourth Edition (Riley, 2009), but lowered to ‘within normal limits’ by the end of therapy. The patient’s score on the Modified Erickson S-24 Scale (Andrews & Cutler, 1974), which assesses attitudes towards stuttering, decreased from severe in the first administration to within normal limits in the fourth administration. The results of the Modified Erickson S-24 Scale indicate the patient’s feelings towards stuttering were negative initially and reflected the attitudes of a person who does not stutter by the end of the treatment period. The patient was also administered the OASES
four times over the course of treatment in which his overall score lowered from a severe rating in the first administration to a mild/moderate rating in the fourth administration. This decrease in scores indicates a lower overall adverse impact over time (Ellis & Sheehy, 2013).

The patient’s feelings toward stuttering shifted from embarrassment to curiosity to interest as noted by the researchers in evaluations across the course of treatment despite an initial negative emotional impact. The researchers also briefly noted that the patient shared feelings of amusement when he stuttered as his disfluent speech became more infrequent. The researchers reported that the increase in the patient’s fluency appeared to be associated with the reduction in overall adverse life impact of stuttering. The impact of stuttering described in this case diverges from the diagnostic criteria that there is no overall adverse impact of neurogenic stuttering (Ellis & Sheehy, 2013).

Consistent with the findings of an emotional impact, Tani and Sakai (2011) assessed the speech of five patients with injury to the basal ganglia that resulted in neurogenic stuttering and noted one participant was anxious about stuttering. The participants ranged in age from eight to seventy-seven, over a ten-year period, and all exhibited neurogenic stuttering. Four of the participants noticed stuttering immediately after lesion, and one did not start stuttering until almost a year after head trauma due to decreased consciousness during that time.

The researchers reported on the participants by reviewing videos to observe secondary behaviors and emotions. The researchers observed that one of the participants was anxious about his disfluencies when reviewing video footage of the participant completing a fluency assessment designed for the study. The tasks included in the fluency assessment were repeating sentences, reading aloud, explaining comic strips, and conversing. The researchers did not note a specific reason, task, or explanation for the anxiety they documented. The other participants were
not reported to be anxious, but the researchers noted that two participants were aware of their stuttering. The methods do not include a section specifically designed to assess emotions despite the findings of possible negative emotions; the researchers noted the findings during other fluency testing. The possible anxiety exhibited by one of the participants is inconsistent with the diagnostic criteria of no emotional impact despite evidence of neurogenic stuttering (Tani & Sakai, 2013). Additionally, the presence or absence of a life or participation impact was not noted in the study.

Consulting with the participants on emotions and life impact is not widely used when diagnosing neurogenic stuttering. Vanhoutte et al.’s case study (2014) assessed the speech and neural impact of a 28-year-old woman (MH) diagnosed with neurogenic stuttering who expressed concern about her stuttering without explicit assessment addressing emotions or life impact. Neurogenic stuttering began following the third of five hemorrhagic strokes and stuttering severity increased from mild to severe following the fifth stroke and surgery in Wernicke’s area. MH also began to state automatic speech patterns unprompted (counting and reciting days, weeks, and months). MH’s stuttering-like disfluencies included sound/syllable repetitions, prolongations, blocks, broken words, and tense pauses in initial phonemes. The researchers assessed MH through speech and reading samples, four administrations of a battery of neurophysiological tests, and three phonological tests across four sessions (Vanhoutte et al., 2014).

Following MH’s fourth stroke, the researchers began neurophysiological testing across four periods. MH reported being unaware when she was using behaviors to escape or avoid moments of stuttering but did note concern when stuttering initially onset and when stuttering severity suddenly increased from mild to severe. Data on emotional impact was collected
through patient report following the development of stuttering symptoms. The brief report of emotional symptoms included awareness and concern about stuttering but did not further elaborate on any emotional impact or compare specific emotional changes past concern. The possible emotional impact diverges from the diagnostic criteria of no emotional impact associated with neurogenic stuttering (Vanhouette et al., 2014).

Overall, four of the existing seven studies indicated a potential emotional or life impact of neurogenic stuttering in some participants, which diverges from the diagnostic criteria of no emotional impact associated with neurogenic stuttering. Additionally, although some findings aligned with the diagnostic criteria of no emotional impact, only two of the seven studies directly addressed the emotional and life impact of neurogenic stuttering, using formal adverse impact testing (e.g., OASES and the Modified Erickson S-24 Scale in Ellis & Sheehy, 2013; analog scales in Perino et al., 2000) or discussing the emotions and life impact directly with the participants.

2.9 Purpose of the Current Study

Unlike developmental stuttering, which has a well-documented and consistent potential for adverse impact, the potential emotional and life impact of neurogenic stuttering is unclear. Although some research suggests that there is no emotional impact of neurogenic stuttering (Canter, 1971; Leder et al., 1996; Lebrun et al., 1990; Perino et al., 2000), other research indicates that negative impact can be present, but is perhaps different or less severe than the impact of living with developmental stuttering (Theys et al., 2008; Ellis & Sheehy, 2013; Tani & Sakai, 2011; Van Houtte et al., 2014; van Raaphorst, 2018). There is a plethora of research on coping mechanisms, emotions, and overall adverse impact associated with developmental stuttering to inform its diagnosis and treatment (Corcoran & Stewart, 1998; Plexico et al., 2009;
Tichenor & Yaruss, 2020), but the potential impact of living with neurogenic stuttering has not been well-documented.

Much of the research on emotions associated with neurogenic stuttering that does exist is subjective based on clinicians’ perceptions of the client’s adverse impact. The client’s perspective is extremely valuable because many aspects of a fluency disorder are unobservable (e.g., effort, confidence; Cohen & Hula, 2020). In many of the studies reviewed in the previous sub-sections, the unobservable aspects of stuttering received limited attention. The research that reports no emotional impact has been applied to make generalizations about the emotions and life impact of people with neurogenic stuttering. For example, Tani & Sakai (2011) noted anxiety in one participant but did not include how that was determined beyond clinician report after viewing recorded interviews of a fluency measure. Beyond the lack of documentation overall, the researchers did not include what specific situations or words might increase anxiety.

Additionally, the findings of Lebrun et al. (1990) and Leder (1996) both reported no emotional impact and did not designate specific measures of emotional or life impact. The claims were made based on researcher observations. Leder (1996) cited the diagnostic criteria of no emotional impact despite reporting the client referring to the time when he was receiving therapy and stuttering as a “very upsetting time.” The lack of reported emotions or life impact is particularly problematic given that the absence of an emotional impact is a common diagnostic criterion for neurogenic stuttering. The accepted generalization of no emotional impact may contribute to the lack of adverse impact testing or further explanation of noted emotions within most studies aside from using the OASES and the Modified Erickson S-24 Scale in Ellis and Sheehy’s study (2013) and analog scales in Perino et al.’s study (2000).
Better understanding the lived experiences of people with neurogenic stuttering is critical in more accurately diagnosing neurogenic stuttering and in developing appropriate treatment protocols. It seems reasonable that developing stuttering without warning could have an emotional impact on the individual in the moment and over time if the acquired stuttering persists. The purpose of the qualitative study is to thoroughly investigate the experience of living with neurogenic stuttering with emphasis on potential emotional and life impact. The current study will address:

1. What, if any, is the impact of living with long-term neurogenic stuttering (more than 6 months) in terms of emotions, thoughts, and social participation?

2. If there is a life impact associated with living with neurogenic stuttering, when and how do people who live with neurogenic stuttering perceive that it develops?
CHAPTER 3

METHODOLOGY

3.1. Study Design and Theoretical Rationale

This exploration of the lived experiences of people with persistent neurogenic stuttering is a qualitative interview study supplemented with quantitative data including information about demographic characteristics and formal assessment using adverse impact testing (online administration of the Overall Assessment of the Speaker’s Experience with Stuttering- Adult, OASES-A; Yaruss & Quesal, 2006) and a measure of behavioral stuttering severity (Stuttering Severity Instrument Fourth Edition, SSI-4; Riley, 2009).

There are two broad research method categories when collecting data: qualitative and quantitative methods. Quantitative research methods aim to represent a subject in a population through standardized, quantifiable means. Qualitative research methods aim to provide a deeper understanding of an experience through more descriptive means (Queirós et al., 2017). The means may include researcher interpretation of life experiences and understanding how one attributes meaning to their experiences (Merriam & Tisdell, 2016). Mixed methods research aims to combine both qualitative and quantitative methods to provide a deeper explanation of an experience. Qualitative methods have often been associated with fields such as anthropology and sociology but have become more common in speech and language research. The shift from predominantly quantitative methods to include more qualitative stuttering research reflects the multidimensional and variable nature of individual’s experience of living with stuttering that cannot always be replicated in an experimental setting (Tetnowski & Damico, 2001). Aside from providing descriptive data, qualitative studies may act as ‘pilot’ research to provide in-depth information about a topic that has yet to be fully studied (Palinkas, 2014). The idea of
triangulation was used to include both primary qualitative and supplementary quantitative data in the research. Triangulation refers to the use of multiple forms of data, both quantitative and qualitative in this case to provide an in-depth understanding of an experience. This differs from traditional mixed methods research which supports the use of both qualitative data and quantitative data together as primary forms of information (Denzin, 2012). The current study utilized quantitative data to add information about the behavioral experience of stuttering and to have an in-depth understanding of the lived experience of neurogenic stuttering through comparison of reported emotions to norms.

During the interviews, an interpretivist approach was used to derive meaning from the interviews through active engagement with the participants (Langley & Meziani, 2020). This is done through building rapport in a short period of time with a conversational style and creating an open environment for the participant to share thoughts and feelings. The questions themselves were neutral to avoid influencing what the participants shared. The questions did not directly include the words ‘emotions’ or ‘life impact’ to avoid funneling the participants’ answers to fit the research questions (Langley & Meziani, 2020).

The study was rooted in contextual constructionism, which assumes that even when the same or ‘correct’ methods are used, there will not be a singular reality in the data (Madill et al., 2000). There were other contextual factors, such as researcher interpretation and participant thoughts and feelings, that varied across interviews. In this way, the culture and contexts of both the researcher and participant merged and the ‘convergence of ideas’ created a fuller interpretation of the data (Madill et al., 2000). The researcher’s contexts were used to interpret rather than ‘find’ themes in the data to best represent the meaning of each individuals’ lived experience (Braun & Clarke, 2019).
Due to the changing nature of the researcher’s understanding of the lived experience of neurogenic stuttering based on the current study, a specific hypothesis was not created which might limit the analysis (Agee, 2009). This also means that research questions emerged throughout the process to encompass the lived experiences that were discussed in interviews (Agee, 2009).

3.2 Participants

The participants for the study included seven individuals diagnosed with neurogenic stuttering that persisted for six months or longer. Purposeful sampling was used for recruitment to ensure that the participants could be found due to the relatively rare nature of neurogenic stuttering and to ensure participants fit the criteria for inclusion in the study (Palinkas, 2014). Participants were recruited using social media posts (e.g., Facebook stuttering support groups - Stuttering Community, Stuttering Arena, YouTube channels, r/Stutter community page on Reddit), and direct contact with speech language pathologists who have worked with people who stutter (e.g., Stuttering Foundation of America, Veterans Affairs Hospitals, American Speech-Language-Hearing Association Special Interest Groups) (See social media posts, email scripts, phone call scripts, and Special Interest Group script in Appendices A through I). Approval was required from web page administrators to post recruitment advertisements to some stuttering support groups. Participants were sent an email with inclusion criteria and screening questions if they expressed interest in the study as well as an explanation of the compensation provided if they completed all portions of the study (see Appendix B for participant screening email). If participants met all criteria they were sent scheduling information (See Appendix C for scheduling email). The criteria for participation included: 1) self-report of a primary medical diagnosis, injury, or event which caused the onset of acquired neurogenic stuttering, 2)
persistence of stuttering for at least six months following the primary diagnosis with at least occasional stuttering currently, 3) no known previous stuttering (e.g., developmental stuttering, concomitant pharmocogenic stuttering, psychogenic stuttering), 4) no concomitant speech or language diagnoses (e.g., aphasia, dysarthria, apraxia of speech), and 5) proficient in English and living in the United States. If it was learned that a participant did not meet all of the criteria at any point in the study (e.g., based on conversation in the interview), their interview transcripts and survey outcomes were re-reviewed for potential exclusion and any exclusions were noted in the manuscript.

The study utilized ‘information power’ as outlined by Malterud et al. (2016) to determine when recruitment ended. Information power relies on the idea that fewer samples with more information and relevant data can provide more insight to the study than copious samples with little information. On the other hand, if samples contain little information, more data needs to be collected (Malterud et al., 2016). The sample must continually be evaluated as research continues to determine the power of the information collected, and the need for more information. There are six factors to consider when choosing the power of the sample: the aim of the study, sample specificity, use of established theory, quality of the dialogue, and analysis strategy. The aim of the study was narrow in that it aimed to look at the potential emotional and life impact of individuals with neurogenic stuttering, not across all types of stuttering. In terms of specificity, participants were individuals with neurogenic stuttering that met the inclusion criteria for the study across etiologies. Although there were varying etiologies, the information power was considered high due to the restrictions in type of stuttering and criteria. In terms of established theory, the study relied on an interpretivist approach and contextual constructionism, both established theories. The quality of the dialogue was difficult to determine prior to the
interviews, but was assessed during the study based on researcher-participant interactions, and ‘articulateness’ of the participants. Lastly, the analysis strategy used in the study was reflexive thematic analysis, which aims to give in-depth information about a smaller sample so fewer participants were required than a quantitative study. Overall, these factors were used to predict that the qualitative interviews would provide more robust information so fewer participants were necessary for the study (Malterud et al., 2016). Part of reflexive thematic analysis relies on the undetermined nature of the outcomes of the study. Thus, some qualitative researchers assert that the exact sample size cannot be determined ahead of time or limited by any set methods before data collection begins, such as recruitment until saturation (Braun & Clarke, 2021). Additionally, Sim et al. (2018) assert determining an exact sample size goes against the idea that ‘themes’ are not found because criteria for research would state that if enough instances were found then research would stop. Malterud et al. (2016) suggest approximating a sample size before research begins and adjusting as more information is collected, which is the method that was used in the current study.

The following table describes the demographic data for each participant in the study as collected through the Qualtrics survey sent to individuals after participation in the interview. Each participant chose a pseudonym at the beginning of the qualitative interview to allow for anonymity during research participation.
Table 2

**Participant Demographic Data**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Gender</th>
<th>Race/ ethnicity</th>
<th>Occupation</th>
<th>Time since onset</th>
<th>Etiology</th>
<th>Diagnosis</th>
<th>Family history</th>
<th>OASES Overall score</th>
<th>SSI-4 severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maya</td>
<td>44</td>
<td>female</td>
<td>White</td>
<td>Teacher Assistant</td>
<td>22 years</td>
<td>TBI — car accident</td>
<td>yes</td>
<td>no</td>
<td>mild/moderate</td>
<td>moderate</td>
</tr>
<tr>
<td>Alexander</td>
<td>69</td>
<td>male</td>
<td>White - Hispanic</td>
<td>Retired</td>
<td>5 years</td>
<td>multiple</td>
<td>yes</td>
<td>no</td>
<td>moderate</td>
<td>moderate</td>
</tr>
<tr>
<td>Morty</td>
<td>32</td>
<td>male</td>
<td>White</td>
<td>Unemployed</td>
<td>4 years</td>
<td>TBI — physical head injury</td>
<td>unsure</td>
<td>no</td>
<td>moderate</td>
<td>moderate</td>
</tr>
<tr>
<td>Birdy</td>
<td>57</td>
<td>female</td>
<td>White</td>
<td>Speech Language Pathologist</td>
<td>25 years</td>
<td>Brainstem mass</td>
<td>yes</td>
<td>yes</td>
<td>mild/moderate</td>
<td>mild</td>
</tr>
<tr>
<td>Batman</td>
<td>40</td>
<td>male</td>
<td>White</td>
<td>Unemployed</td>
<td>6 months</td>
<td>TBI — electrocution</td>
<td>yes</td>
<td>no</td>
<td>severe</td>
<td>very severe</td>
</tr>
<tr>
<td>Gwendolyn</td>
<td>60</td>
<td>female</td>
<td>White</td>
<td>Semi-retired</td>
<td>1.5 years</td>
<td>Mini-stroke</td>
<td>yes</td>
<td>yes</td>
<td>moderate/severe</td>
<td>very mild</td>
</tr>
<tr>
<td>Tracy Smith</td>
<td>57</td>
<td>female</td>
<td>Black/African American</td>
<td>unemployed</td>
<td>3 years</td>
<td>TBI — car accident</td>
<td>yes</td>
<td>no</td>
<td>severe</td>
<td>very mild</td>
</tr>
</tbody>
</table>

**3.3 Procedures**

The virtual study began with recruitment when participants reached out to the researchers through email. After participants provided informed consent, the qualitative interviews were conducted including an optional reading sample. Then a Qualtrics survey was sent to the participant (including OASES questions and demographic data). When the participant completed both the interview and survey, compensation was sent to an email provided in the survey. Lastly, analysis of the interview content and behavioral stuttering severity were completed.

The qualitative portion of the study began when a time and date were established via email to meet for a virtual interview. A one-time, semi-structured interview was completed over Webex with myself and the participant in attendance. Verbal consent for participation was collected by reviewing the consent form with the participant before the interview began. Additional online consent was collected before the Qualtrics survey began (see Appendix J for online consent form). Before the interview began, I addressed confidentiality, and gave the
participant my contact information as well as the faculty mentor’s contact information so that if they had any questions following the interview they could reach out (Turner, 2010). The semi-structured interview guide used in the interviews addressed the overall experience of living with neurogenic stuttering and the primary areas of interest in this study including: general information, emotions, and life participation. Questions about reactions to the development of neurogenic stuttering over time were embedded in each of the primary areas of interest sections (See Appendix K for semi-structured interview guide). Participants answered the questions to the extent that they chose. the interview guide began with inclusion criteria were asked of the participant, and they were asked to elaborate on the details of the criteria. I conducted each interview to ensure that all interviews and questions followed a similar course while allowing for participants to share freely (Turner, 2010). I conducted the interview and followed the participant’s lead in what they felt was important to talk about in each general section of the interview guide to allow for open discussion and participant-led interpretation of the topic. This provided a deeper understanding of the meaning in the statements made by the participants (Pessoa et al., 2019). All interview transcriptions were stored in a password protected document on OneDrive, and access was only given to myself and the research mentor.

The Qualtrics survey included questions about demographic data and questions from the sections of the OASES-A. The OASES assesses four main sections: general information about stuttering, how the speaker feels about their stuttering, communication across situations, and impact on quality of life using a Likert scale rating (1= always, 5= never) (Yaruss & Quesal, 2006). The entirety of the OASES was included in the Qualtrics survey. The OASES yields a severity score in each of the four sections assessed. The individual severity scores were averaged
to determine an overall impact of stuttering on the individual’s life (Yaruss & Quesal, 2006). Each section score and overall severity scores were recorded. The participants’ OASES severity scores were compared to norms, with the knowledge that the normative data for the OASES did not include people with neurogenic stuttering (Yaruss & Quesal, 2006). A precedent has been set with use of the OASES clinically with an individual who developed neurogenic stuttering in Ellis and Sheehy’s study (2013).

When the interview and Qualtrics survey were completed the participant was sent a $20.00 gift card electronically through Amazon using the email that they provided in the interview. To receive compensation the participants only needed to provide an email address, no additional personal information was necessary. After the qualitative and quantitative data were collected, analysis of the qualitative interview information began for each participant to understand their experience with neurogenic stuttering.

Data analysis began following each interview by transcribing each discourse verbatim. Transcription was completed by myself and an undergraduate student in the Speech, Language, and Hearing Sciences department. Each discourse was transcribed verbatim through manual transcription or NVIVO software transcription and then myself and the undergraduate research assistant re-reviewed the transcriptions to ensure accuracy. The transcripts were stored in a password-protected OneDrive file that was accessible to only myself and the faculty mentor.

After the interview discourse was transcribed, the Stuttering Severity Instrument Fourth Edition (SSI-4; Riley, 2009) was used to assess behavioral stuttering severity. The SSI-4 protocol was followed for each participant. The OASES and SSI-4 provided more information about each participants’ stuttering behaviors, thoughts, and emotions to better understand their
overall experience. The quantitative data was used to better understand the participants, not to be used for analytic comparison between participants.

3.4 Analysis

To understand the experience of neurogenic stuttering, thematic analysis was used to identify, analyze, and report patterns in the data collected. The data from the study were analyzed using reflexive thematic analysis across the qualitative interviews. Reflexive analysis refers to the ongoing engagement with the data to reflect the underlying ideas (Braun & Clarke, 2020). Identifying patterns in the data through themes allows for the full depth of information to be collected from the samples to report the experience and reality of living with neurogenic stuttering. The six steps of reflexive thematic analysis are as follows - become familiar with the data, code the transcriptions, create initial themes, review the themes again, define and name the themes, and write the analysis (Braun & Clarke, 2006). An additional step, abstracting meaningful units, occurred between becoming familiar with the data through transcription and coding the transcripts (Attride-Striling, 2001). Meaningful units were abstracted from the data by grouping information discussed about a topic related to stuttering. A new meaningful unit was created when the individual switched topics (e.g. the onset of stuttering, family interactions) or began discussing a new experience.

The first step was transcribing the interviews and tentatively labelling meaningful units with possible codes in the left margin of the transcript following each discourse analysis (see Appendix L for a list of themes and codes). The second step was added to Braun & Clarke’s (2006) six steps of thematic analysis to account for extraneous information. The additional step is known as abstracting meaningful units (Attride-Striling, 2001). In this study, meaningful units from the transcripts were chosen as they related to the experience of living with neurogenic
stuttering. The process of transcription and abstracting meaningful units was repeated with each new participant. After the first transcription was completed, the third step of coding began. Codes were chosen as they related to the meaning of the utterances that were abstracted from the sample. Codes were added to a log where they could be referenced when transcribing and labelling other interviews. Transcription of samples and subsequent interviews with new participants was concurrent so that analysis and codes reflected each new sample (Braun & Clarke, 2006). Within each code there was a ‘core concept’ which described the idea in a succinct way (Braun & Clarke, 2019). After each of the transcripts had initial codes, the transcriptions were collectively analyzed for recurring overall potential codes that provided points of analytic comparison. These overall codes formed the basis for tentative themes, the fourth step, to describe the experience of living with neurogenic stuttering.

It is important to note that themes did not ‘emerge’ from the data or the codes, as they were not ‘hidden’ entities to be found. The themes in the study reflect the meaning of an utterance as interpreted by the researcher. Part of reflexive analysis includes the researcher acknowledging her own perceptions that shape interpretation (Braun & Clarke, 2019). So, the themes were not simply the topics discussed; the main idea was shaped by the researcher’s own interpretation of the thoughts and experiences (Braun & Clarke, 2020). The themes were chosen using a latent standpoint in which the exact words used (semantic analysis) were not coded, rather the overall idea that the participant was trying to convey was coded (Terry et al., 2017).

Additionally, the prevalence of a specific theme was not identified as more or less important to allow for equal import of all experiences. Researcher interpretation was important in determining what was meant by the participants’ words (Braun & Clarke, 2006). By using
abstract concepts for coding rather than direct words or questions, the actual experiences of the participants were addressed. The fifth step took place when themes were reviewed to see how closely they aligned with the participants’ ideas shared in the interview. After revisiting the data samples, the overall themes were identified and their descriptions and names were chosen. The themes were written up and used to capture the overall experience of neurogenic stuttering rather than describing a single experience of any of the participants (See Appendix L for list of themes in the data). To ensure credibility of research, the first author created an audit trail which provided the faculty mentor a way to become familiar with and provide feedback on the procedures used during analysis (Carcary, 2020). Additionally, the faculty mentor individually coded a subset of meaningful units and compared them with the first author’s to promote discussion of differences and similarities in interpretation.

After both myself and the faculty mentor reviewed the themes, a list of themes was sent to the participants to review with a brief description of each. Member checking of the themes allowed the participants to share how closely the overall samples’ themes aligned with their own experiences. The comments of participants about the themes were taken into consideration before finalization of the themes. This is known as testimonial validity which is in-line with contextual constructionism, one of the underlying principles of the research (Madill et al., 2000). The final step of thematic analysis occurred when the data was analyzed and written (Braun & Clarke, 2006).
CHAPTER 4
RESULTS

The primary purpose of the current study was to describe the experience of living with neurogenic stuttering, with emphasis on potential emotional and life impact. A secondary purpose of the study was to determine when and how people who live with neurogenic stuttering perceived that it developed, if relevant.

The data consisted of 387 meaningful units abstracted from seven qualitative interview transcripts. The transcriptions did not include disfluencies in the text, as overt characteristics of stuttering were not of primary interest in the current study. From the meaningful units, 126 codes were assigned, organized, and collated into four overall themes that described the experience of living with neurogenic stuttering. Supplemental quantitative data (OASES-A & SSI-4) were used to describe the behavioral and potential emotional impact of living with neurogenic stuttering to add to the rich description of the lived experience. OASES scores ranged from mild/moderate to severe life impact. SSI-4 scored ranged from mild to very severe behavioral stuttering severity.

4.1 Themes

The data analysis process resulted in the development of four progressive themes that captured experiences described by the participants – struggle, life changes, coping, and identity. All participants contributed to each of the four themes to varying degrees. Figure 4.1 (below) represents the cycle that participants described of progressing through the themes. The initial theme experienced by each participant was struggle. As a participant experienced struggle, they then often had associated life changes. Next participants began to cope with living with neurogenic stuttering. Participants then often began to develop or accept their identity as a person with neurogenic stuttering to varying degrees. The cycle continued with new struggles arising as a person experienced novel challenges in different life contexts.
4.1.1 Struggle - Waves of internal and external struggle as stuttering persists through life stages and experiences.

Participants shared the ways in which they struggled throughout their new way of communicating that involved stuttering. Struggle, whether internal or external, was described in the life experiences across the interviews to varying degrees and was one of the most common themes represented in the data. For the purpose of the current study internal and external struggle are discussed separately, although the internal and external experiences described were interdependent. For example, some participants described feeling embarrassed (internal) due to others making fun of them (external).

Struggle was one of the first experiences in living with neurogenic stuttering for the participants, often immediately after onset. Onset of stuttering was accompanied by feelings of “depression,” “isolation,” (Batman) “frustration,” (Maya) “embarrassment,” (Tracy Smith) and
“annoyance” (Morty). The struggle often came in waves, lessening as a participant moved through stages of recovering from the injury or diagnosis that caused neurogenic stuttering, but resurfaced when new challenges arose. The experience of struggling with the experience of stuttering was not all participants main concern (e.g., anxiety about having another stroke - Gwendolyn), while for others stuttering was “way deeper than just a speech problem,” (Batman) and “[affected] daily communication in every way” (Alexander Porter). The degree to which each participant described struggling at the time of the interviews varied greatly based on their environment, support system, coping methods, and time since the onset of injury or diagnosis.

Internal struggle encompassed challenges that a person faced in the ways that they thought and felt about communication. Internal struggle included feelings such as embarrassment (Tracy Smith), anger (Maya), and sadness (Batman). Internal struggle also included the thoughts that a person experienced when processing social situations and relationships. Batman shared the difficult emotions and internal struggle in living with neurogenic stuttering:

When you go from normal to a person with disabilities pretty much overnight, it takes a toll on your mentality, your physicality. It's easier to believe that somebody has an injury when you can see it with your eyes ... When you see somebody such as me, that looks normal, it's hard to see the injury.

Gwendolyn similarly expressed feeling as if people did not understand that there was more occurring than what others could see when she stated, “Other people say, ‘I think your speech is fine. Why do you come [to the speech language pathology clinic]?’ ... And it's not their place to say that because it might be good that day.”

Internal struggle also related to the behavioral experience of stuttering. Alexander Porter described feeling a loss of control when stuttering that was like a “teacup filling up and the
words spilling out.” Other participants shared internal struggle while stuttering of not being able to “get the words out” (Gwendolyn) or conversation being “harder” when trying to implement strategies to speak fluently (Morty).

The internal struggle of the “education process” (Alexander Porter) of understanding neurogenic stuttering was expressed across the participant interviews. Numerous participants asked questions of the researcher about the symptoms, experience, and prognosis for persistence of neurogenic stuttering. Questions included: “[What] coping skills [do others] use?,” “[Do others] feel the same way about [stuttering]?” (Alexander Porter) “Do people get more and more control over it?” (Batman) “I do wonder if it will ever go away,” (Tracy Smith) “Where did this come from?” and “Why can't I get the words out?” (Gwendolyn). Some participants shared that they were extremely focused on making sense of their stuttering, such as Birdy, who was “consumed with [her] own understanding” initially. Others were making sense of stuttering because they were hoping that they could understand how their stuttering might progress or cease. Batman shared that he was trying to understand because he “[doesn’t] want to live like this for the rest of [his] life.”

External struggle refers to interactions from the outside world which caused an internal reaction discussed by many participants as they interacted with the people and community around them. As Maya shared, “my struggles are much more in your face,” when comparing her stuttering to other mental health or life struggles. Birdy shared her experience of having to educate others stating, “I think we have a long way to go in learning and educating people about verbal diversity and being okay with that and being comfortable with the different ways that people talk and communicate.” This form of struggle did not rely solely on the individual’s environment and community, but instead the broader context of society where there is more
“ignorance” (Alexander Porter) about stuttering. Having struggles within society in this way pertained more to the experiences of others and how they reacted to the participants’ stuttering. Participants described feeling “distant,” “self-conscious,” (Alexander Porter) “rushed,” (Morty) “invalidated,” (Birdy) and “judged” (Batman) when interacting with others. Morty also described external struggle during communicative interactions on the phone when he shared, “They hung up thinking it was a prank. I just called them back and asked to speak to someone else.” External struggle extended beyond the general public to more specifically include speech language pathologists, doctors, and other health care providers. Participants shared that speech language pathologists “had no idea what to do with me” (Alexander Porter) or doctors did not believe that all symptoms were “real and valid” (Batman) due to a lack of knowledge about neurogenic stuttering.

External struggles related to the ways in which participants stuttered when interacting with others and the world around them. External struggles impacted the internal experience of adjusting to stuttering. Reactions from others impacted the ways in which participants perceived themselves. Many participants expressed feeling that others could understand their internal experience from looking at them, including their thoughts and emotions; other participants expressed feeling that the way they were perceived did not match their experience because neurogenic stuttering is an “invisible injury” (Batman). Participants experienced feelings of anxiety and stress when the perceptions of others did not match their self-perception. Batman and Gwendolyn expressed feeling that others could not see their stuttering and assumed that they did not “struggle” (Gwendolyn); Tracy Smith described the internal struggle of feeling as if everyone could see her stuttering when she was in public even though it was not overtly evident, “I just felt like that day the disability was all over me. Like you can visually see it. And that's
how I feel every time I leave the house and go out like people can look at me and see that I stutter.” Each participants’ story shared the common thread of feeling misunderstood by the public around them in how they were perceived as a person with neurogenic stuttering. Although how the participants were perceived was not concerning to other people, it was a struggle for the participants as Tracy Smith shared, “[others] may not see [stuttering] as an issue, but for me it is a big deal.”

4.1.2 Life Changes – Learning to accept and live with new experiences as a person with neurogenic stuttering.

The life changes experienced by the participants in the study related to their speech, as well as the activities, occupations, and social situations they regularly participated in prior to the onset of neurogenic stuttering. As the participants experienced new life changes, they accepted the new changes to varying degrees and learned to adjust to new experiences. Similar to struggle, the degree of acceptance of life changes varied by situation and person. Some life changes related more to conversation such as Tracy Smith sharing, “you take that for granted that you'll always be able to speak and enunciate your words and communicate clearly … I just feel like I have to relearn everything.” Other implications included loss or changes in work (Morty, Gwendolyn, Alexander Porter, Tracy Smith), changes in relationships (Morty), as well as participating in new activities, such as support groups (Maya, Birdy).

Many participants explained how they had to adjust to changes in their speech, such as new “difficulty involved in a casual conversation” (Alexander Porter). Maya shared how beginning to speak in a new way was “fascinating” because she “spent the first twenty-one years of [her] life completely fluent.” This life change in becoming a person with neurogenic stuttering
was at the core of being diagnosed with neurogenic stuttering – the person spoke one way their entire life and then had to grapple with an unexpected change in their speech.

Some participants expressed changes in the activities that they regularly participated in, either by adding new activities to their lives or deciding to no longer participate in certain activities after the onset of neurogenic stuttering. Maya and Birdy both began to attend weekly National Stuttering Association (NSA) meetings. Maya referred to the group within her NSA chapter as her “stamily” (stuttering family). Many participants echoed a similar sentiment of finding a community or ‘family’ within a support group. Other participants no longer attempted certain activities that they previously enjoyed, such as acting, because “it’s quite an emotional process and I would not want to do that [while stuttering]” (Alexander Porter). Participants discussed participating less in social interactions, “having difficulty involved in a casual conversation,” (Alexander Porter) avoiding new social situations, and changing the ways they participated in familiar social interactions (e.g., talking with family and friends).

Work can be a large part of a person’s social circle and interactions. Four of the seven participants became unemployed or retired due to their medical diagnoses and concerns about communicating with stuttering in their careers. The participants were forced to grapple with the life change of no longer working in their selected field, such as teaching (Tracy Smith), manufacturing (Morty), and acting (Alexander Porter). Alexander Porter shared the struggle of no longer working as an actor stating, “I made my living speaking.” Others, such as Birdy, a speech-language pathologist reported finding ways to include their stuttering in their career to support or work with people who stutter. Maya also shared how being a person with neurogenic stuttering gives her a “connection” in her career working with children with disabilities due to her understanding that “[the] children that learn differently ... experience the world differently as
well.” For someone like Maya or Birdy, they used their identity as a person with neurogenic stuttering to add to their skills and career. Other participants had to take on a new career or work-identity to experience the life change of becoming a person with neurogenic stuttering.

Gwendolyn shared her experience in changes in social participation related to romantic relationships when she stated, “It did kind of put me on hold as far as even trying to like, date someone seriously, because I'm afraid my speech is going to go awry.” Others experienced changes in their personal lives with relationships either changing or ending. Maya shared that her friendships changed due to being at different junctures in life when recovering from her car accident and learning to cope with stuttering socially.

Family and friends also had to adapt to life changes when their loved one acquired stuttering. Some described their communities as supportive, such as Morty, who stated, “I have friends that helped ... I’m lucky.” Others such as Tracy Smith’s family were still learning to adapt. She shared,

When the stuttering starts [my mother] doesn't want to hear me stutter, and I think it's just probably something internal with her. She doesn't want to see me stuttering. So she'll say, ‘Just don't talk, don't try to talk.’

The ways in which a person’s family, friends, and community reacted to their stuttering was not always perceived as a reaction to who the participant was as a person, but instead a reflection of the new life changes experienced because “it’s frustrating for them too” (Tracy Smith). Birdy similarly shared that family and friends’ reactions were often from a place of misunderstanding, “They didn't believe me. They thought I was making [stuttering] up.” In the same way that some participants with neurogenic stuttering accepted, acknowledged, or even celebrated life changes
associated with acquiring stuttering, their support system also learned to live through their own frustrations and misunderstandings.

4.1.3 Coping - Developing a coping style that suits the individual’s needs for understanding, self-acceptance, and community.

Participants shared the ways that they coped with developing neurogenic stuttering and living as a person with neurogenic stuttering. Coping was a personal response used to manage the emotions and stress that came with the life changes and struggle the participants faced. The coping methods described in the interviews were both adaptive and maladaptive. Adaptive coping related to positive experiences that helped the participant live as a person with neurogenic stuttering. Maladaptive coping was used by participants to avoid situations that were stressful or uncomfortable; maladaptive coping through avoidance did not contribute to open stuttering. The adaptive coping methods described in the participant interviews included: finding ways to disclose stuttering (Batman), identifying as a person with neurogenic stuttering (Maya), talking with family and friends (Morty), joining support groups (Birdy), advocating for the self and others (Maya), educating others (Batman), and meeting people who stutter (Birdy). Some forms of adaptive coping were widely used by participants while others were more specific to a single participant’s needs or lifestyle. Coping was not always productive for the participants and became a maladaptive experience.

Some participants shared that they settled into ways of coping while others expressed that they were still “experimenting” (Gwendolyn) with ways of coping. For example, Tracy Smith shared she had not had the resources or readiness to find healthy ways to cope with stuttering because she was needed to “heal first” from the injuries related to her car accident. Participants who had learned ways to cope that worked for them also often initially shared the confusion
about where to start before “experimenting” (Gwendolyn) with different ways of coping. Coping often began with the need for understanding stuttering including educating oneself and the community. Alexander Porter shared his experience in seeking understanding after stuttering began with encephalitis, stating, “I learn what other people are going through, and listen to their stories and what’s happening, and I match it up with my own experience.” Having the ability to relate to and understand one’s own experience through the experiences of others was used by other participants to cope.

Many participants expressed finding support from others, through organized or unorganized platforms with family, friends, groups, organizations, and work, to be a beneficial coping mechanism. Of the seven participants, three specifically sought support through creating or joining communities of other people who stutter. Organized support groups included the National Stuttering Association (NSA) and r/Stutter community page on Reddit. Maya described her experience with meeting other people who stutter sharing, “We all speak differently but we are liberated when we’re together.” The new group identity achieved through finding others with neurogenic stuttering, or other people who stutter, was beneficial for “sharing our stories and learning and inspiring each other.” (Birdy) Maya shared that she used multiple forms of support to cope stating, “The most effective thing for me was finding the NSA (National Stuttering Association). Like finding people who get it. And speech therapists, they will help work with you, and they will help you hit other small milestones.” Support for the participants ranged from one-on-one personal relationships to National Stuttering Association meetings, as well as group and individual speech therapy. Five of the seven participants attended speech therapy for stuttering after the onset of neurogenic stuttering. Speech therapy provided support to many participants and helped them to “[see] change” (Morty) in their stuttering and secondary
behaviors (e.g. blinking/closing eyes, hand wringing, foot tapping, avoiding eye contact, and ‘grimacing’).

Other participants found ways to associate positive meaning and change with neurogenic stuttering as a coping mechanism. For example, Maya stated, “It changed how I could relate to other people as well. Like if a deeply depressed person can see me as an ally because they see that I struggle in life too.” Finding positive meaning did not mean that challenges were gone, and that a participant could only see the positive aspects of living with neurogenic stuttering in all instances. Instead, for someone like Maya, positive meaning making meant finding ways that stuttering may add to life and using those to move forward, such as advocating for or relating to others. Other examples of positive meaning making included a desire to help others who went through similar challenges, acknowledging the ways that stuttering added to conversation by making it interesting with ‘frippery and curly cues,’ (Alexander Porter) and inspiring advocacy in others, such as Maya’s daughter wanting to advocate for her mother at school. In resisting hardships and finding ways to cope, such as spending time with other people who stutter, participants often began to celebrate other people who stutter as well as themselves. Birdy shared, “people who stutter are truly, incredibly insightful, intelligent and amazing humans to work with.”

Forms of coping used exclusively by one or two participants as they began to understand their stuttering and learned ways to cope included using humor to cope (Alexander Porter, Morty), meditation (Alexander Porter), writing poetry (Maya), using speech strategies (Birdy, Morty), and educating others (Birdy, Maya). Using humor to “diffuse” (Alexander Porter) difficult situations was a specific form of coping used by two of the seven participants. Morty shared that there were times when people thought that he was “joking” and “at first it would
bother me but then I would start to laugh and just tell them a lot of people make [that] mistake.” Alexander Porter also shared that he used a similar form of humor to cope as he learned that others were “not making fun of [him]. [They] just kind of want to join in with [him].”

Maladaptive coping was not reported by all participants but was used by some participants to avoid unpleasant experiences or to ease stress and anxiety. The presence of maladaptive coping did not mean that the participants had not found adaptive or beneficial ways of coping; the two were not mutually exclusive. Instead, many coping strategies were specific to a situation or experience, so participants found both adaptive and maladaptive ways of coping based on context. Tracy Smith shared the coping mechanism of letting her family members speak for her in public or when she interacted with unfamiliar listeners because “it was a relief to have someone else speak for [her].” Morty also described letting others finish his sentences because stuttering “slows down the conversation” and “[his] friends can talk a lot faster.” Other forms of maladaptive coping included avoiding verbal conversation by communicating through other means (e.g. email; Birdy), “debating” whether or not to speak (Alexander Porter), retreating to the “background” in conversations (Gwendolyn), and ruminating on stuttering.

4.1.4 Identity - Learning to grapple with a new identity that was not chosen by balancing a novel way of presenting to the world while remaining authentic to their past self.

The participants in the study described taking on the new identity of a person with neurogenic stuttering. Developing a new identity as a person with neurogenic stuttering later in life led to changes in the way that participants perceived themselves within the context of their other identities, such as parent, caregiver, friend, child, actor, teacher, and artist among others. Birdy shared how the intersection of her identities as a person with neurogenic stuttering and a woman had affected her life,
Professionally, personally, [stuttering] makes you look weak, it makes you look more vulnerable, it makes you look less truthful, it makes you hard to read, you know, all of those things that are magnified more when you are a woman more than a man.

Many participants also took on new identities, lost identities, or adapted their existing identities. Batman described his change in identity stating, “I was the guy that laughed all the time, that talked, that took my son on outings and now we just hang out inside.” Identities were often constructed around careers and social circles which changed for many participants after the onset of neurogenic stuttering, causing participants to have to learn how to identify in these circles in new ways.

Stuttering was often perceived by the participants to be their first noticeable identity listeners ‘focused’ (Alexander Porter) on. Alexander Porter shared that the focus was on his speech because “[people are] not listening to what I’m trying to communicate and it is hella hard enough to communicate without [the communication partner] stopping to listen to the stutter.” Maya similarly shared that when she was speaking, people were “really not listening to a word [she was] saying.” Participants like Alexander Porter and Maya shared that they presented to the world first as people with neurogenic stuttering when speaking. Maya shared the impact of presenting first as a person with neurogenic stuttering, “how I speak and how I present myself to the world was so important to me.” In feeling that their first noticeable identity is a person with neurogenic stuttering, participants other identities, such as parent, actor, or social-being, were overshadowed.

Finding others with the shared identity of neurogenic stuttering was beneficial for some participants in learning to accept their new identity. Participants often began to recognize themselves in other people with neurogenic stuttering or other forms of stuttering. Maya shared
one of her first experiences at a support group with people who stutter stating, “There were medical doctors, there were lawyers, there were architects, all these highly intelligent people who shared something about them and they all stuttered.” In seeing other people who stutter, participants began to recognize their own traits in others, and see the other positive traits that they may not have recognized due to internalized stereotypes associated with stuttering, such as having a lower IQ or being less social.

A large part of making sense for the participants was accepting stuttering as a part of themselves. Maya stated, “I’m memorable now and that’s kind of cool.” Alexander Porter described neurogenic stuttering as “easier to embrace because it is an interesting stutter.” Although not all participants were at a place of complete acceptance, many found ways to begin accepting their stuttering. Gwendolyn shared “I'm learning because it's new to me. I don't really want it to be me, I just wanted it to go away when it was at its worst, but it was the beginning.” Birdy shared her experience stating, “It wasn't who I thought I was, but we all had [sic.] change and grow in time through the years.” She continued, “Do I want it to go away? Oh, that would be awesome. But I can't. It's not something that defines my success as a communicator.” Alexander Porter shared similar sentiments stating,

The number one tool that helped me was not to take it so seriously. It’s not going to kill me, it’s not anything, and to learn to accept it as part of my personality. Whether it dissipates or whether it gets worse. Those are two things I can’t control right now, but what I can control is how I react to it.

Self-acceptance of stuttering was experienced at different levels by all participants. Some participants came to a point of acceptance as a person with neurogenic stuttering and felt as though they were “lucky to love [stuttering] as part of [themselves].” (Alexander Porter) Maya
also shared, “I knew that people considered me a stutterer, I didn’t consider myself a stutterer … And now I love my stutter. If you don’t like it, then screw you.” Other ways of working towards self-acceptance included having the freedom to openly stutter and “let the stutter run ragged,” (Alexander Porter) and not allowing stuttering to “[make] choices for you” (Birdy) in deciding when to speak. To come to a place of self-acceptance, participants shared that they used means like advocating to promote self-acceptance. Birdy stated, “It's a part of the job of being a person who stutters, is being able to share information and talk about it.”

At first the “sudden” (Batman) new identity of being a person with neurogenic stuttering was often “difficult” (Tracy Smith) to adjust to. Maya did not initially consider herself to be a person with neurogenic stuttering. Later she took on the identity of a person with neurogenic stuttering as she coped with the life changes that she experienced. Birdy also shared how she began accepting her new identity as a person with neurogenic stuttering sharing, “To say that it's a big part doesn't mean that it's a bad thing. It is a part, you know, like hair color. It's just there.”

In a similar sentiment, Alexander Porter compared his stuttering to other attributes stating, “I’m not happy about these wrinkles and about my skin sagging, but I gotta keep it. I’ve gotta carry them on with me. It’s just part of me, so that’s what I get for hanging around.” Acceptance and identification as a person with neurogenic stuttering was not necessarily synonymous with celebrating the new identity, but recognizing it could be another more neutral part of who participants were.
CHAPTER 5

DISCUSSION

The purposes of the current study were to explore the potential emotional and life impact of living with neurogenic stuttering, along with when and how impact (if present) develops. We determined that an emotional and life impact was present for each of the seven participants in the current study, which was captured in four themes pertaining to struggle, life changes, coping, and identity change. Although not entirely the same, there were parallels between impact reported by people with neurogenic stuttering in the current study and the existing literature on impact associated with developmental stuttering. Evidence of life impact associated with neurogenic stuttering in this study diverges from current diagnostic criteria for neurogenic stuttering, which cites lack of impact as an indicator of neurogenic stuttering. The timeline for the development of a life and emotional impact could not be determined from the current study, but warrants further investigation in future research.

5.1 Neurogenic Versus Developmental Stuttering Characteristics

The experience of living with neurogenic stuttering described by participants in the current study had some similarities when compared to living with developmental stuttering in terms of the emotional and life impact. The experiences, coping methods, emotions, perceptions by others, and microaggressions associated with developmental stuttering in the literature were similar to many of the participants’ descriptions in the current study.

The lived experiences described by participants with neurogenic stuttering in this sample were similar to those that are documented in the literature among people with developmental stuttering. For example, Constantino et al. (2020) described how some people with developmental stuttering decrease the amount they communicate in response to negative listener reactions. Tichenor and Yaruss (2020) described decreased life participation and emotions, such
as anxiety and fear, associated with developmental stuttering which were also present for some participants in the current study. Participants described avoiding conversations with new communication partners, and coping strategies, such as letting others speak for the participant or letting others finish a sentence or phrase, to avoid stressful communicative interactions.

Compared to developmental stuttering, there were also similarities with how people with neurogenic stuttering coped. Adaptive coping mechanisms, such as reducing limitations and changing the environment, were described in both Plexico et al.’s study (2009) and the current study. Maladaptive coping included avoidance, as well as increased energy into coping with stuttering (e.g., increased use of strategies) described in both studies.

Adaptive coping described in the current study included positive meaning making. Boyle et al. (2019) recently reported benefits of living with developmental stuttering, and these benefits can align with how adults with neurogenic stuttering in the current study were coping. Boyle et al. (2019) reported three main themes: personal benefit, relationship benefit, and gained perspective in living with developmental stuttering. Many participants in the current study found new social support and often deepened their existing friendships and familial bonds that provided support. The perspective gained by participants in Boyle’s study (2019) and the current study included experiences such as a sense of appreciation and finding positive meaning in challenges. Positive meaning making was not the goal or outcome for all individuals with neurogenic stuttering in the current study but paralleled the experience of finding benefit described by Boyle et al. (2019).

The emotions associated with developmental stuttering were often reflected in the participants of the current study’s experiences. The same feelings of isolation, frustration and embarrassment described in the current study were described by the participants of Plexico et
al.’s study (2009). Participants in Corcoran and Stewart’s study (1998) described feelings of helplessness and fear associated with stuttering which were reflected in the experience of the participants in the current study. Corcoran and Stewart (1998) also described participants as feeling as if they had ‘no control’ which was widely expressed by participants in the current study.

The perception of neurogenic stuttering may differ from that of developmental stuttering, because there is often a known cause. One of the struggles that an individual with developmental stuttering may face is that for others it is often hard to understand a condition that has no known cause. Developmental stuttering can be hard to understand for others because a singular etiology cannot ‘explain’ why someone stutters (Boyle, 2016). Boyle’s study (2016) reported a lack of understanding from others leading to more stereotypes and stigma towards people with developmental stuttering. With neurogenic stuttering, there is often a known etiology of stuttering, caused by either a neurological diagnosis or injury. Many of the participants in the current study reported sharing their medical etiology before disclosing that they are a person who stutters. It may be easier for others to understand a medical cause, or for the participant to rationalize for themselves. Another person may be more understanding or accommodating to the person with neurogenic stuttering because there is a set cause, but more research is needed.

One of the experiences of living with developmental stuttering that may apply to neurogenic stuttering is encountering microaggressions in daily interactions. Coalson et al.’s study (2022) outlined types of microaggressions that adults who stutter may experience. The most common microaggression themes were patronization, second-class status, and perceived helplessness. The microaggressions described by the participants in the current study with neurogenic stuttering often matched the experiences outlined by Coalson et al. (2022).
Participants of the current study described the theme of listener avoidance most often on the phone when the listener hung up, asked the participant to call back at a different time, or asked to have someone else speak. It is important to note that not all participants described listener avoidance and shared that in-person people were more accommodating than on the phone.

Coalson and colleagues’ (2022) theme of perceived helplessness, which encompasses infantilization and intellectual inferiority, was also described by participants in the current study. A common form of infantilization described by participants in the current study was being told ‘slow down’ when speaking to be understood or to stutter less. Other forms of infantilization described in the current study were family and friends speaking for the person who stutters (e.g., ordering at restaurants, speaking to other adults) and finishing a word or sentence when a person was stuttering. Intellectual inferiority was described by one participant as a family member telling her that she was no longer intelligent because of how she spoke. Another form of intellectual inferiority described by two participants was internalized stigma of feeling that intelligence and stuttering are correlated, which they projected onto other people who stutter in their community. Many of the experiences, coping mechanisms, associated emotions, perceptions by others, and microaggressions experienced by people with developmental stuttering were also reported by participants with neurogenic stuttering in the current study.

5.2 Diagnostic Criteria

To clinically distinguish neurogenic stuttering from other forms of stuttering, such as developmental stuttering, frameworks of diagnostic criteria are used in decision making (Canter 1971; Lundgren et al., 2010; Manning & DiLollo, 2018; De Nil, 2019). The original diagnostic criteria for neurogenic stuttering presented by Canter (1971) included no emotional impact indicating that there was not an expected life or emotional impact associated with living with
neurogenic stuttering. This finding may not be reflective of the experience of all people with neurogenic stuttering. The results of the current study indicate that there is an emotional and life impact of living with neurogenic stuttering for the seven participants which diverges from the current diagnostic criteria.

Three considerations are used when choosing evidence to inform a diagnosis: research on the subject, clinician preference, and client perspective (ASHA, 2005; Cohen & Hula, 2020). Evidence based practice requires that speech language pathologists use the most valid and reliable research available. Less information is available about neurogenic stuttering when compared to other forms of stuttering, but when presented with the conflicting accounts pertaining to diagnosis it is important to keep in mind that emotions may be present for a person with neurogenic stuttering. The life and emotional impact of neurogenic stuttering may still differ from developmental stuttering, but it is important to recognize both as equally valid to best serve people with neurogenic stuttering. Further research into the lived experience of neurogenic stuttering would be beneficial to provide more accounts and experiences that continue to develop our notion of what it means to live with neurogenic stuttering.

5.3 Emotional and Life Impact of Living with Neurogenic Stuttering

The current literature on the topic of neurogenic stuttering is divided as to whether or not neurogenic stuttering is associated with emotional and life impact. Some studies report no emotional and life impact (Lebrun et al., 1990; Leder et al., 1996; Perino et al., 2000), while others have found evidence of life and emotional impact (Theys et al., 2008; Tani & Sakai, 2011; Ellis & Sheehy, 2013; Vanhoutte et al., 2014). Results from the current study support the latter body of evidence. The four studies that reported a life impact in the literature noted emotional impact such as feelings of frustration, fear, irritation, curiosity, embarrassment, crying, anger,
and awareness of stuttering. The life impact outlined in the four studies that match the experiences described in the study include situational anxieties related to stuttering (e.g. avoiding verbal communication, fearing unfamiliar listeners, changing careers). The participants in the current study each reported a life and emotional impact of neurogenic stuttering that corroborated and added to the current reports of an emotional impact (Theys et al., 2008; Tani & Sakai, 2011; Ellis & Sheehy, 2013; Vanhoutte et al., 2014). All individuals with neurogenic stuttering will not necessarily have an emotional and life impact, but emotional impact testing should be included in the assessment of neurogenic stuttering to determine if an impact is present.

5.4 Progressive Themes

The primary purpose of the study was to assess the potential for an emotional and life impact following the diagnosis of long-term neurogenic stuttering. The main areas of concern related to emotions, thoughts, and social participation to determine if an emotional or life impact were present for the seven individuals in the study. The reality of living with neurogenic stuttering, like any human experience, is far more nuanced and diverse than a singular lived experience. The themes – struggle, life changes, coping, identity - are meant to represent the overall lived experience of neurogenic stuttering without trying to compromise the integrity of each participant’s individual experiences.

The themes represented in Figure 4.1 show the progressive nature of the development of the emotional and life impact of living with neurogenic stuttering for participants in the current study, often starting with struggle and ending with identity integration. There was a sense of struggle across the interviews that permeated the early experiences of each individual. The first theme of struggle came in waves for each participant, seeming to subside as they adjusted to life
changes and learned to cope, but then resurfacing when new challenges were presented. The participants came to the last point of the cycle when they developed an identity related to their stuttering, but the cycle did not end there. The arrows continue around showing the waves of struggle that resets the cycle. There were still negative emotions and experiences which arose and challenged the individuals to lean into their past experiences to determine how to handle new struggles. As participants built coping skills and community, there was a general sense that they were then equipped with the skills to handle new challenges that they might not have known how to manage before. The emotional and life impact of living with neurogenic stuttering did not end when a participant developed an identity as a person with neurogenic stuttering; the participants continued to progress through the themes.

The themes that were developed for the data suggest that there is a potential life and emotional impact of living with neurogenic stuttering. It may differ for some from the life impact of living with developmental stuttering, but the impact on emotions, participation, occupation, and wellbeing should still be explored in clinical relationships with people with neurogenic stuttering. Some of the participants discussed how they view themselves differently than people with developmental stuttering because they did not develop throughout childhood as a person who stutters; They grew up and identified in a certain way before suddenly and unexpectedly taking on this new identity as a person with neurogenic stuttering. There were difficulties as well as positive experiences that shaped each participants’ relation to their stuttering. It is important that the emotions and life impact of neurogenic stuttering be explored with each individual to best serve those seeking speech therapy. The life impact of living with neurogenic stuttering from the qualitative interviews was also corroborated by the OASES scores which ranged from mild/moderate to moderate impact of stuttering on quality of life.
5.5 Role of Timeline in the Development of Emotional and Life Impact

Although there is not a set timeline of when each theme of the study will occur, time is an important factor in the experience of living with neurogenic stuttering as those who had more recent onset of neurogenic stuttering related more to the earlier themes of struggle and life changes rather than the later stages of coping and identity. Three of the participants who began stuttering at least five years prior to the interviews indicated a lessened emotional and life impact compared to onset. The remaining four participants lived with neurogenic stuttering for less than four years and still indicated a moderate to severe life impact. The development of a life and emotional impact was more individualized than a set timeline for when an impact may develop. One participant had only stuttered for six months at the time of the interview, which is helpful in noting that a life impact was perceived to develop within six months of diagnosis for one participant. Participants who came to a place of self-acceptance after stuttering for at least 20 years provided an example of how a life and emotional impact may develop and change over time. It would be beneficial for future research to investigate how emotional and life impact of neurogenic stuttering may change over time.

5.6 Other Associated Life and Emotional Impact

The experience of neurogenic stuttering is situated within the broader context of living with a semi-recent neurological diagnosis or injury. The causes of the onset event varied by participant and the emotional and life impact associated with other impairments affected the individuals to varying degrees. The struggles associated with stuttering and learning to cope with life changes and a new identity cannot be taken out of the context of living with a broader diagnosis or injury such as a stroke, TBI, or electrocution. Just as each individual learned to live and identify in new ways with stuttering, they had to adjust facets of their life to accommodate a
neurological diagnosis or injury. The neurological event and neurogenic stuttering may have produced similar emotions and life changes that cannot be divided as they are related to one another. The emotional and life impact of stuttering cannot be ignored for each of the participants of the study, but adds to their lived experience as they learned to struggle, cope, and identify in a new way.

5.7 Limitations and Future Research

The current study’s findings are limited because qualitative research cannot be generalized to an entire community. Although the current study’s participants experienced an emotional and life impact of living with neurogenic stuttering, this may not be true for all people with neurogenic stuttering. It is also not possible to wholly separate the lived experiences of neurogenic stuttering from the experiences of living with a neurological injury or diagnosis. In the same way that there is a possibility for an emotional and life impact related to stuttering, there is the possibility that a person may have an emotional or life impact from their diagnosis or injury. In the study meaningful units were carefully extracted from the transcriptions that were expressly related to stuttering, not the effects of the medical diagnosis or injury. The sample does not represent the experiences of individuals with neurogenic stuttering that has lasted for less than six months. Looking to the life experiences of those more recently diagnosed may be beneficial in determining when and how a life and emotional impact develops. It is important to reflect the experiences of those living with neurogenic stuttering in the acute phase in addition to the experiences shared related to long-term neurogenic stuttering in the current study.

Future research should consider the intersectionality of identities when taking on a new identity as a person who stutters and how that relates to previous race, gender, sexual, and socioeconomic identities as well as their current identities among others. A person’s identity as a
person who stutters is not completely separate from the neurological injury or diagnosis that caused the onset of stuttering. The lived experiences of each participant was also not solely related to stuttering as they may have other identities which impact how they interact with the world and their own stuttering. The factor of time also requires further research to fully understand how time impacts the development of a life and emotional impact of living with neurogenic stuttering. Future research should consider the development of an impact as well as how the impact may change over time for an individual with neurogenic stuttering. To accommodate the factor of time it would be beneficial to conduct research within the first six months that a person lives with neurogenic stuttering as well as the time period after to determine short versus long-term impact.

An interesting finding of the study was that two of the seven participants had a family history of stuttering. To be included in the study, participants could not have previously stuttered in childhood, but two had immediate family members who stuttered. It is possible that these participants had a latent neurological propensity to stutter that was expressed as a result of neurological injury or decline. This finding that 29% (2/7) of participants had a family history of stuttering warrants further research to determine if this is a common background characteristic among people with neurogenic stuttering.

5.8 Conclusion

The purpose of the study was to provide a potential description of the emotional and life impact of living with long-term neurogenic stuttering. From the seven qualitative interviews, it was determined an emotional and life impact of living with neurogenic stuttering was evident for each of the participants. Recognizing that there may be a potential emotional and life impact of
living with neurogenic stuttering will hopefully guide research and treatment in the direction that best benefits the person with neurogenic stuttering seeking speech therapy.

When diagnosing developmental stuttering, social, emotional, professional, and life impact may be used for diagnosis and justification of therapy provision with adults (Ingham et al., 2012; Sønsterud et al., 2020). It is important to take the same considerations into account when providing therapy to individuals with neurogenic stuttering, because we cannot assume that a life impact is not present; further research is needed in this area. Therapy goals related to social and emotional impact should be considered when working with people with neurogenic stuttering. The inclusion of social and emotional objectives is not supported by current research for people with neurogenic stuttering, because much of the diagnostic criteria state that there is no emotional impact (Canter, 1971). It should not be assumed that people who live with neurogenic stuttering do not experience emotional or life impact. Thorough, holistic assessment is warranted, particularly for those who have been stuttering for 6 months or more.
Appendix A

Social Media Statement to Participants
Did you start stuttering later in life following a medical diagnosis, injury, or event? I am a student at Western Michigan University and would love to hear about your experience living with stuttering that emerged later in life. The study includes an interview, survey, and optional reading sample that will take about 1-1.5 hours to complete virtually over Webex. If you are eligible for participation and complete the study, you will receive a $20 electronic gift card. Please contact us at natalie.k.devries@wmich.edu to learn more or set up a time to meet.

To participate in the study participants should have a known diagnosis or injury that was associated with the onset of neurogenic stuttering after childhood, stuttering that has lasted 6 months or longer, and no known diagnoses of other types of stuttering or speech and language disorders. Participants must also be living in the United States and consider themselves to be proficient in English.
Appendix B

Participant Screening Email
Dear [insert participant’s name],

Thank you for your interest in our study. This study involves a one-time interview over Webex and a brief survey about living with neurogenic stuttering. There are a few criteria that must be met in order to participate in this study. In this brief screening, you will be asked some questions to determine your eligibility to participate in our research study. It should take less than 3 minutes to complete. You may decline to answer any question, however declining to answer a question may impact your ability to participate in the study. The information you share will not be associated with any other data we possibly collect during the research study and will be permanently deleted at the conclusion of the study.

Please respond to the following questions:

1. How did you begin stuttering?
2. When did you begin stuttering, and are you currently stuttering?
3. Did you stutter as a child?
4. Have you or a speech pathologist ever raised concerns about your speech or language other than stuttering?
5. Please verify that you live in the United States and identify as proficient in English.

We look forward to hearing from you soon!

Natalie DeVries
Appendix C
Scheduling Email
Dear [insert participant’s name],

Thank you for your interest in our study. We would love to meet with you in a one-on-one virtual interview to discuss your experience living with stuttering that onset later in life. Before the study begins the consent information will be reviewed with you, which will outline what participating in the study entails. If you are still interested in learning more about or participating in the study, please send your availability over the next two weeks and I will email to confirm a time. If you complete the interview and survey, you will receive a $20 gift card for your participation.

We look forward to hearing from you soon!

Natalie DeVries
Appendix D

Email Script Sent to Speech Language Pathologists
Hello,

My name is Natalie DeVries, and I am a graduate student at Western Michigan University working under the mentorship of Dr. Hope Gerlach-Houck. I am currently working on my thesis researching the experiences of individuals living with neurogenic stuttering. Have you worked with any clients who exhibit or have been diagnosed with neurogenic stuttering? If so, we’d appreciate your help with recruitment! The inclusion criteria for the study are:

1. A neurological diagnosis or injury that caused neurogenic stuttering.
2. Stuttering that has lasted for at least 6 months or longer, and continued stuttering (even occasional) currently.
3. No known diagnosis of stuttering in childhood or adolescence.
4. No other speech or language diagnoses.
5. Proficient in English and living in the United States.

If you feel that you have worked with an individual who meets these criteria and would be interested in participating, please let us know or feel free to forward this email to them so they can reach out themselves. The study is expected to take approximately 1 to 1.5 hours and involves completing a brief survey and an informal virtual interview about their experiences living with stuttering that onset later in life. Participants will be compensated with a $20 Amazon e-giftcard.

Best,

Natalie DeVries
Appendix E

Reminder Email Script Sent to Speech Language Pathologists
Hello,

My name is Natalie DeVries, I recently reached out about my thesis research. I am a graduate student at Western Michigan University working under the mentorship of Dr. Hope Gerlach-Houck. I am currently working on my thesis researching the experiences of individuals living with neurogenic stuttering. I was again wondering if you have worked with any clients who exhibit or have been diagnosed with neurogenic stuttering? If so, we’d appreciate your help with recruitment! The inclusion criteria for the study are:

1. A neurological diagnosis or injury that caused neurogenic stuttering.
2. Stuttering that has lasted for at least 6 months or longer, and continued stuttering (even occasional) currently.
3. No known diagnosis of stuttering in childhood or adolescence.
4. No other speech or language diagnoses.
5. Proficient in English and living in the United States.

If you feel that you have worked with an individual who meets these criteria and would be interested in participating, please let us know or feel free to forward this email to them so they can reach out themselves. The study is expected to take approximately 1-to 1.5 hours and involves completing a brief survey and an informal virtual interview about their experiences living with stuttering that onset later in life. Participants will be compensated with a $20 Amazon e-giftcard.

Best,

Natalie DeVries
Appendix F

Phone Call to Speech Language Pathologists
If a speech pathologist answers the phone, the key points that will be discussed will be:

- Introduction (e.g., name, status as a graduate student, research mentor)
- Purpose of the study
- Ask if the speech pathologist has worked with people with neurogenic stuttering.
- Collect an email address to share more information about the inclusion criteria if the speech pathologist expresses interest or indicates that they know a person with neurogenic stuttering.
Appendix G

Voice Mail to Speech Language Pathologists
“Hello, my name is Natalie DeVries, and I am a graduate student at Western Michigan University working under the mentorship of Dr. Hope Gerlach-Houck. I am currently working on my thesis researching the experiences of individuals living with neurogenic stuttering. I was wondering if you have worked with any clients who exhibit or have been diagnosed with neurogenic stuttering? If so, we’d appreciate your help with recruitment! If you are interested or feel that you have worked with a person with neurogenic stuttering who may be interested in participating in an interview study, please feel free to call me back at this number, or email me at natalie.k.devries@wmich.edu”
Appendix H

Special Interest Groups Post
Hi Colleagues,

I am hoping you can help my/a graduate student, Natalie DeVries, recruit adults with neurogenic stuttering for her thesis project. The purpose of this qualitative, interview-based study is to explore the lived experience of people with neurogenic stuttering.

The inclusion criteria for the study are:

1. A known neurological diagnosis or injury associated with the onset of neurogenic stuttering.
2. Stuttering that has lasted for at least 6 months or longer, and continued stuttering (even occasional) currently.
3. No known diagnosis of stuttering in childhood or adolescence.
4. No other speech or language diagnoses.
5. Proficient in English and living in the United States.

If you know someone who meets these criteria who may be interested in participating, please inform them about our study by sharing this message with them. The study is expected to take approximately 1 to 1.5 hours and involves completing a brief survey and an informal virtual interview about their experiences living with stuttering that onset later in life. Participants will be compensated with a $20 Amazon e-giftcard. If you or someone you know has questions or interest in participating, please reach out to us at natalie.k.devries@wmich.edu.
Appendix I

Message to Youtube Channels
Did you start stuttering later in life following a medical diagnosis, injury, or event? I am a student at Western Michigan University and would love to hear about your experience living with stuttering that emerged later in life. The study includes an interview, survey, and optional reading sample that will take about 1-1.5 hours to complete virtually over Webex. If you are eligible for participation and complete the study, you will receive a $20 electronic gift card. Please contact us at natalie.k.devries@wmich.edu to learn more or set up a time to meet.

To participate in the study participants should have a known diagnosis or injury that was associated with the onset of neurogenic stuttering after childhood, stuttering that has lasted 6 months or longer, and no known diagnoses of other types of stuttering or speech and language disorders. Participants must also be living in the United States and consider themselves to be proficient in English.
Appendix J

Online Consent Form
Western Michigan University
Department ofSpeech, Language and Hearing Sciences

Principal Investigator: Hope Gerlach-Houck, Ph.D., CCC-SLP

Student Investigator: Natalie DeVries, B.A.

Title of Study: Neurogenic stuttering: Exploring potential emotional and life impact

You are invited to participate in this research project titled "Neurogenic stuttering: Exploring potential emotional and life impact"

STUDY SUMMARY: This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. Participation in this study is completely voluntary. The purpose of the research is to: describe the potential emotional and life impact of living with neurogenic stuttering and will serve as Natalie DeVries’ thesis for the requirements of the Master’s in Speech-Language Pathology. If you take part in the research, you will be asked to answer a series of interview questions online with the researcher over Webex and fill out a related survey using Qualtrics online. Your time in the study will take approximately 1-1.5 hours. Possible risk and costs to you for taking part in the study may be discomfort from answering sensitive questions, and time to complete the survey. Potential benefits of taking part may be funds from participation in the survey in the amount of $20. Your alternative to taking part in the research study is not to take part in it.

The following information in this consent form will provide more detail about the research study. Please ask any questions if you need more clarification and to assist you in deciding if you wish to participate in the research study. You are not giving up any of your legal rights by agreeing to take part in this research or by signing this consent form. After all of your questions have been answered and the consent document reviewed, if you decide to participate in this study, participation will be used in lieu of signing this consent form.

What are we trying to find out in this study?

There are known impacts of living with other forms of stuttering (e.g., developmental stuttering). The current study aims to determine if there is a similar or different potential impact on emotions or life participation when living with neurogenic stuttering.

Who can participate in this study?

To participate in the study you must meet the criteria of 1) A neurological diagnosis or injury associated with the onset of neurogenic stuttering. 2) Stuttering that has lasted for at least 6 months or longer, and continued stuttering (at least occasionally) currently. 3) No known diagnosis of stuttering in childhood or adolescence. 4) No other speech and language diagnoses. 5) Proficient in English and living in the United States or Canada.

Where will this study take place?
The study will take place during a one-time interview meeting using Webex. You will join the Webex link and then be directed to an online Qualtrics survey link following the interview.

**What is the time commitment for participating in this study?**

The interview will be completed in a one-time format online over Webex. The interview portion is anticipated to take approximately 1 hour. The survey portion will be completed immediately following the interview and will take approximately 30 minutes. Participation in the study should take no longer than 2 hours overall.

**What will you be asked to do if you choose to participate in this study?**

If you choose to participate in the study, you will be asked a series of questions that you may answer to the extent that you feel comfortable. You will then be sent a link to a Qualtrics survey where you will provide basic demographic information (e.g., age, ethnicity, etc.) and a standardized survey about the life impact of stuttering.

**What information is being measured during the study?**

The information from the interview will be analyzed for themes in the topics discussed. The survey information will be used to calculate impact scores in four areas of life impact to give an overall life impact score.

**What are the risks of participating in this study and how will these risks be minimized?**

The risks of the study include the potential of discomfort that might be evoked in the interview. This risk will be minimized by allowing for breaks if you request, and the ability to skip questions if you do not feel comfortable answering.

**What are the benefits of participating in this study?**

There are no explicit benefits to your participation in the study.

**Are there any costs associated with participating in this study?**

There are no costs of participating in the study.

**Is there any compensation for participating in this study?**

Compensation will be provided after completion of both the interview and Qualtrics survey. You will provide an email address at the end of the survey where the funds will be sent electronically in the form of a $20 gift certificate.

**Who will have access to the information collected during this study?**

The information collected in the interview and survey will be de-identified for confidentiality. The information will be stored in secure One Drive files that only the advisor and approved researchers will have access to. The data will be presented through a thesis defense and presentation at a conference.
What will happen to my information or biospecimens collected for this research project after the study is over?

After information that could identify you has been removed, de-identified information collected for this research may be used by or distributed to investigators for other research without obtaining additional informed consent from you.

What if you want to stop participating in this study?

You can choose to stop participating in the study at anytime for any reason. You will not suffer any prejudice or penalty by your decision to stop your participation. You will experience NO consequences either academically or personally if you choose to withdraw from this study. The investigator can also decide to stop your participation in the study without your consent.

Should you have any questions prior to or during the study, you can contact principal investigator, Hope Gerlach-Houck, at hope.gerlach@wmich.edu or the student investigator, Natalie DeVries, at natalie.k.devries@wmich.edu. You may also contact the Chair, Institutional Review Board at 269-387-8293 or the Vice President for Research at 269-387-8298 if questions arise during the course of the study.

This study was approved by the Western Michigan University Institutional Review Board (WMU IRB) on 7/29/2021.

Participating in this interview and survey online indicates your consent for use of the answers you supply for research purposes.

This consent document has been approved for use for one year by the Western Michigan University Institutional Review Board (WMU IRB) as indicated by the stamped date and signature of the board chair in the upper right corner.
Appendix K

Semi-structured Interview Guide
Consent and Inclusion criteria:

- Have you had a diagnosis of neurogenic or acquired stuttering from a speech-pathologist? Self-report?
- Do you have a current diagnosis of other speech or language disorders or concerns (e.g. apraxia, aphasia, dysarthria)?

General Information:

- Tell me about when and how you began stuttering.
- We’ll get into the details in a bit, but can you start by telling me about your overall experience with stuttering currently.
  - Walk me through a day in your life as a person who stutters.
- What do you wish people and society knew about developing stuttering later in life?
  - Are there things you wish your friends and family knew?
  - Are there things you wish the general public knew?
- Some people anticipate stuttering or know they are going to stutter before they do. Do you ever know moments of stuttering are about to happen before they do? What are some things you do when you anticipate that you’re about to stutter?
  - Do you ever have any physical reactions to stuttering?
  - [If more information is needed]: Some people who stutter have tension when stuttering, or blink, look away, etc.
- How often do you think about your stuttering?
  - Are there times or places where you think about stuttering a lot?
  - When do you think about stuttering a lot?
  - When do you rarely think about stuttering?
  - Do you ever think about stuttering when you aren’t stuttering?
  - Have your thoughts about stuttering changed since you first started stuttering?
- Since you started stuttering, what have your family and friends’ reactions been?
  - Have there been any other notable reactions to your stuttering from anyone else you have encountered?

Life participation:

- Since your stuttering started, would you say that there has been a change in how much you participate in activities you enjoy? Or has there been no change?
  - Think about who you interact with. Think about where you go.
- Has your relationship with family and friends changed at all because of stuttering or have the remained the same?
  - If yes, how?
- Let’s talk about what it’s like to stutter in some specific situations.
  - What has it been like to communicate at work?
- If you’re a parent, what has it been like to live with neurogenic stuttering as a parent?
- If you have a romantic partner, how have you all dealt with the stuttering together?
  - Have you ever attended a stuttering support group or speech therapy for your stuttering?
  - Tell me a little about that.
    - What has been helpful/unhelpful about it?

**Emotions:**

- What was it like for you when your stuttering first onset?
  - How did you cope with it when it first began?
- How have you coped with stuttering since it started?
- Do you feel like stuttering gets in the way of your life in any way? How so?
- Do you feel like stuttering adds to your life in any way, how so?
- Do you ever talk with others about your stuttering?

**Closing questions:**

- What do you hope the future looks like for you as it pertains to your stuttering?
- What else do you think is important that I know about your experience with neurogenic stuttering?
- Is there anything else that you want to share?
- Can you choose a fake name that will be used throughout the study to protect your privacy?
- What email should we send the Qualtrics link to and the gift certificate when the survey is completed?

Note: sub-bullets denote additional probing questions that may or may not be asked depending on the participant’s response.
Appendix L

Themes and Codes
Struggle - Waves of internal and external struggle as stuttering persists through life stages and experiences

- Self-isolation
- Feeling unseen
- Avoidance
- Feeling misunderstood
- Enigma
- Feeling othered
- Fear for society
- Observed
- Experienced stigma
- Physical reactions
- Depersonalized
- Lack of control
- Unpredictability
- Judgement from others
- Concerning to others
- Family’s worries and fears
- Negative reactions to others
- Miscommunication
- Helpless
- Need for change
- Need to communicate
- Negative speech conditions
- Preoccupation when speaking
- Interacting with unfamiliar listeners
- Pushed outside comfort zone
- Underserved by an institution
- Loss of connections
- Negative emotions
- Struggle
- Other’s expectations
- Speaking for the sake of others
- Seeking validation
- Inconsistent support
- Contradictory feelings towards stuttering
- Unsure how to move forward
- Dysfunction
- Negative interactions
- Mental health
- Needing independence
- Seeking control

Life Changes – Learning to accept and acknowledge new experiences as a person who stutters

- Changes in expectations for self
- Lost skills
- Forced reliance on others
- Feeling time pressure
- Personal gain
- Energy into stuttering
- Pushed outside comfort zone
- Reality versus possibility
- Effect on occupation
- Changes in participation
- Recovery
- Reaction to onset
- Increase in stuttering
- Etiology
- Onset
- Recognition of stuttering
- Ability
- Before onset
- Effects of onset event
- Opportunities created

Coping - Developing a coping style that suits the individuals needs for understanding, self-acceptance, and community.

- Desire to help other people who stutter
- Testing self
- Exposure to stuttering
- Flexibility
- Empathy
- Persistence
- Resilience
<table>
<thead>
<tr>
<th>Prior lack of knowledge</th>
<th>Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time to cope</td>
<td>Community</td>
</tr>
<tr>
<td>Seeking connection</td>
<td>Seeking community</td>
</tr>
<tr>
<td>Humor to cope</td>
<td>Family interactions</td>
</tr>
<tr>
<td>Accountability</td>
<td>People with neurogenic stuttering</td>
</tr>
<tr>
<td>More concern about other impairments</td>
<td>People with neurogenic stuttering</td>
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<tr>
<td>Comparing stuttering</td>
<td>Connection</td>
</tr>
<tr>
<td>Confusion about stuttering</td>
<td>Relation to others</td>
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<tr>
<td>Understanding own stuttering</td>
<td>Visibility</td>
</tr>
<tr>
<td>Desire to know more</td>
<td>Education</td>
</tr>
<tr>
<td>Perception</td>
<td>Neutral to others</td>
</tr>
<tr>
<td>Making sense</td>
<td>Positive reaction to own stuttering</td>
</tr>
<tr>
<td>Advocating</td>
<td>Positive interactions</td>
</tr>
<tr>
<td>Educating others</td>
<td>Positive emotions</td>
</tr>
<tr>
<td>Coping</td>
<td>Positive reactions to others</td>
</tr>
<tr>
<td>Acceptance</td>
<td>Normalcy</td>
</tr>
<tr>
<td>Choosing fluency</td>
<td>Ease of speaking</td>
</tr>
<tr>
<td>Taking space in conversation</td>
<td>Contentment with diagnosis</td>
</tr>
<tr>
<td></td>
<td>Neutral effect on life</td>
</tr>
<tr>
<td></td>
<td>Strategies</td>
</tr>
</tbody>
</table>

**Identity - Learning to grapple with a new self-identity that was not chosen, by balancing a novel way of presenting to the world and staying authentic to the true self**

<table>
<thead>
<tr>
<th>Conscious effort to maintain self</th>
<th>Personality in conversation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grouped because of stuttering</td>
<td>Internalized stigma</td>
</tr>
<tr>
<td>Noticeable disability</td>
<td>Critical of self</td>
</tr>
<tr>
<td>Stuttering separate from self</td>
<td>Trying to ‘fit in’</td>
</tr>
<tr>
<td>Diversity</td>
<td>Pervasive</td>
</tr>
<tr>
<td>Change in conversational style</td>
<td>Not ‘you’</td>
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<tr>
<td>Outward presentation</td>
<td>Abnormal</td>
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<tr>
<td>Awareness of self</td>
<td>Engrained in life</td>
</tr>
<tr>
<td>Identity</td>
<td>Societal expectations</td>
</tr>
<tr>
<td>Positive fluency</td>
<td>Authentic speech</td>
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<td></td>
<td>Admiring others who stutter</td>
</tr>
</tbody>
</table>
Appendix M

HSIRB Approval
Date: July 29, 2021

To: Hope Gerlach, Principal Investigator  
    Natalie DeVries, Student Investigator for thesis

From: Amy Naugle, Ph.D., Chair

Re: IRB Project Number 21-07-05

This letter will serve as confirmation that your research project titled “Neurogenic stuttering: Exploring Potential Emotional and Life Impact” has been **approved** under the **expedited** category of review by the Western Michigan University Institutional Review Board (IRB). The conditions and duration of this approval are specified in the policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note: This research may only be conducted exactly in the form it was approved. You must seek specific board approval for any changes to this project (e.g., *add an investigator, increase number of subjects beyond the number stated in your application, etc.*). Failure to obtain approval for changes will result in a protocol deviation.

In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the IRB for consultation.

The Board wishes you success in the pursuit of your research goals.

A status report is required on or prior to (no more than 30 days) July 28, 2022 and each year thereafter until closing of the study.

When this study closes, submit the required Final Report found at [https://wmich.edu/research/forms](https://wmich.edu/research/forms).

Note: All research data must be kept in a secure location on the WMU campus for at least three (3) years after the study closes.
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