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Talking About Aphasia: The Two Voices of Insight

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Abstract

This thesis aims to understand the lived experience of communication disorders (CDs), including the challenges, stigmas, and misconceptions related to CDs. It draws upon in-depth interviews with speech-language pathologists (SLPs), participant observations of people with aphasia, and observations of aphasia forum websites. During the data collection process, people talked about the stigmas and hardships of CDs and the subjective experience of having trouble communicating with others. This thesis will use their words and ideas to highlight the important aspects of coping with and treating CDs. It discusses how people with aphasia think about space, their body, and time, and considers how people with CDs negotiate interactional contexts and experience stigma. The experience of living with a CD is complex, and in order to fully understand it we need to look beyond the biological perspective. The inability to use language hinders people from showing themselves as thinking and acting individuals in everyday life, and because society ties intelligence and maturity to language, those with CDs have their identity threatened. This thesis includes suggestions for improving rehabilitation and treatment, as well as areas for future study.

Table of Contents

Chapter 1

Introduction

Language and Communication

What makes gossip, novels, debates, celebrity interviews, and class discussions so special? They require language, and humans are the only known species on Earth that have it (Sedivy, 2014). Talking is a universal principle of Homo sapiens, making language a true defining trait of what it means to be human. In order for language to evolve, humans underwent physiological changes (e.g., vocal tract, biting jaw muscles, and gene mutations) and experienced societal changes (e.g., the need to live together cooperatively and develop a way to communicate with each other clearly; Harrub, Thompson, & Miller, 2003). According to the nativist view presented by cognitive scientist Steven Pinker, our genes program us to have a capacity for language (Sedivy, 2014). In other words, humans grow their use of language based on a genetic blueprint. However, other researchers, such as Derek Bickerton, have argued the anti-nativist view, which is that language comes from our impressive cognitive abilities, and our brains have evolved to hold the capacity for complex language (Sedivy, 2014). This view disputes the claim that language is preprogrammed in our genes. Despite these competing theories, there is general consensus that human language is a unique capacity that differentiates us from other animal species. It functions differently than other cognitive abilities, is to some extent specialized in different parts of the brain, and affects the way we evaluate the world (Levinson & Holler, 2014; Sedivy, 2014).

Hockett (1960) outlined linguistic design features that are common to all known human languages (see summary in Hauser, 1996, p. 47-48). The features highlight the extraordinary way human language is constructed and processed. Language can be broken down into five levels of

linguistic analysis: phonology, morphology, semantics, syntax, and pragmatics. Phonology is the most basic level of analysis, involving the smallest unit of speech called a phoneme, such as /ba/ and /pa/. Morphology is the study of sub-lexical units of words. Morphemes are the smallest component of a word that has meaning, such as –ed, –est, and –un. Semantics is the study of linguistic meaning. Words are pointers to concepts either as denotations (i.e., the definition) or connotations (i.e., additional nuances). Syntax refers to the grammatical rules for combining worlds into meaningful phrases and sentences. Lastly, pragmatics is how people use language in contexts, such as in discourse and conversation. Social factors (e.g., nonverbal cues such as nodding, pointing, as well as joint attention) also affect language use (Hockett, 1960).

While the components of language are fairly straightforward, the localization of language in the brain and the biological processes of communication are much more complex. The brain has about 100 billion neurons and even more neural connections, making hard to pull apart the brain and study its components (Herculano-Houzel, 2009). Another difficulty is the expansive complexity of the brain's functions. However, we cannot know how language fully operates without knowing how it works in the brain. Simply comprehending a spoken word requires the utterance of the spoken word, the primary auditory cortex sending information to the Wernicke's area of the brain in the left hemisphere, Wernicke's area matching the word to a lexical entry (i.e., representation of language in the brain), and the meaning being retrieved from memory (Sedivy, 2014). Neurolinguists have found that the left side of the brain is primarily involved in language production and comprehension and the right side is involved in prosody (intonation), diffuse semantic relationships, coherence and inferences, jokes, and orthography (Harley, 2010). However, language tasks, especially complex ones, actively recruit other brain areas which make

the localization of language function more complex and ambiguous (Gonzalez-Castillo et al., 2012).

Besides the biology of language, researchers have also examined language as a performance to convey communicative goals and behaviors. Social competence usually requires interpersonal communication and/or language, and language serves a fundamental role in human socialization (Gallagher, 1993). Communication is defined as the process of understanding and sharing meaning (Pearson & Nelson, 2000). Communication is constant, transactional, a process, irreversible, and learned, making it a fundamental part of people's lives (McLean, 2011). Human communication takes form in objects, sounds, and sights that enter into almost every transaction with the environment, and the business of living in a society or culture could not exist without them (Fearing, 1962). People must constantly integrate social inferences with linguistic information in order to decipher meaning from language (Sedivy, 2014). The pragmatic level of analysis takes into consideration linguistic context (e.g., how "yes" can mean different things), situational context (e.g., things in the world help construct the language we use), and social context (e.g., how we use language based on our relationships and roles). H. Paul Grice, a British philosopher of language, reasoned that listeners infer aspects of a speakers' intended meaning that cannot be directly derived from the linguistic code (Sedivy, 2014). People are constantly making inferences about a speaker's meaning based on certain shared fundamental assumptions regarding communication as a purposeful and cooperative activity. Grice also created maxims of cooperative conversation, which are mutually shared assumptions between hearers and speakers about how rational speakers behave: speakers should not say what they believe to be false, should communicate relevant information clearly, and should make their contribution to communication as informative as required (McCann & Higgins, 1992).

Overall, language is a dynamic phenomenon rooted in biological, cognitive, and social processes and shaped by contexts. Damage or errors in any of these areas can lead to problems with communication and use of language. A large portion of our lives is spent communicating with others, making the ability to produce and comprehend language essential skills for smooth functioning in society.

Communication Disorders

For most people, speaking is an effortless process that is taken for granted. For about 40 million people in the United States who suffer from communication disorders (CDs), however, using language is a daily struggle (Tanner, 2007). Some causes of CDs include hearing loss, neurological disorders, brain injury, mental retardation, drug abuse, physical impairments such as cleft lip or palate, emotional or psychiatric disorders, and developmental disorders (American Speech-Language-Hearing Association [ASHA], 2005).

With regards to disorders related to speech, the National Institute on Deafness and Other Communication Disorders (NIDCD) estimates that 7.5 million people nationally have trouble using their voices; by the first grade about 5 percent of children have noticeable speech disorders, and more than 3 million Americans stutter (NIDCD, 2010). Fluency disorder, or stuttering, is one kind of speech disorder. Fluency is defined as the effortless flow, rate, and rhythm, and patterns of stress and intonation in speech production (Altholz & Golensky, 2004). Stuttering is characterized by disrupted synchrony of respiration, phonation, and articulation, and the listener tends to notice stuttering through the speaker's repetition of sounds or syllables, prolonging of sound, making unusual pauses between sounds or syllables, or repeating sounds (Bloodstein, 1993; Huilt, 1996). Approximately 5 percent of people will stutter at some point in their lives (Mansson, 2000), however, more recent research has indicated that the prevalence

could be as high as 8 percent (Yairi & Ambrose, 2013). Onset of stuttering usually happens between the ages of three and five (Dalton & Hardcastle, 1977). About 5 percent of all children will go through a period of stuttering that lasts six months or more, but three-quarters of those will recover during schools years, leaving about 1 percent with a long-term problem (NIDCD, 2008). As for language disorders, between 6 and 8 million people have some form of language impairment, including the roughly 1 million people who suffer from aphasia (i.e., the inability to use or understand language) in the United States (ASHA, 2013).

Aphasia is another CD that is caused by damage to the part of the brain that is responsible for language, typically the left side of the brain (NIDCD, 2010). The primary signs of the disorder include difficulty in speaking, listening, reading, and writing, and individuals may also have other complications, such as dysarthria and apraxia (i.e., motor speech disorders), or swallowing problems (ASHA, 2013). It is crucial to note that aphasia is not correlated with intelligence. Most commonly seen in adults post-stroke, aphasia can also be a result of a brain tumor, infection, head injury, or progressive neurological disorders, such as Alzheimer's disease, dementia, and Parkinson's disease (National Institute of Neurological Disorders and Stroke [NINDS], 2015). For the estimated 1 million people in the United States today who have aphasia, the type and severity of the disorder depends on the precise location and extent of damaged brain tissue.

Broadly speaking there are two types of aphasia: fluent and non-fluent (NIDCD, 2010). Damage to the temporal lobe (the side portion) of the brain can result in a type of fluent aphasia called Wernicke's aphasia, which accounts for about 16 percent of people with aphasia (Penderson, Vinter, & Olsen, 2004). People with this type of aphasia have difficulty understanding spoken or written language, which is why this type is also called receptive aphasia

(NINDS, 2015). People with Wernicke's aphasia may speak in long, nonsensical sentences and even make up words. For example, someone with this aphasia may say, "You know that smoodle pinkered and that I want to get him round and take care of him like you want before" (NIDCD, 2010). These individuals are usually unaware of their production errors.

Another type of aphasia, Broca's aphasia, is a non-fluent aphasia and caused by damage to the frontal lobe (NIDCD, 2010) and is found in about 12 percent of people with aphasia (Penderson, Vinter, & Olsen, 2004). Also known as expressive aphasia, people with Broca's aphasia typically speak in short phrases that make sense but require great effort. Individuals usually understand speech and know what they want to say, but cannot find the words he or she needs (NINDS, 2015). They are aware of the difficulties, which is why they can become easily frustrated. People with Broca's aphasia tend to have right-sided weakness or paralysis of the arm and leg because the frontal lobe is responsible for motor movements. An additional type of non-fluent aphasia, global aphasia, occurs in 32 percent of people with aphasia and is caused by severe and extensive damage to the language areas of the brain (NIDCD, 2010). These individuals have severely limited language abilities, and lose almost all language function. They have difficulty comprehending and expressing language, and cannot read or write.

Lastly, anomic, or amnesia aphasia, is the least severe type of aphasia, and patients have difficulty using the correct names for certain objects, people, places, or events (NINDS, 2015). This type accounts for 25 perfect of people with aphasia.

A speech-language pathologist (SLP) diagnoses an individual with aphasia through an evaluation to determine the type and severity of aphasia (ASHA, 2005). The assessment includes auditory comprehension (i.e., understanding spoken language), verbal expression (i.e., producing automatic sequences, naming objects, and having conversations), reading and writing (i.e.,

understanding or producing letters, sounds, words, sentences, and paragraphs), and functional communication (i.e., using gestures and other supportive means of communication when the person has trouble getting their point across verbally). Aphasia is usually first detected by the physician treating the person for a brain injury or neurological disease who then sometimes refers the patient to an SLP. However, studies have suggested that people with aphasia caused by dementia and other degenerative neurological conditions are under-referred to SLPs (Bhimte & Rangasayee, 2015; Taylor, Kingma, Croot, & Nickels, 2009). In some cases, a person will completely recover their language skills spontaneously. This prognosis is especially true if they had a transient ischemic attack (TIA), which is a type of stroke in which blood flow is temporarily interrupted but quickly restored (NIDCD, 2008). However, for most cases treatment needs to start as early as possible, and recovery is not quick or complete. The type of treatment an SLP administers will depend on the type and severity of aphasia. Treatment can be done in individual or group settings, aims at improving the specific language skills affected by damage to the brain, utilizes the remaining language skills the person has, and teaches other methods of communication (ASHA, 2013). Rehabilitation usually involves intensive exercises with SLPs that include reading, writing, following directions, and repetition. Computer-aided therapy may be used to supplement standard rehabilitation procedures (NINDS, 2015). The prognosis of aphasia is difficult to predict, and the cause of brain damage, area of brain damage, and the age, health, motivation and educational level of the individual influences how effective treatment is (NIDCD, 2008). Many health professionals also believe that the most effective treatment begins as early as possible.

In general, the lack of public knowledge and awareness of CDs is a problem that has been increasingly discussed in the speech-language pathology field. Debates center around the need to

increase public awareness of the terms used to describe different disorders (Walsh, 2005), greater recognition of the role of the profession in relation to CDs, and greater awareness of the need to increase publically-funded services for people with CDs (Ferguson, 2014). Specifically, research has shown that public awareness about aphasia is low (Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002). There is also debate around public acceptance of those with CDs; however, there is little examination of the paradox involved in fixing the disorder and seeking acceptance for the continuing disorder (Ferguson, 2008b). Current debates and research suggest that there may be a gap in the understandings of family members and people with aphasia on the one hand, and the understandings of the professional community on the other (Ferguson, 2014). Professionals tend to talk about aphasia primarily in medical terms to family members and support groups. This tends to intellectualize the consequences of aphasia, and may prevent acceptance of the disorder (Ferguson, 2008b). There is a need to raise awareness about public support for people with CDs through research designed to explore the understandings and reactions to communication difficulty from the perspectives of those most intimately affected (Flynn, Cumberland, & Marshall, 2009).

Chapter Overview

My thesis draws upon in-depth interviews with SLPs, participant observations of people with aphasia, and observations of aphasia forum websites. During the data collection process, people talked about the stigmas and hardships of CDs and the subjective experience of having trouble communicating with others. In my thesis I will use their words and ideas to highlight the important aspects of coping with and treating CDs. For the most part I will be using the terms CD and aphasia interchangeably throughout my thesis, however, when talking about children I will only use the general term CD.

To situate the experience of CDs, Chapter 2 will consist of my literature review. Here I will draw from prior research on chronic illnesses and introduce the notion of stigma. Chapter 3 will describe the research method procedures used to analyze the interviews, participant observations, and aphasia forum websites. This chapter will also explain how data from aphasia forum websites was triangulated with interview and participant observation findings. Chapter 4, the first data chapter, discusses how people with aphasia think about space, their body, and time. Chapter 5 considers how people with CDs negotiate interactional contexts and experience stigma. This chapter will look at the centrality of language to our everyday lives, the stigmas of CDs, and suggestions for practice. Unlike Chapter 4, this chapter will include themes about children with CDs. Finally, Chapter 6, the discussion, will examine the importance of illness narratives in the rehabilitation of people with CDs. The inability to use language hinders people from showing themselves as thinking and acting individuals in everyday life, and because society ties intelligence and maturity to language, those with CDs have their identity threatened. The discussion will also include implications for improving rehabilitation and treatment, as well as areas for future study.

Chapter 2

Literature Review and Theoretical Framework

Medical sociology seeks to explore the social aspects of health, the experiences of illness and treatment, and interactions between patients and medical professionals. Specifically, medical sociology and medical anthropology have paid great attention to the subjective experience or illness narratives of patients. The onset of illness poses a threat to one's body and self-integrity, and can disturb the harmony between the physical, social, and moral self (Comaroff, 1982). Bury (1982) explains chronic illness as a biographical disruption that challenges people's taken-for-granted assumptions about their bodies, selves, and the social world in which they live. The meaning of illness draws on social and cultural resources and shapes how individuals learn to navigate and understand illness. Since the emergence of scientific medicine during the Enlightenment, medicine has been based on scientific principles that provide solutions to illnesses and diseases (Risse & Warner, 1992). With the rise of modern European states in the seventeenth and eighteenth centuries, medicine's sphere of influence expanded into previously non-medical areas. Today, the social process of medicalization applies medical knowledge to behaviors that are not evidently medical or biological. Sociologists frame the process of medicalization as a form of social control that grants power to medical professionals over the domains of our everyday lives, not just the sick bed (Conrad, 1992; Szasz, 2007; Zola, 1982). The biomedical model of illness tends to neglect the views of the patient, the role of context in shaping illness, and how the responsibility for discovering and labeling illness is squarely in the hands of the medical practitioner. Medical care is becoming more scientific, with heavy emphasis on making medical decisions "rational, explicit, quantitative, and formal" (Gordon, 1988, p. 258).

Western medicine frames disease as deviance of the body that needs to be controlled in order to prevent chaos, based on assumptions that illness and disease are threatening to order and being (Becker, 1977). Kleinman (1988) argues that illness and disease are fundamentally different. Illness refers to the social, lived experience of suffering and symptoms, including how the sick person and his or her wider social network perceive, live with, and respond to symptoms of disability. Illness is not only a personal experience, but a social one that is organized within structural and institutional contexts. Disease, on the other hand, is the practitioner's perspective of the ailment. Allegedly, disease is a biomedical construct, and this means it is conceptualized as a deviation from the biological norm. Essentially, lived experiences are silenced by Western medicine's emphasis on biological phenomenon. Therefore, clinical care for the chronically ill is a potential source of conflict because people who cannot be cured must continue to live with their illness. Unfortunately, the biomedical model devalues the psychosocial concerns of illness and overvalues the need to control symptoms. As a result, the chronically ill are disempowered (Kleinman, 1988).

Since the 1950s, medical sociologists have challenged the biomedical perspective and theorized how individuals integrate illness into their identity (Williams, 2000). The voices of people who are ill are just as important as those of medical professionals. Talcott Parson, the founder of medical sociology, analyzed illness as a form of social deviance and explained how the "sick role" was a social mechanism for controlling this deviance. In the sick role, a person must recognize certain rights and obligations (Parsons, 1951). The person who is sick is exempt from normal role obligations and is not deemed responsible for falling ill only so far as they seek treatment and make getting well a priority. As a functionalist, Parsons' sick role discouraged secondary gains of illness and reintegrated the individual back into society through a return to his

or her normal role capacity as quickly as possible (Williams, 2005). Therefore, the Parsionian sick role focuses on institutional expectations rather than actual human behaviors (Segall, 1976; Williams, 2005). Parsons has been criticized for the sick role's incompatibility with chronic illness because the assumption of returning to "normal" is prefaced on acute illnesses. Many chronic illnesses can lead to CDs, such as stroke, traumatic brain injury, Alzheimer's disease, dementia, mental illness, and autism (Block et al., 1993). These illnesses cannot be treated within acute care framework. Unfortunately, many practitioners inappropriately use acute care to treat chronic illness, which can result in fragmented care, incomplete information, and socially isolated individuals (Charmaz, 1983; Sveilich, 2005; Wagner, Austin, & Von Korff, 1996). Medical practices, especially those in primary care, are organized to respond to acute illnesses, relying on patient-initiated visits, relief of symptoms, and assurance that there are no urgent medical crises (Wagner, Austin, & Von Korff, 1996). This leaves little room for medical professionals to address the perhaps less emergent but still severe needs of patients with chronic illness. In practice, physicians must redesign their approaches to chronic illness by changing the resources, amount of contact, and alternative types of health professionals available to adequately address chronically ill patients.

Chronic illness has been framed as a biologically disruptive event that shifts one's normal life trajectory to an abnormal and unpredictable one (Bury, 1982). An illness disrupts our Western values of order of the body and coherent narratives (Becker, 1997). In the former, when the body is stricken with an illness, one's sense of wholeness and indestructability disintegrates. In the latter, when people cannot reconcile disorder of the body, they cannot create meaning and order through their narratives. Suffering with chronic illness comes from bodily disruption and the difficulty of articulating or alleviating this disruption. Another issue is Western neoliberal

conceptions of personal responsibility for health. When a chronic illness is diagnosed, people feel responsibility for regaining their health and restoring normalcy. Thus, while Parsons' theory of the sick role has been criticized for not accounting for chronic illness (Segall, 1976; Williams, 2005), it still recognizes how people feel obligated to assert themselves as moral authorities of their health. However, they may not always succeed in living up to society's expectations because of normalized ideologies of health and illness. Discourse about the limits of medical control over chronic illnesses is not very common (Becker, 1997).

Chronically ill people feel a loss of self because of the lack of medical knowledge and certainty about their condition. Their former self-images of healthy identities dwindle away without the development of equally valued ones (Charmaz, 1983). The accumulated loss of positive self-images can result in negative consequences, including "loss of productive function, financial crisis, family strain, stigma, and a restricted existence" (p. 169). CDs are associated with an unemployment rate of 41.9% compared with 29.5% for the same working-age population without disability in the United States (Ruben, 2000). In the 21st century, being a valued and productive member of society is significantly determined by one's communication skills. Basically, people who are chronically ill suffer from a diminished self in their own as well as the eyes of social others.

People with chronic illnesses tend to keep them concealed from others, if at all possible, for fear of social reprisal (Becker, 1981; Charmaz, 1991; Sveilich, 2005). The symptoms they experience can be on and off, unpredictable, and never really go away. Invisible chronic illnesses must be further analyzed in order to understand how sufferers navigate symptoms and their social world. People with concealed illnesses do not feel socially sanctioned by Parsons's sick role unless they are diagnosed, given medical care, or seen as having a legitimate condition by

others (Dumit, 2006). Disease comes ostensibly from a diagnosis due to a doctor administering an objective test and making a diagnosis, however, *illness is a lived experience*. More research about the experience of living with chronic illnesses would allow us to understand the physically and socially debilitating nature of the institutional barriers that prevent chronic illnesses from being seen as a priority in research and public advocacy, and the struggles people with chronic illness face every day.

Illness Narratives

Telling stories is a universal part of being human, and the development of the human language has made it possible for humans for construct elaborate and meaningful narratives. Stories construct and maintain our everyday life, as well as repair and restore meaning when our lives are threatened. Personal narratives may be re-examined and re-fashioned in order to maintain a sense of identity (Bury, 2001). Research into the narratives of illness has been embraced by the sociology community as an acceptable way of studying the subjective experiences of people (Bauman; 1986; Cronon, 1992; Faircloth, 2004). While some argue that there has been an over-emphasis in the literature about using narratives to get the true, authentic experience of the individual (Ellis & Bochner, 1996), this neglects the dynamic nature of narrative composition, formulation, and presentation (Bury, 2001; Faircloth, 1999).

Illness narratives have helped sociologists and anthropologists obtain firsthand accounts of being diagnosed with various ailments (Becker, 1997; Bury, 1982; Frank 1997; Kleinman, 1988). These narratives highlight biographical disruption in which the relationship between the individual self and social world is threatened. They explore the links between identity and culture in a way that cannot be easily quantified into numbers. Research on stroke survivors has shown that they deem themselves to be less capable, independent, and in control compared

people who have not had a stroke (Ellis-Hills & Horn, 2000). It is difficult for these survivors to construct a valued social identity without the support of other people (Anderson & Whitfield, 2013). In sociology, illness narratives can be richly analyzed as sources of data within historical and cultural contexts to understand how they influence the ordering of everyday experience in response to illness (Hydén, 1997). People construct narratives based on certain stocks of knowledge that are available to the storyteller (Gubrium & Holstein, 1998). Illness narratives are told as a social activity that is constructed within the context of disruptive events and experiences. Riessman (1990) explains how in interpretive sociology, narrative analysis leads the researcher to understand gaps between experience and the telling of that experience. Accordingly, it is important to recognize that "narratives are always edited versions of reality, not objective and impartial descriptions of it … and interviewees always make choices about what to divulge" (p. 1197). Narratives come in many different forms (e.g., oral, written, textual, in collective or individual situations) and are shaped by age, gender, race, class, cultural, and historical contexts. Perhaps more importantly, illness narratives allow others to bear witness to conditions such as CDs that would otherwise be nearly impossible to understand.

Illness narratives, especially for chronic conditions, are ambiguous in nature because there is no clear end. Narratives assume a beginning and middle that are given meaning and direction through the end (Hyén, 1997). The uncertainty associated with illness makes it hard to know how the situation will develop and how to give symptoms meaning (Good, 1994). Illness narratives thus rely on the possibilities of many endings, which mean that these narratives are in constant negotiation and change. Another important aspect of illness narratives is that they can be from two different vantage points: that of an ill perspective and of the healthy person (Wiltshire, 1994). To speak from the ill person's point of view is to identity with the illness and

suffering. Talking as the healthy person makes illness seem extraneous and befallen on the body. The articulation and narration of illness is the focus of illness narratives. These narratives make it possible for people to share their illness stories and for other people to perhaps better understand illnesses.

Traditionally, illness narratives have been marginalized within medicine because they do not fit the biomedical model of diagnosis through scientific facts. The "clinical gaze" of medicine focused on the inner bodies of patients (Hydén, 1997). Patient's views of illness were associated with terms such as "illness-behavior" or "lay-perspective." More recently, patient's speech acts have become seen as an important part of illness and possible space to stand up to the voice of medicine. Narrative expressions are the most powerful form for expressing suffering. However, analyses of texts that present descriptions about aphasia, a type of CD, that are designed for the lay public show that the experience of aphasia is depersonalized (Armstrong, Ferguson, & Mortenson, 2011). There is a striking absence of the voice of people with aphasia, and the perspectives of the texts are geared to engage non-aphasic readers (Ferguson, 2014). While there is more appreciation for illness narratives, their application to some illnesses is lacking.

Hydén (1997) argues that illness narratives accomplish five things: "to transform illness events and construct a world of illness, to reconstruct one's life history in the event of a chronic illness, to explain and understand the illness, as a form of strategic interaction in order to assert or project one's identity, and lastly, to transform illness from an individual into a collective phenomenon" (p. 55). Institutional contexts, such as a medical care environment, reflect and reinforce who narrates, how they narrate, and for what purposes they narrate (Agar, 1985).

Illness narratives can be categorized into narrative types in order to recognize themes and meaningful connections. For instance, Arthur Frank (1997) in his text, *The Wounded Storyteller*, conceptualized a framework of narrative types in understanding the experience of illness. Frank identifies the restitution, chaos, and quest narratives. No narrative fits exclusively to any one type. However, having categories makes analyzing illness narratives easier. At any point during an illness narrative the type can change, showing the dynamic nature of retelling illness stories. The restitution narrative refers to the assumption that one's health will return to normal. The chaos narrative happens when a person feels hopeless, overwhelmed, and that their life is meaningless. Lastly, the quest narrative is when "sick" individuals treat their illness as a learning journey and embrace the uncertainty. I hope that my research will expand on each of these narratives and show the complexity of narratives from the perspectives of SLPs and people with aphasia. The two sides of CDs (i.e., the clinician and the patient) can illuminate the clinical and interpersonal meanings of language.

Many studies that examine the illness narratives of people with chronic illnesses have been done on chronic fatigue syndrome, arthritis, epilepsy, stroke, and autism (Charmaz, 1983; Gray, 2002; Scrambler, 2004). While some of these conditions can lead to CDs, there has been little research that focuses on CDs in general. Furthermore, the literature has failed to address the lived experience of losing the ability to communicate normally in the social world and what that does to one's sense of personhood (Cartmill Simmons-Mackie & Damico, 2003; Kovarsky, 2014; Nund, Ward, & Scarinci, 2015). The primary goal of my research is to address these shortcomings and examine the treatment for people with CDs, as well as their quality of life in general. People with CDs experience extraordinary struggles because the nature of their disorders prevents them from sharing their illness narratives and the benefit of connection

through stories. They must manage their biological symptoms in addition to various social hardships. All people use illness narratives to rework their identities and make sense of their ailments, and those with language impairments have unique struggles.

The current literature on treatment for CDs defines improvement in terms of linguistic progress through standardized tests and focuses on the biological mechanisms behind language impairments (Brookshire & McNeil, 2014). However, research on the subjective experiences of CDs would allow us to examine how this type of disorder affects the totality of the person. The field of linguistics has been criticized for its overly narrow focus on the structural properties of language and neglect of the aspects of social life that make language relevant (Hymes, 1987). Through a range of discursive activities, the shared rules for the production and interpretation of cultural behavior are actualized (Sherzer, 1987). Language and culture can be analyzed within the context of speech events, but also a variety of social activities. The ethnography of CDs studies communicative incompetence and disorder as they emerge in a variety of social activities (Kovarsky & Crago, 1990). Previous ethnographic accounts of CDs have shown that the nature of CDs is based on cultural values, beliefs, and communicative interactions (Crago, 1990). How a community reacts to communicative competence or incompetence needs to play a major role in what constitutes disabilities and the role of SLPs (Basso, 1996; Kavorsky, 1990). Research suggests that clinical discourse practices should focus on speech events within and outside of therapeutic settings in order to gain an understanding of clinical efficacy that relates to the generalization of therapy gains in different communicative contexts (Kavorsky, 1990). Overall, this type of research on CDs recognizes the relationship between disorders of communication, culture, and professional practice (Kavorsky, 2014). It does not make sense for clinicians to enter different cultural groups with a priori taxonomies when attempting to determine a CD, showing

the importance of looking beyond the linguistic and mechanistic elements of this type of disorder (Kavorsky, 1990).

According to the French phenomenological philosopher Merleau-Ponty (1974) who wrote about the philosophical connections between language and aphasia, a type of CD, reducing aphasia to biological mechanisms makes the impairment seem the same as all other illnesses that are based in neurological damage. It negates the individualized experiences of people with aphasia. Merleau-Ponty (1993) is critical of science and identifies its shortcomings:

> Science manipulates things and gives up living in them. Science is and always has been that admirably active, ingenious, and bold way of thinking whose fundamental bias is to treat everything as though it were an object-in-general – as though it meant nothing to us and yet was predestined for our use. (p. 121)

Clinicians who solely focus on the science of aphasia are removed from the lived relationships with their patients, and this reduces people with aphasia to objects who are not lived wholes or have value beyond their language disorder. While Merleau-Ponty does not completely disregard the importance of science, he understands that an objective body is not the lived body. In other words, biological explanations of aphasia do not necessarily reflect the lived experiences of having the disorder. Aphasia is not just a mechanical problem in the brain situated within an information machine, i.e., the body (Merleau-Ponty, 1993).

Likewise, symbolic interactionists such as George Herbert Mead (1934) understand that the self is a product of social interactions and not the biological preconditions of interactions. Mead's concept of the "generalized other" is central to this theory, which he defines as the generalized attitude of a social group (Mead, 1934). Individuals define their behavior in relation to the generalized attitude of the social group they are involved with. According to Mead, society exists only when people interact with each other in ways that they find meaningful through linguistic interchange, self-reflexivity, and human agency (Prus, 1996). The self is social, not

innately biological. Mead connected the development of the self to children's language competence, and suggested that children foster a sense of self through language interactions and being able to take the perspective of particular others (Turner, 2006). Sociologist Charles Cooley (1902), who was influential to Mead's theories, developed the "looking glass concept" based on the idea that individuals develop a sense of self based on how others perceive them. People are constantly interpreting the perceived responses from others.

Phenomenology and symbolic interactionism can explore the link between world experiences of CDs and theoretical, scientific knowledge (Chamberlain-Salaun, Mills, & Usher, 2013; Hinckley, 2014). These perspectives can shed light on gaps in theory and practice and clinicians' biases and interpretations of experienced clinical phenomena. It is important to note that understanding the lived experiences of disability does not deter from cognitive understandings of scientific knowledge that form of basis of treatment (Hinckley, 2014). Instead, combining professional knowledge with information about the lived experiences of communication disability can expand our understandings in meaningful ways. Ethnographic approaches can explore the realms of clinical interactions that cannot be addressed through traditional forms of scientific inquiry (Benner, 2001). Phenomenology has many other applications to CDs, including the role of the clinician and person-centered care, how individuals adapt and live successfully with communication impairments, the long-term social and behavioral consequences of living with language impairment, the progressive experience of bodily recovery, and strategies of primary caregivers of individuals with communication impairment (Hinckley, 2014). Instead of just focusing on the individual person with a CD, symbolic interactionism understands the social phenomenon of CDs and the importance of considering the role of the communication partner during interactions (Hersh & Armstrong,

2014). Thus, phenomenology and symbolism interactionism provide a foundation for studying person-centered care and the meaningfulness of all aspects of interventions for CDs.

In my research I will look at the lived experiences of individuals with CDs through four dimensions of lived experience of interest to phenomenologists (van Manen, 1990): lived space (spatiality), lived body (corporeality), lived time (temporality), and lived human relations (relationality). I will draw on quotes and stories from SLPs, individuals with aphasia, and aphasia forum websites to examine each dimension and argue that healthcare needs to incorporate lived experiences into clinical practices and research.

Stigma

Stigma has long been applied to different illnesses (Becker 1981; Bury 1982; Corrigan, 2000; Earnshaw & Chaudoir, 2009; Fine & Asch, 1988; Sayce, 1998). However, the stigmatization of CDs, such as aphasia, has not been discussed significantly in the literature. A considerable amount of the research on stigma within the behavioral sciences has been contributed by social psychologists that have used concepts from the social cognitive approach to understand how people construct categories and link them to stereotypes (Crocker et al., 1998). However, the sociological perspective looks at the lived experience of the stigmatized and the structural issues that lead to discrimination (Link & Phelan, 2001). My research attempts to focus on the sociological perspective and understand the life experiences of and stigmas associated with CDs. Goffman (1963) describes stigma as an attribute that is discrediting, and a discredited stigma is one that is overt while a discreditable one is not. Either way, that person's social identity is tainted. Stigmatized individuals can feel a sense of shame because those without the stigmatized trait discriminate against those who experience stigma. Stigmas are not universal, and depend on social and historical context (Dovidio, Major, & Crocker, 2000). Link and Phelan

(2001) describe stigma as the conjunction of "labeling, stereotyping, separation, status loss, and discrimination" when power differences occur (p.377). Stigma is a matter of degree, meaning that some groups are more stigmatized than others and labels are experienced in different ways.

Goffman (1963) explains how stigmas are a result of a gap between "virtual social identity" and "actual social identity" where one's virtual identity is the expected character attributes and actual identity is the character attributes the person in fact possesses. In the United States, we ascribe personal responsibility for health, and those who cannot stay healthy are seen as failures (Becker, 1998). Stigmatized conditions, such as CDs, often begin with the societal reaction (anticipated or realized) to a norm violation. Eventually, the person begins to expect stigmatizing reactions from others, anticipate those reactions, and thus internalize the stigma as a mark of shame and spoiled identity (Kleinman, 1988). Social structures reflect and reinforce stigma. Because stigmatized individuals anticipate negative interactions with non-stigmatized individuals, they may arrange life to avoid these interactions (Goffman, 1963). Disability and illness places disabled people in a degraded position where they are discredited or discreditable (Zola, 1982).

Chronically disabled people especially can feel rejected, ridiculed, inhuman, or blamed for their disability (Goffman 1963; Kleinman, 1988). Research has examined enacted and felt stigma in the context of autism and chronic and disabling conditions (Charmaz, 1983; Gray, 2002; Scrambler, 2004). The first is overt rejection or discrimination that stigmatized people experience while the latter refers to the feelings of shame or fear of rejection (Gray, 2012). The distinction between these two stigmas is important because one refers to stigma in interactional contexts and the other to the biography of the individual.

Even children with CDs face stigma. Peers play an important role in the opportunities to develop social competence through role modeling, practicing language skills, and offering feedback; however, children with specific language impairments (SLIs) have an increased difficulty interacting with peers (Gallagher, 1993, 1999). SLIs are a type of CD, such as stuttering, impaired articulation, a language impairment, or a voice impairment, that delay the mastery of language skills in children who have no hearing loss or other developmental delays (NIDCD, 2008). When communication is impaired, children's self-concept, roles, and way of living might be affected (Van Riper, 1971), and common emotional responses to speech impairment include frustration, anxiety, guilt, shame, fear, stress, grief, denial, helplessness, anger, depression, isolation, and low self-concept (Crowe, 1997). Individuals with CDs have difficulties with peer interactions that can persist from childhood through adolescence (Ferguson, 2014). Parents and teachers tend to rate adolescents with CDs as less socially involved with others than typical peers (Tomblin, 2008). Furthermore, individuals age 7 to 16 with CDs reported higher levels of victimization at age 11 (Conti-Ramsden & Botting, 2004) and fewer friends (Durkin & Conti-Ramsden, 2007) than typical friends at age 16.

A considerable body of research has examined stigma as related to families of children with disabilities (Baxter, 1989; Francis, 2012; Gray, 1993). According to this literature, parents of children with disabilities experience what Goffman defined as "courtesy stigma." This is a stigma by association where people who are close to stigmatized individuals are stigmatized themselves. Parents of children with disabilities experience courtesy stigma because they are members of the same family rather than because of any sharing of the disability itself (Francis, 2012; Gray, 2012). Courtesy stigma is supposedly a result of the "moral" failings of these parents because of their inability to normalize the kids' behaviors, and also parents are deemed

responsible for the children's behaviors. The nature of a child's symptoms can also affect the stigma experience of their parents. Parents of autistic kids whose symptoms are more severe, which can include communication problems, are far more likely to experience stigma (Gray, 2002). However, they may be less likely to receive "blame" for their kids' bad behavior because the medicalization of autism views the condition in biomedical rather than moral terms (Francis, 2012).

Overall, past literature has not focused on the factors that influence the degree of stigmatization experienced by people with CDs (e.g., severity, type, age, gender, etc.) or their social role with chronic language impairment, and I hope to uncover some of these factors in my research.

Chapter 3

Methodology

Current Study

The current study uses qualitative methods to examine the subjective experiences of living with CDs, including proxy accounts of those who work with them. The term "qualitative research" is defined as an inductive methodology that produces findings not found by statistics or means of quantification, and theories are generated from data (Strauss & Corbin, 1998). While research on stigmas and disabilities is growing, it is important that research specifically focuses on CDs because communication is so fundamental to society. Also, we unfortunately do not have detailed knowledge about the importance of social support centers for individuals with CDs. The goals of this study are to understand the narratives of people dealing with CDs, including the challenges, stigmas, and misconceptions related to CDs. Furthermore, this study looks at the ways to inform the public about the facts of CDs and how to negotiate interactional contexts with people who have a CD. Examining these topics can help us understand how to support people with CDs and treat them with respect.

Participants

In this mixed-methods study, data were gathered through in-depth personal interviews and participant observations. With three practicing speech-language pathologists (SLPs) with at least 20 years of experience and one graduate student obtaining her master's in speech-language pathology, the study sample consisted of four participants. All interviewees resided in Massachusetts. Jackie and Sarah are two white female SLPs working in public school systems. Jackie is in her 50s and works in an elementary school (grades K-4). She has always worked with children as an SLP for over 20 years, and knew going into the field that she wanted to work with

young children. Sarah, also in her 50s, works at a school for kindergarten and first grade children. She has been an SLP for over 30 years and primarily has worked with children in Shrewsbury; however, she has some experience working in a hospital setting. Justin is a white male in his 60s with over 40 years of experience as an SLP. He is currently a Clinical Supervisor, Facilitator of Aphasia Community Group, and Clinical Speech-Language Pathologist at an outpatient rehabilitation center. He also has past experience working in acute care, at skilled nursing facilities, and with pediatric patients. As a child he needed speech therapy for stuttering. Sarah has a bachelor's degree in speech-language pathology, and Jackie and Justin continued their education and received their master's degrees. Allie is a first-year master's student studying speech-language pathology. She entered her undergraduate career as a political science major, but switched to speech-language pathology after taking a couple linguistics courses. Allie was involved in both clinical and research experiences as an undergraduate, however, in her master's degree she is focusing on clinical work. Currently, she is primarily exposed to persons with aphasia.

Demographics Graph

Name	Gender	Age	Race	Highest Degree Earned	Years of Experience	Primary Clientele Population	Location of Work
Jackie	Female	50s	White	Master's	>20 years	Children	Public Elementary School
Sarah	Female	50s	White	Bachelor's	>30 years	Children	Early Childhood Center (K-1st grade)
Justin	Male	60s	White	Master's	>40 years	Adults with aphasia	Outpatient Rehabilitation Center
Allie	Female	20s	White	Master's (currently enrolled)	<3 years	Adults with aphasia	University Center for Language, Speech, and Hearing

Also, observational data was collected from attendance at five Aphasia Weekly Group meetings and one Aphasia Community Group meeting in Boston, Massachusetts. Each weekly group included seven to fifteen persons with aphasia, one SLP, and two master's program students. The Aphasia Community Group meeting had around 40 participants, primarily persons with aphasia and family members. However, some non-family caregivers and professionals attended. The meeting lasted three hours. Although I do not know the exact demographic breakdown of the participants I observed, the youngest participants were in their 20s and the oldest were in their 70s. The majority of the participants were white, middle-class individuals. The primary cause of aphasia was stroke, and there was a small group of people who experienced a TBI or had a progressive neurological disorder (e.g., Alzheimer's dementia, etc.).

Procedures

Participants were recruited through nonrandom, convenience and snowball sampling (participants whom the student researcher established rapport with or the director suggested as good to talk with) from Boston University's Academic Speech, Language & Hearing Center, and public middle/high schools in Shrewsbury, MA. Participants were eligible if they had a CD, were a parent/caretaker of someone with a CD, or were a clinician/researcher in the field of CDs or stigmas. All interviews were held at a time and place most convenient for the participant, and were done in-person or on the phone. Before each interview began, informed consent to be interviewed and recorded was obtained in the form of both verbal and written consent. All participants were reminded of the confidentiality of their interviews and were given numbers and pseudonyms to protect their identities. They were also told they could choose to stop the interview at any given time, although none of them did. Interviews lasted an average of one hour and were audiotaped using a small audio recording device. I collected qualitative information

regarding the subjective experiences and stigmas of CDs through individual, semistructured, open-ended interviews. This interview style ensured consistency across groups while also allowing participants flexibility in their responses.

Probes were used to elicit further discussion on responses. The questionnaire (see appendix) covered 4 primary domains: (1) broad questions about health in general (e.g., "How is your overall health currently?" "Any recent changes in your overall health?"); (2) specific questions about the disorder (e.g., "Tell me about your CDs," "If a parent/caregiver, when did you start caring for someone with a CD? If a clinician/researcher, how long have you been in this role and why did you choose this career path?"); (3) impact of the disorder on life (e.g., "Do you think there are stigmas associated with your condition in general?" "How has caring for/researching someone with this type of condition changed the way you live?"); (4) the impact of illness narratives (e.g., "How to do feel about research that focuses on narratives and stories instead of experiments and surveys in order to learn more about disorders?).

Observations were done at five Aphasia Weekly Groups held at Boston University. These group meetings are aphasia-friendly environments that help aphasic individuals practice conversation, watch and discuss films, improve writing skills, or learn the basics of computers. Boston University's Aphasia Resource Center offers nine different Weekly Groups. Two observations were at a "Toastmasters Group," two were at an "Aphasia Community Chorus" group, and one was at a "Book Group." Each session lasted an hour and a half and had between 7 and 12 participants and was held in a conference room or classroom. Weekly Groups are held 10-12 times per year. I observed participants by sitting at the same table where they were having group discussions (e.g., Toastmasters and Book Group) or within the circle of chairs participants were sitting (e.g., Chorus Group). Before each session I introduced myself and briefly explained

my research. Following my introduction, the aphasic individuals also introduced themselves. I sat quietly and attentively during the sessions and wrote down notes. I engaged in the participants' activities, such as the breathing and motor oral warm-up exercises in the Aphasia Community Chorus.

Observation was also conducted at one monthly Aphasia Community Group meeting in Boston, Massachusetts for people with aphasia and their family and caregivers. At the meeting I gave a presentation about the topic of my thesis to about 40 people and facilitated a panel discussion about the stigmas of aphasia. Individuals with aphasia, family members, and caregivers participated in the discussion. After the presentation and discussion, participants divided into small "breakout" sessions to share ideas, feelings, and concerns. Family members met separately. I observed the "breakout" session for persons with aphasia and took notes. The participants talked about events going on in their lives and their experiences of having aphasia.

SLPs use narratives to construct the meaning of interventions within a clinical setting, while also illuminating the perceived experience of CDs. It is possible that SLPs can serve as proxy and highlight the experiences of CDs for those whose language impairment is so severe that a relatively short one-on-one interview is not feasible. Through my interviews and observations, I aimed to understand how people with CDs navigate the social world, reflect on their experiences, and behave during informal discursive activities. SLPs articulated clinical practices but they also perceived efforts at identity construction from people with language impairments. Many themes were paralleled across these two perspectives.

To triangulate the narrative and observational data, a targeted content analysis of aphasia forum websites was conducted. This procedure builds on the works of symbolic interactionists studying online communities and their interactions (Denzin, 1998, 1999; Waskul, 2003;

31

Williams & Copes, 2005). Since online forums have their own "norms, rules, own emotional

vocabulary – guidelines for posting, acceptable subjects, regular users, leaders old-timers, and

constant circulation of newcomers" (Denzin, 1998, pp. 99-100), a selective analysis was

undertaken.

I directed my attention to the aphasia forum websites *Aphasia Hope Foundation* and

Daily Strength Aphasia Support Group because they seem to have the most content and most

recent updates. For both, individuals who join the forums have the ability to create a profile and

interact with others based on the guidelines set in place by those who administer it. Participants

on the forums have options for discussion based on the various threads already constructed or by

creating their own threads. However, they each have distinct organizational styles. The *Aphasia*

Hope Foundation forum has five general topics: Caregivers, Survivors, Professionals,

Researchers, and Advocacy. Within those topics, participants construct their own threads. The

Daily Strength Aphasia Support Group forum has 27 general topics that participants have created

(as of 4/18/16). The topics with the most replies include: "Does speaking get better some days

than others?" (20 replies), "Aphonia" (11 replies), "global aphasia" (12 replies), and "What best

helps in this situation?" (7 replies).

Data Analysis

There are many ways to study and analyze qualitative narratives. Ethnography is a

qualitative research approach that emphasizes studying an entire culture and becoming immersed

in the culture as an active participant (Atkinson, 2005). This research style accepts that observers

are also participants who reflect, order, interpret, and give meaning to events in light of their

culturally available beliefs, but they try to analyze data using systematic inquiry. It refers to

research about people's lives, lived experiences, behaviors, emotions, feelings, and cultural

phenomena. Many researchers gather data through ethnography, including observations and interviews (Frost, 2011). Qualitative research is especially useful when trying to explore the meaning or experiences of people with problems such as chronic illness, addiction, divorce, and the act of "coming out" (Strauss & Corbin, 1988).

Qualitative research has many advantages because it focuses on participants' personal experiences. Data are based on the participants' own categories of meaning and is useful for gaining novel understandings when researching understudied, complex phenomena (Travers, 2001). It also uses data, such as feelings, emotions, and thought processes, which are hard to quantify using conventional quantitative methods (Strauss & Corbin, 1990). In the end it produces a narrative description of a phenomenon (Genzuk, 2003). Overall, qualitative data is based on the human experience, which can be more powerful and compelling than quantitative data, especially when the data are the product of a story. This study will draw from two qualitative research approaches to analyze the data: grounded theory and phenomenology.

All interviews were audiotaped, and tapes were transcribed verbatim to ensure systematic analysis of discussions. Transcriptions were examined line by line for emergent themes, as suggested by grounded theorists Strauss and Corbin (1998). Data were sorted into categories and developed into concepts (Strauss & Corbin, 1990). Both my advisor and I coded the interview transcripts to increase reliability. My advisor and I discussed the meaning of codes and how they can be refined and adjusted to improve our understanding of living with CDs. Information provided by the participants was determined to be a "theme" if multiple participants repeated the same or similar comment.

After themes arose, axial coding (i.e., the process of relating categories and themes using inductive and deductive thinking) was used to develop subthemes and link themes together, a

process consistent with the literature (Strauss & Corbin, 1998). In qualitative analysis, data collection ends when saturation is achieved and no new information emerges (Krueger & Casey, 2009). Therefore, saturation occurred when all the concepts were well defined and explained, and no new information could be extracted from the data (Corbin & Strauss, 2008). The caveat, however, is that saturation is limited due to the sample size (n=4). Despite this limitation, many common themes emerged across the transcripts. Similarly, I looked for common themes across my participant observations and aphasia forum websites. I used these websites by periodically checking up on various discussions that substantiated or disputed the findings from my interviews and participant observations. I looked for posts that had two or more replies or had keywords in the title.

Themes were organized into four realms: spatiality, corporeality, temporality, and relationally. These realms have been investigated in phenomenology, one of many qualitative approaches that aim to develop a complete, accurate, and clear description and understanding of a particular human experience or phenomenon (Hinkley, 2014). According to Merleau-Ponty (1974), phenomenology is the philosophical study about how we, as human beings, do not experience the body as a detached experience because the body is its own consciousness and a vehicle directed toward phenomena in the world. Through our bodies we communicate with the world. Hence, the philosophy of Merleau-Ponty can be applied to the lived experience of aphasia because the inability to use language and the body poses significant problems to people with aphasia. The following chapters will present these themes and experiences.

Limitations

All studies have limitations, and this one is no exception. The contributions of the present research must be considered in light of the study's limitations. Due to the small number of

interviews and the sampling strategies utilized, respondents might be more homogenous than a general population of SLPs and individuals diagnosed with aphasia. Many participants knew each other, especially those from the Aphasia Weekly Groups, which could influence responses and might mean they share similar views and beliefs about CDs.

Another limitation is the small number of SLPs interviewed. The views in this study do not claim to represent the opinions of all SLPs. Furthermore, although the findings from this study may be applicable to other individuals with aphasia, drawing from multiple speech and hearing clinics, rehabilitation centers, hospitals, private practices, and geographic locations and income levels would allow for greater understanding of the subjective experience of CDs. Lastly, the nature of acquiring data required participants to speak. The results may be limited precisely because those with a stigmatizing disability may have difficulties communicating their experiences. For this reason, we opted to include the targeted content analysis on online forums to allow us to compare and contrast findings from observational data and the comparatively confidential forums.

Chapter 4

The Lived Space, Body, and Time of Communication Disorders

This chapter uses a phenomenological lens to present findings on the lived experience of CDs and how that experience is embodied and socially, environmentally, and mentally constructed. It primarily focuses on aphasia, a type of CD that affects one's ability to speak, write, and understand language, both verbal and written. Out of the four interviews, Justin and Allie talked explicitly about aphasia. This chapter will focus on three aspects of living with aphasia: space, body, and time, using data from the five Aphasia Weekly Groups, one Aphasia Community Group, and interviews with Justin and Allie. It covers how individuals adapt and live with a chronic CD, the progressive experience of bodily recovery, and the temporal relations between identities before and after the onset of an acquired CD. This chapter will also emphasize the sensory and perceptual experiences of the world in so far as it is experienced by persons with aphasia, and while SLPs cannot tell us about "lived experiences" if they do not have them, they can be "proxy" accounts. While many of the goals clinicians have are medical or linguistic in nature, they also focus on working with clients to restore the meaningful dialogue that may have been lost after the onset of a CD. This work aims to channel the autonomous voices of people with CDs. First-person accounts of the experience of aphasia and reflections of clinicians working with them allows for the exploration of how theoretical, social, cultural, and professional thinking influence our understandings and interpretations of communication disabilities. A narrative vantage point helps us understand aspects of clinical practices that are difficult to measure through traditional scientific methods, such as the meaning of stroke experience, client's rehabilitation goal priorities, and conceptions of ethical care (Hinkley, 2014).

It can also help recognize theory-to-practice gaps and how clinical practice is actually implemented.

Lived Space (Spatiality)

Movement through the world is limited for people with aphasia who had a stroke (the most common cause of aphasia), brain injury, or have a neurological disorder because many of them need a wheelchair, cane, or leg brace (ASHA, 2015). If we create meaning of space by inhabiting space, then the experience of the body is a source of the expression of space (Merleau-Ponty, 1974). People with aphasia in a wheelchair or with a cane are forced to slow down their expression and experience of space. If they are in a wheelchair they often cannot independently move through space and must rely on the mutual understanding with others that they want to be pushed, unless they are capable of operating an electric wheelchair. The privilege of intentional activity is severely reduced. A stroke or traumatic injury changes where you can and cannot go. Persons with aphasia talked about the onset of the disorder as a point when their life slowed down or stopped. There is a sense that movement through life was drastically altered by an event (e.g., stroke, traumatic brain injury (TBI), etc.). For example, a white female in her 60s with aphasia was nearly nonverbal after a TBI, and she has continued to go to speech therapy for over a decade in order to regain her speech:

My life stopped. It changed. I had to recreate it.

All of the individuals with aphasia I observed who were not retired during the onset of aphasia could not continue the jobs they had pre-aphasia, and most were currently unemployed. Many had previously worked in social service jobs or business where articulation is necessary. They reported that the meaning and purpose to life they felt going to their jobs every week was gone. They found meaning going to therapy, support groups, or elementary jobs. Their leisure time was

affected as well. Many men used to participate in sport activities and used their body movements as an expression of their athleticism and coordination. But, now they can only watch sporting events. Instead of staying physically active by playing football or soccer with friends, they go to weekly physical therapy. Their day-to-day routines and movement through the world are drastically altered. These men have lost an important social activity and embodied experience that allowed them to be active and feel a sense of accomplishment through effort, skill, or courage (Carless & Douglas, 2008). The meaning they express through movement (e.g., jobs, leisure, etc.) has changed.

Limited mobility makes people with aphasia more reliant on others. One African American woman in her 60s who participated in the Aphasia Community Chorus was in a wheelchair with limited movement of her extremities, neck, and face. If she wanted something as simple as a tissue, then she had to make an audible sound and scrunch her face so that another person could understand that she needed help with something related to her face. She couldn't use her arms to reach her face, so she had to have someone help her. Her being-in-the-world was essentially based on the assumptions and understandings of those around her. She could see and comprehend the space around her; however, her motor intentionality was practically lost. Her bodily space was stationary, and her movement through the world was subservient to others. Objects did not exist for her arm to grasp, stairs were not present for her to walk up, and movement through space was from outside the body, i.e., others.

Reliance on others and spatiality is also important in the patient-caregiver relationship. I observed many spouses and caregivers speaking for their loved ones who had aphasia. On the one hand, this can be helpful to move past awkward interactions in public and group settings. Spouses and caregivers can convey language for a person with aphasia. A few caregivers

mentioned on the aphasia websites that they are better at understanding what their loved ones are trying to say than doctors, nurses, and SLPs because they spent the most time with their loved one. On the other hand, an aphasic person's voice risks becoming invisible. Physically, an aphasic person's body occupies the same amount of space, but another person dictates a part of his or her being-in-the-world. At the same time, some caregivers expressed frustration because they had trouble understanding what people with aphasia were saying. One man whose brother suffered a TBI said,

> *Im so sad..I cant understand what he is trying to say and it is depressing him so much. he shouldn't have to deal with this alone but I don't know what to do.*
> *(http://www.dailystrength.org/c/Aphasia/forum/12778920-help-our-family)*

The dynamic between people with aphasia and their caregivers is complex. People with aphasia can feel isolated and stuck because their caregivers speak for them, rendering their voice invisible, or cannot even understand what they are saying, making their attempts to speak meaningless. Language impairment can create a barrier between people with aphasia and their caregivers, creating a feeling of isolation and remoteness.

Bodies take up space; however, many individuals with aphasia feel that in addition to moving through space, being recognized as a person is challenging. A white woman in her 50s who acquired aphasia through a stroke was frustrated that she was not treated like a competent person in the doctor-patient relationship. She attended Toastmasters and Aphasia Community Chorus, and her speech had improved incredibly over the past few years.

> *I feel invisible when I go to the doctor's office. The doctor talks to the person who is with me. They act like I'm not there, and I want to say, 'Hey, I'm here!'*

If being-in-the-world is based on a communicative relationship with the world (Merleau-Ponty, 1974), then this individual with aphasia was sometimes treated or felt as a being-in-itself. She was an object that was not perceived as a body with intentional movements. Her mode of being,

or "virtual social identity," was simply to exist in this context of the doctor's office. However, from her subjective point of view, or her "actual social identity," she was a being-for-itself who has a consciousness and wants to interact with the world. Her "virtual social identity" is the language and speech impaired individual and her "actual social identity" would be the competent and productive individual who can engage in conversations. Because the doctor knew about her impairment through interactions, she embodied a spoiled identity in this context. She found it hard to balance the conflict between her "virtual" and "actual" social identity. Her ability to interact was limited because her language capacity was impaired, and this situation created a complex dynamic between engaging in the world and being perceived by the world.

Many persons with aphasia also experienced the feeling of being in a foreign country because of their language impairment. Justin, an SLP who has been working with persons with aphasia for over 40 years, used the foreign country metaphor to convey how challenging it is for people with aphasia to navigate the world:

> *Having aphasia is like being in a foreign country where you can hear people, you can read the signs, but you don't know what they are saying.*

They do not feel "at home" walking around once familiar places because, depending on the severity of their condition, they may not be able to read signs, talk to cashiers and taxi drivers, or go for walks easily. They also cannot always distinguish syllables and sounds, such as voices, horns, engines, and laughter, making it hard to make sense of the social environment. Language makes places and objects seem more clear and familiar. Language is how we immerse ourselves in a culture and feel a sense of belongingness.

However, unlike foreigners who can pick up new languages through frequent interactions and practice, individuals with aphasia are dealing with language impairment from damage to the brain. Aphasia is a chronic condition and recovery is slow moving. Individuals with aphasia can

feel like they are a foreigner in a place they know they once felt at home. People with aphasia

may feel isolated because they cannot extract meaning from the content in the world, and it is an

overwhelming experience. One woman with aphasia who is 25 posted in the *Daily Strength*

Aphasia Support Group that her communication problems make her feel confined in the world

and she fears losing her job.

> *I am terrified of the idea of being trapped inside my head without being able to*
> *communicate.*
> *(http://www.dailystrength.org/c/Aphasia/forum/20591177-progressive-aphasia)*

This young woman feels like she is cut off from the world because of her language impairment.

One man with aphasia in his 50s that I observed was both a foreigner, in the literal sense, and felt

like a foreigner because of his language impairment. The man was a cardiac surgeon in the

Middle East and was performing surgery when the hospital was bombed and he suffered a

traumatic brain injury. He was transported to Boston for treatment and now resides in the city.

He is dealing with moving to a new culture in a different part of the world, navigating an

unfamiliar place, and he has a severe CD.

Lived Body (Corporeality)

As previously stated, Merleau-Ponty (1974) recognized that our bodies are perceptually

open to the world. We act with our bodies and cannot become disembodied. Our embodiment of

situations affects how we experience them. Thus, we cannot just look at the physiological and

psychological mechanisms behind experiences. Individuals with aphasia explained their

experience of aphasia in both biological and phenomenological ways. Every time I went to a new

Weekly Group everyone had to introduce him or herself to me. When doing so, most people

mentioned their stroke or injury. The experience of acquiring aphasia was described in physical

terms (e.g, blood clot, bump on head where brain injury happened, damage to part of brain that

controls language) and also metaphors (e.g., "feels like my brain is spaghetti," "something is

blocking the words," etc.). While the physiology of the stroke or traumatic brain injury was important to these people, they also used metaphors to describe the subjective experience of what they felt was going on with their bodies.

Corporeality is important to individuals with aphasia because their bodies experience many changes. Their bodies or beings cannot participate in the world like they used to because their mobility is limited. They cannot use language to demonstrate their presence or body efficiently. Merleau-Ponty (1974) explains in the *Phenomenology of Perception* that "language certainly has an inner content, but this is not self-subsistent and self-conscious thought … It presents or rather it is the subject's taking up of a position in the world of his meanings" (p. 225). The body plays an important role when speaking. Persons with aphasia can lose the ability to perform fluid movements with their body and lose many modes of communication (e.g., written, oral, expressive, and receptive language, hand gestures and other body language, verbal and non-verbal language, etc.). The Aphasia Community Chorus showed the importance of the body in language and provided a safe space for persons with aphasia to improve their vocal muscles, articulation, body posture, and confidence. The SLPs who ran the group noted the chorus sounded better when people were "getting into it" and used their bodies and emotions to sing. Part of treating aphasia is treating body language and movement. Recovery from stroke or traumatic brain injury is not just a recovery of bodily functions, but also recovery of the "social body" – a reconnection to social practice (Doolittle, 1994).

However, the freedom and intentionality of the body is limited for persons with aphasia. They essentially have to re-learn how to use their body even to do basic tasks, such as taking a shower, going for a walk, or brushing their teeth. Routine tasks with the body become unfamiliar and need to be consciously practiced with greater thought and intention. Aphasic individuals

described to me that their bodies feel useless. Their spouses have to start working again or take up extra shifts to make up for lost income and to pay for medical expenses. Allie, a first-year graduate student who works with persons with aphasia, said that most of her patients are older men who are frustrated that they cannot take care of their families anymore. They cannot provide income, pay the bills, or manage the house. They do not embody a patriarchal role and they feel emasculated. Their bodies and language abilities are weak and inferior.

> *For the majority of people I've worked with have been men and, you know they're older men and they come from traditional households where they may have that, I don't want to say like patriarchal role but you know they have that head out household mentality. So when they're no longer able to make those decisions or they're no longer able to express themselves or tell their wife, "Oh, we need to make sure the lawn's mowed," they no longer have control over that … you slowly have these responsibilities and decisions that no longer become yours … I think it's just this misconception that you can't handle it or they no longer kind of think through a problem to solve independently when that's not necessarily the case.*

The extra work that caregivers and families have to do can strain relationships. A 14-year-old daughter of a man with aphasia said that she found it hard that she cannot communicate very well with her father, and she sees her parents' relationship deteriorating.

> *I worry about my father, but I think I worry even more about my mom because this has effected her life almost more it seems … For twelve years she worked as a stay at home mom, her dream job … But now since my dad can't work she has to be the one to sit at an office desk all day and order furnishings for hotels and the rich. And I admire her for this so much but I know that she feels helpless … I know that she is very unhappy and I just don't know how to make her happy anymore because she is always angry with everyone now.*
> *(http://www.aphasiahope.org/forums/?wpforumaction=viewtopic&t=40484.0)*

Acquiring aphasia can affect the entire family and it changes relationships. This daughter feels helpless and unable to help either of her parents. She cannot easily accept the fact that her parents, who were "high school sweethearts," are not happy anymore. Her parents' identities have changed.

One white woman with aphasia in her 60s said that she does not embody the same person in the eyes of her nieces and nephews anymore even though she feels like she is still the same person:

> *I used to be the fun aunt before my stroke. Now my little nieces and nephews won't look at me. But I am still educated and fun.*

From the stories I have heard, aphasia is not just a language problem but also a bodied problem. As Merleau-Ponty (1974) explains,

> Language, in its turn, presents no different a problem: a contraction of the throat, a sibilant emission of air between the tongue and teeth, a certain way of bringing the body into play suddenly allows itself to be invested with a figurative significance which is conveyed outside us. This is neither more nor less miraculous than the emergence of love from desire, or that of gesture from the uncoordinated movements of infancy (p. 225).

Language is more than words in the mind – it is an embodied activity. The movement and expressiveness of the body gives meaning to language, and language renders the body visible. This allows us to rethink aphasia, particularly for clinicians. While I did hear aphasic persons talk about aphasia in terms of language components, such as "I know the right words," "can't say long and complicated words," "I can speak better than write," and "I struggle with pronouns," this is only one aspect of the lived experience of aphasia.

The spatiality and corporeality of aphasia shows us that smiling can be just as important as saying, "That's funny," and being talked to like a capable, intelligent person can be just as important as being able to talk. Since aphasia is in the brain and body, language, communication, and the body are intricately connected. People with aphasia may be confused and uncertain about some aspects of their physical and neurological impairments, but they still have thoughts and opinions on how their bodies should be handled. One white woman in her 60s with aphasia who had a stroke after complaining of headaches and being sent home from the hospital felt like doctors neglected her when she tried to advocate for her health. When I met her she had motor

and memory impairments and was angry that doctors did not take her stroke related symptoms seriously. However, she was thankful that her mother could take care of her daughter while she was recovering.

I knew it was wrong, my head. Doctor said, 'aspirin go home.' Then, stroke.

This woman with aphasia went to the hospital complaining of headaches and asked for a brain scan, but the doctor sent her home with ibuprofen and she had a stroke. The frustration of not being listened to by physicians around the time of stroke onset was mentioned in the *Daily Strength Aphasia Support Group*. One woman with aphasia who suffers from hemiplegic migraines felt that the doctors did not recognize her stroke symptoms soon enough because they talked to her briefly and did not perform proper tests on her.

> *It took me a long while to stand up and say for gods sake your body doesnt just lose vision in your sight and pain in chest and arms and pains in head and unable to speak and move for no reason and when they didnt listen ... I shouted even louder and made them listen... thank god i did otherwise i would still be sitting here in pain and in tears thinking what the hell is wrong with me.*
> *(http://www.dailystrength.org/c/Aphasia/forum/2331250-learning-positive)*

Pre-stroke or post-stroke, patients want their voices to be heard and to feel present, just like the rest of us do.

Lived Time (Temporality)

Many people with aphasia struggle with understanding number concepts (e.g., telling time, counting money, adding/subtracting), making the expression and comprehension of time challenging. However, they still use time to describe their identity. Time is "not an object of our knowledge, but a dimension of our being" (Merleau-Ponty, 1974, p. 415). When individuals with aphasia introduced themselves to me the overwhelming majority mentioned how long it had been since their stroke or brain injury. The vast majority of posts from the aphasia forum websites (by people with aphasia and caregivers) also noted age at the time of stroke or how long it had been

since the event. Time is still part of their being-in-the-world, and this shows an explicit

awareness of the stroke or brain injury event and is arguably a strategy to reveal a prior self-

identity that was unimpaired. The lived experience of aphasia is in relation to the time since that

event. Allie has only worked with persons with aphasia for a couple of years; however, she too

saw the importance of temporality in the experience of aphasia:

> *You know the people I worked with had a stoke 10, 15 years ago, it doesn't matter if it had been yesterday. They're still aware of exactly how their life has changed. And that's not something you get used to, not being able to speak fluidly especially, it goes for everyone, but especially if you are an extremely educated person.*

Chronic illnesses have a distinctive relation to time because they are not acute disruptions or

periods of suffering (Charmaz, 1983). As this quote shows, the loss of self and severe identity

change due to aphasia is not valued.

Clinicians use objective language when talking about their patients' prognosis, treatment,

and in predicting future outcomes. While objective language can be useful for recording patients'

progress and creating universal time markers of outcomes, it assumes that people experience

time in a sequential, linear way. Time concepts can be jumbled up in aphasic persons' minds and

they can get confused with the terminology. It is not that individuals with aphasia do not have a

sense of time; they just have trouble conceptualizing numbers or symbolically thinking about

time (e.g., using spatial metaphors). Life can feel like bits and pieces because they cannot always

express dates and the sequential order of events. They can experience a disoriented sense of time

because they cannot label or comprehend numbers. A white woman in her 40s with aphasia who

attended Book Club and was an active participant in discussions introduced herself to me by

trying to explain how long it had been since her stroke:

> *I had a stroke since 4 times ago… umm 3 months ago…no… never mind.*

She seemed more embarrassed than frustrated, and responded to the inability to tell me when she had her stroke by shaking her head and pointing to the next person to introduce him or herself. Some people with aphasia also had memory problems, which complicated the experience of time further. Others were able to comprehend number concepts but naming, writing, and manipulating numbers was hard. The experience of time was different for every person with aphasia. Merleau-Ponty highlighted the notion of a subjective experience of time: "Constituted time, the series of possible relations in terms of before and after, is not time itself, but the ultimate recording of time, the result of its passage, which objective thinking always presupposes yet never manages to fasten on to" (p. 481-482). Aphasic patients demonstrated how language and conceptual knowledge is related to the experience of time. Changes in language ability modify past memories and representations of the future. Many people with aphasia could not think of past memories in terms of exact numbers and objective time language. Some also had deficits in verb form production and comprehension (e.g., verb tenses), meaning that conveying or understanding time references was impaired. People with aphasia, who may not understand number concepts, experience time in an especially fragmented and inexpressible way because the representation of time can be an issue.

CDs alert us to the need to consider the relationship between language and power. The ability to communicate renders people present as a meaningful part of the environment. However, persons with aphasia can be seen as invisible or object-like because of their language impairment. They have lost their ability to communicate and the tool by which the disorder can be addressed or mitigated (Goffman, 1968). Because aphasia is a CD caused by brain damage, the disempowerment persons with aphasia potentially experience is attributable to their acquired neurological impairment rather than a life-long disadvantage. The experience of aphasia can be

depersonalizing because people feel role loss and confusion over their difficulties that began

suddenly and typically later in life. This feeling of neglect is supported by analyses of texts that

present descriptions of aphasia for SLPs and support groups for people with aphasia and show

that across the texts the experience of aphasia was depersonalized (Armstrong, Ferguson, &

Mortensen, 2011; Ferguson, 2014). Therefore, when aphasia is socially constructed as a problem

of the other, people with aphasia become the objects of discussion rather than agentic beings in

their own right.

Chapter 5

Experience of Human Relations

Lived Human Relations (Relationality)

Chapter 4 discussed the challenges of living with CDs in terms of space, the body, and time; however, central to the embodied self is its relationship to the world, ourselves, and with others (Merleau-Ponty, 1974). Husserl (1981) explained how intersubjective intentional experiences make other people present within one's lived experience. We do not experience ourselves as self-contained units, but as part of a community where others are constantly influencing and affecting our lived experiences and shaping the way we are aware of ourselves and others. Reality is socially constructed, though without intersubjectivity there is ultimately no social reality (Berger & Luckman, 1966). Most of our assumptions, expectations and prescriptions, indeed, are socially derived. Specifically, illnesses are framed differently based on time and context, which shapes illness narratives. Illnesses are embedded within cultural meaning, are socially constructed based on how individuals come to understand their illness, and are developed by claims-makers and interested parties, such as clinicians (Conrad & Barker, 2010). Meanings of illnesses, of course, go beyond biology. For instance, leprosy and HIV/AIDS have historically been framed as highly contagious and repulsive diseases (Epstein, 1996; Gussow & Tracy, 1968). Thus, illnesses are as much social products as medical-scientific ones. This chapter will focus on the lived experience of having a CD in the context of relationships with others. Special attention will be given to how social settings establish normative expectations, and how stigma arises when those expectations are violated. Stigma derives from social reactions that lead to discriminatory practices (i.e., enacted stigma) and the expectation of discrimination and devaluation (i.e., felt stigma). This chapter will use data from all four

interviews I conducted with SLPs, my observations from the Aphasia Weekly Groups and Aphasia Community Group, and aphasia forum websites. Unlike chapter 4, this chapter will incorporate experiences of childhood CDs more broadly.

A common theme across the interviews with SLPs was that language is central to our being within the world. One of the most significant experiences with language happens "in the face-to-face situation, which is the prototypical case of social interaction" (Berger & Luckman, 1966, p.28). People communicate through spoken language and non-verbal language. While most of us may take language for granted, acquiring a CD puts into perspective the importance of being able to connect with others through language. Allie, a first year graduate student, became interested in speech-language pathology after taking linguistics courses and understanding how communication shapes our social roles:

> *It impacts them immensely. I mean humans are social creatures so take away the ability to speak or communicate and it's horrific. So you know these people, their place, their role, their family has been drastically altered.*

Justin is an experienced SLP for over 40 years and has given presentations to raise public awareness about aphasia, was involved in an art installation about aphasia, and helped create a documentary film about aphasia. Through his work, he has seen how important the ability to communicate is.

> *You know language is extraordinary. I think it's the most incredible gift we have as a species. It's also very fragile and it's so ubiquitous, it's so everywhere. It's so taken for granted that we don't ... I mean we say you don't realize something is treasured until you lost it like people who can't walk or you know basic human functions. But human communication I think is at the top of the list and when it's gone or even temporarily or mildly impaired, it's a huge, it's a huge loss for the individual because we define ourselves by how we vocally present ourselves to each other ... Imagine that you just suddenly wake up one day and you lose that ability to share that with somebody. That's sinew, s-i-n-e-w, the connective tissue that connects us to each other, and when the mechanism to do that is disrupted, it can be devastating.*

In order to understand life's problems, we need to pay attention to stories and how they are told.

Chronic CDs in particular warrant articulation of illness experiences because the very nature of

them complicates the ability to express those narratives. Communication is a social activity that

starts in infancy. Jackie, an SLP who works with children, also spoke to how critical language

development is to social functioning. Children have to develop the ability to speak as well as

interpret social cues and the interactional rules of communication.

> *I have to keep in mind this age range and all. 5-10 is such as level of language growth, a huge portion of development and not as huge as those first three years, think from birth the 3 the things that you learn communication wise but then you overlay or put under the communication part all the academics and all the social language stuff that kids are learning in between the ages five and ten.*

Relationships – be they with families, friends, other loved ones, or strangers – are very

important to social life, and people with CDs are no exception. Many relationships deteriorated,

but sometimes new ones emerged. Individuals with aphasia mentioned that marriages and close

friendships have deteriorated because not everyone can handle the responsibility or commitment

of helping a loved one recover from aphasia or even the witnessing of such hardships. Friends

and family can either be too overbearing and take away the aphasic person's sense of

independence, or they can abandon the aphasic person in their time of need. Justin has facilitated

support group sessions for both persons with aphasia and caregivers and spoke to the struggles

both groups face:

> *Some family members are incredibly supportive and helpful, some are almost too much so, maybe out of attentive parenting or a sense of guilt, they almost smother the person with the disorder and they will talk for them or do for them even more than they need to and so I often try to have either myself or graduate students tell the client and tell the family members of the client to develop a system to wait until the person with the condition needs to assistance. There's a certain amount as one person put it "dignity in struggling." To let the individual try and convey what they want to say, and if it gets to the point where it's not happening, then they can say I need some help.*

A white woman in her 50s spoke at the Aphasia Community Group as a caregiver for her husband who had a stroke a couple of years ago. He owned a well-known restaurant until his stroke, and when I saw him he was severely language impaired and confined to a wheelchair. The wife found being a caregiver and seeing her husband seriously disabled to be overwhelming:

> *It's surprising when your husband has a stroke who abandons who. And then people you'd never expect to help are there for you.*

As has been unduly reported with various ailments, being the primary caretaker for someone with a CD can be draining, and it is important to make sure these individuals have extra support so they do not burn out. Caretakers described how their role demands patience and empathy, and they are in this role 24/7. The topic threat "What best helps in this situation?" on the *Daily Strength Aphasia Support Group* forum was created by a husband who struggled to get his wife to therapy and felt emotionally exhausted.

> *I cannot get her to understand that she needs to go to therapy … I have all these feelings inside and sometimes feel as though Im going to collapse. Someone give me some ideas, please … Im crying for help and understanding of the horrible situation. (http://www.dailystrength.org/c/Aphasia/forum/7846999-best-helps)*

Unlike my participant observations, the aphasia forum websites included dialogues that were exclusively between caregivers. Specifically in this thread, six out of the seven replies were from other caregivers who expressed similar experiences and frustrations. The other reply was from someone with aphasia who offered advice, including ways to "think out of the box" and design at-home speech exercises. There is also much loved ones need to learn in order to help people with aphasia. People have to talk slower to individuals with aphasia and be prepared to try to help figure out what they are saying. The nature of friend groups and interactions themselves change. Caregivers are constantly in aphasic peoples' space and become integrated into their interactions with anyone else since they may be put in positions to speak on behalf of persons with aphasia.

When parents accept that their child is "not normal" or has "significant problems" with his or her speech, they may reexamine their expectations and conceptualization of "normal children" (Francis, 2015), but they can also be overbearing or ignore the fact that their child has a language impairment. They may have a hard time accepting the fact that their child needs help and do not comply with the home programs that SLPs create. On the contrary, parents may also harbor a lot of grief because of the deep empathy they feel for their children and the challenges they face with their language disability (Francis, 2015).

The two SLPs I interviewed that worked in school settings talked about how there is confusion among parents between normal language development and a clear CD as well as the government regulations SLPs are under to give their services. Jackie felt pressure from parents to extend her role as an SLP beyond what legal regulations allow her to do in the school system:

> *Parents overall are just completely thankful with their kid, that's generally the feeling … and then there are some parents who disable their child. You try to convince them he or she has done really well, they're really functioning well. That sometimes can be hard because we have to stick by the regulations, and some parents are like "keep giving them more help," but we have to stick to the laws for what is feasible and appropriate education. So that's the other range of parents who want more from us. I understand you may want more but we're only regulated to give you this, so if you want more you have to go elsewhere.*

Sarah is an SLP who has worked with children in towns of varying socio-economic statuses, and observed that parental reactions depended on class:

> *My first job out of college I worked in a town that serviced five different towns, we were a collaborative. Five different towns. And we were in, really more or less three that were pretty affluent … the way it usually worked out was that those affluent parents were like, "I want services for my kid, fix this now. I want him to be perfect he has to go to Harvard." And the less affluent families were often almost offended when you said their child was developmentally delayed. You know we want to give your child speech services and "he's fine, he's just like me he's fine."*

Jackie and Sarah suggest that, particularly for more affluent families, many parents adhere to Frank's (1997) restitution narrative, which assumes treatment will ameliorate or fix children's CD. Children's problems impacted parents themselves, and they felt compelled to actively "cultivate" the children's well-being through therapy instead of believing that children will develop "naturally" if they are safe and loved (Francis, 2015). The ambiguity of many CDs, especially in childhood, reflects the social construction of disability. The body has an impairment (i.e., language ability) while society creates the disability through regulations over what constitutes a language impairment that warrants support services (Oliver, 1996). There is nothing inherent about CDs that make them stigmatizing; rather, the social response stigmatizes CDs (Conrad, 1987). Parents may have stronger or more relaxed expectations regarding language ability, which may conflict with government regulations. Disability cannot be reduced to a mere biological problem located in an individual's body because the physical and social landscape of society reinforces what is considered "normal" or disabled (Conrad & Barker, 2010). Some parents disagree with SLPs on what is considered within the realm of normal speech for children. While this shows the tension between lay and medical knowledge with respect to the cultural legitimation of symptoms, it may also suggests that parents may engage in stigma avoidance and deny that their child has a language impairment in order to create positive impressions of their children and themselves (Goffman, 1963).

Stigma

People with CDs can become stigmatized when social others are confronted with evidence of an undesirable attribute that differentiates them from the norm. Stigmatization occurs during shared speech encounters when the person with the speech disorder fails to follow social norms of verbal communication, creating a feeling of uneasiness for all actors involved

(Butler, 2013). This feeling of uneasiness is related to the social stigma of dysfluent speech. CDs can be considered an invisible, or concealable, stigma because language impairment is not visible until a speech interaction. The cognitive difficulties associated with concealing can lead to emotional difficulties and distress (Ullrich, Lutgendorf, & Stapleton, 2003).

However, social interactions typically demand that people speak; remaining silent may have several negative consequences for the speaker, such as not obtaining information, eliciting negative responses from others, and social exclusion (Gluszek & Dovidio, 2010). Justin, an SLP who facilitates the Aphasia Community Group, has heard numerous stories from clients about the struggles of having a language disability:

> *More than many disabilities, aphasia has sometimes been called, or referred to as an invisible disability because although the person might be in a wheelchair, they might have a brace, that may not be the most obvious thing until they try and open their mouth and talk or until somebody asks them a question and they struggle to answer it. Aphasia by its nature is more invisible and so we have to try to find ways of educating the public that disability comes in many forms and not so much focus on the "dis" part but the "ability" part.*

This quote exemplifies that the coping demanded of people with disabilities is less a function of their impairments than the mode of organization of society and the attitudes of non-disabled people (Finkelstein, 1980). Disability places the person with a CD in a difficult situation where others react to him or her with great ambivalence, ranging from gross inattention to embarrassing overconcern (Zola, 1982). Persons with aphasia said they were talked down to, spoken to loudly as if they are deaf, not given time to finish sentences because others finish phrases for them, corrected for every language mistake, and they feel judged for trying to use alternative methods of communication (e.g., gestures, pictures from a communication book, iPad or computer communication system, etc.). Likewise, Justin said that persons with CDs felt stigmatized in interactions:

Well the top things have been they assume the person is in psychiatric trouble, they assume they have a psychiatric disorder, they might assume they're deaf or hard of hearing and so they increasingly they increase their voice ... They may come to the conclusion that they are mentally challenged, that they may have an intellectual disorder because they can't respond, and also if there's an accompanying physical impairment like in hemiplegia or a facial asymmetry that contributes too... because there are some people who get it and there are some people that don't and what I've heard repeatedly over the years and over decades is people going out in public to restaurants and banks and retail and other interactions with people who have no idea ... And the last thing that ever occur to them is that they just have a disorder of language.

This quote is an example of enacted stigma where persons with CDs are unfairly treated by others. They are given labels that do not correspond to their actual identity or are just unkind. Similarly, previous research has found that stereotypes of stutterers include assuming that they are nervous, incompetent, mentally ill, or are deaf individuals (Altholz & Golensky, 2004). Allie, a first year master's student, also understood that persons with CDs are often labelled as cognitively impaired:

I think that one of the biggest misconceptions is that you have a major cognitive impairment and you are no longer smart. And so people start taking away responsibilities from you. And they just treat you differently. They think, "Oh you're seeing a speech pathologist, you're receiving these services, you had this injury to your brain" whether it be a stroke or tumor and you're no longer intelligent and that's not the case. You can have a communication disorder and be extremely successful and intelligent.

During interactions, language is strongly connected to competency and intelligence. Many people incorrectly assume that language impairment is directly related to intelligence and ignore the individuals with aphasia. The speech-pathologists and individuals with aphasia I talked to felt that overall people want to be helpful, yet, the stigmatization of aphasia is socially debilitating for those who have the disorder. Persons with aphasia felt socially isolated and noted how difficult conversations are with others. One white woman with aphasia in her 20s was getting her PhD in chemistry when she had a stroke and was frustrated that other people are not always patient or willing to let her talk. She could not complete her PhD, and is now working towards a

managerial position at CVS. Overall, she was a very positive person and friendly, and wanted to become more involved in advocacy work for aphasia. Her advice was:

> *They don't try to know me. Need patience, don't talk for me.*

This woman experienced enacted stigma in the form of social exclusion. Furthermore, a white male in his 50s who came to the Aphasia Community Group with his wife felt that after his stroke he experienced a loss of identity. Having a language impairment appeared to represent a loss of humanity and dignity.

> *Your own experience is silenced, your identity gone. But I'm good at reading body qualities.*

According to Goffman (1963), "mixed interactions" between stigmatized and nonstigmatized persons can be challenging to negotiate because stigmatized people, like those with CDs, feel unsure of how social others will identify and receive them. They essentially feel defined by their stigmatized disability and resist such conflation.

The speech-pathologists who worked with children tended to talk about how children with CDs can be seen as "immature" as oppose to "cognitively impaired," "psychiatric," or "unintelligent." Sarah, an SLP who works with kindergarten and 1st grade students, stressed that parents and teachers change the way they interact with children who they think are immature because of a CD. She remembered during our interview that an audiologist told her it is not good for a child to be seen as the "class pet" or "baby" of the class because this will impact their development and learning.

> *I think the thing that bothers me more is those cognitively intact kids who have significant articulation errors. Like my child last year with cerebral palsy … So, what does that do to your self-esteem? You know, because of her cerebral palsy she was always drooling, so that alone would make her peers think that she's a baby. She couldn't be understood clearly, and the saddest thing about that is, we met with her family and so on, is that they didn't ask her to speak because they knew she had a hard time … you know teachers looking at a child like that, as somebody who they're not going to question because it's*

going to put them on the spot well that's going to impact their learning. It's easy to assume that they're immature across the board because their language is immature.

To minimize prejudice, many people with CDs choose to be silent and socially isolated. According to Justin, persons with aphasia avoid public interactions; and Sarah mentioned that children isolate themselves from peers and chose not to participate in class. Constantly monitoring the risks and benefits of speaking in public can be draining, and prolonged anxiety over anticipated stigma and discrimination can negatively affect health outcomes (Puhl & Heuer, 2010). Meaningful relationships may become restricted. Stigma prevents people with aphasia from having the benefits of shared knowledge, experiences, and interactions with others.

Factors that Affect Stigma

Stigma is not universal across CDs and is dependent on contextual factors. The speech-pathologists and individuals with aphasia I talked to identified three factors that affect associated stigma: age, obtrusiveness, and knowledge. These factors have been corroborated in previous research as influencing illness related stigmas. For illnesses that are framed as aging diseases, being diagnosed at a young age is considered more stigmatizing and a disruption to one's biography (Beard & Neary, 2013; Faircloth et al., 2004). Obtrusiveness has been defined in the literature as "failure to sustain the many minor norms important in the etiquette of face-to-face communication" that "can have a very pervasive effect upon the defaulter's acceptability in social situations" (Goffman, 1963, p. 129). Thus, individuals with CDs are disadvantaged in navigating an activity that is central to defining normative behavior. Also, knowledge about an illness contributes to how it is publically framed as a stigmatized condition and influences the availability of resources people have to learn more about their illness (Beard & Neary, 2013; Smith et al., 2011).

Both speech pathologists who worked with children mentioned how stigma and discrimination is not as issue between young peers, and many young children do not even notice language disorders but "learn" to see difference. Discrimination based on language ability is not innate, or in other words people are not born to see this kind of difference. Jackie, an SLP at an elementary school, has witnessed children with various degrees of language impairment interact with each other:

> It doesn't come into account as much when they're younger because they're so self-centered anyways. And there tend to be more adults around, so I don't find little kids are picking on each other for communication disorders. I do think that as kids gets older there's definitely more of an awareness ... It's not like "oh he or she is worse than me" but that they're different and that's certainly a natural development for kids to start to be aware of differences of themselves and other people. What is really positive that I've seen is, and again I think it's because of the school environment and the push for acceptance and an inclusive model.

Sarah works with even younger children and also does not see stigma or discrimination because of language impairment in this group:

> We can say with confidence at the kindergarten and first grade level, peers don't even notice. They really don't. It's rare that a peer would notice something like that. The bigger issue is when that kindergartener or first grade child has an older sibling. And the other siblings have friends coming over and now you've got a third grader who wants to mock the five year old.

It seems we are socialized to "see" some disorders in certain ways. That is, CDs are socially constructed as meaningful and negative rather than simply different.

Besides age, another factor that affects stigma is obtrusiveness. Sometimes people with CDs have facial or bodily disfigurement (e.g., cleft palate), aids for motor movement (e.g., wheelchair, brace, cane), or multiple disorders that are very visible during face-to-face interactions. Such persons with aphasia often felt that they were stigmatized before they even spoke because of co-occurring disorders or impairments. Thus, some people with CDs are managing both visible and invisible stigmas. Physical impairments can make movement through

the social world complicated and sometimes inaccessible. Jackie said that the more severe the

physical and language impairment, the more stigmatized people feel:

> *I think the obvious ones are that people would notice the most, like stuttering, certainly because they are right out there. I do think that in articulation disorders if there's really a clef palate, something more motorically based, something that they tend to be more obvious or if a student is multiply impaired, if they have cerebral palsy or some other sort of motor-based speech impairment. And then you switch over to the autism spectrum to kids who aren't communication effectively or they're screaming at an assembly, not necessarily out of behaviors but that's just who they are … So I think that's maybe not a clear enough answer because it's not CDs but it can be a big part of multiple other disorders, and those are the ones that have the most stigma attached to them and definitely the most noticeable.*

Justin primarily works with persons with aphasia as a result of stroke, and many clients have

braces or are in wheelchairs:

> *And then of course the physical disability that accompanies so many strokes, visual and motoric and walking and ambulation, and they have to use anything from a brace to a quad cane to a walker to a wheelchair. That can be very limiting. Very painfully slowly our culture and our infrastructure is becoming more disability friendly with things like ramps and things but it's not happening fast enough.*

Lastly, lack of knowledge about and exposure to CDs can increase stigma. As has been

reported with so many other ailments, people who have friends or family that have a CD are

more likely to understand the experiences of someone who has a CD and are more empathetic.

Knowledge about CDs can decrease the fear and uncomfortableness that lead to stigmas. Like

anything else, exposure is key. Justin said,

> *Sometimes people are intolerant, and they just hang up the phone if it's one the phone or they'll just try and get away from the person and other people will say "take your time it's fine I understand, my grandmother or my friend or so and so had a stroke and so I understand." So it's sometimes getting your foot in the door and having people get it and then the world can open up for them. So it's really kind of a crash course that you have to take or perhaps teach over and over again every time a person with aphasia or some kind of CD interacts with somebody who is unfamiliar with it, they might become afraid. Not the person with the disorder but the person interacting with them and the conversation.*

Like all SLPs, Jackie is very familiar with and exposed to CDs, and recognized that she may interpret interactions with people with CDs differently than others:

> *And then certainly if you think, you know I think it's always cool if you're at Dunkin Donuts and you see someone using at iPad that they're communicating with and using ProQuo I'm like awesome! Whereas other people are probably like what?*

People with CDs can feel very isolated because of stigmas. The aphasic individuals I observed discussed having periods of depression after acquiring aphasia and many did not have a strong social support network at the time to turn to. Some people with aphasia isolate themselves because they are embarrassed that others will not be able to understand them and they will be humiliated. They do not initiate conversations and they try to avoid going out in public. Disclosing their condition to others is challenging because not many people know what aphasia is, and people are not always patient with individuals who have aphasia. The woman with aphasia from Chapter 4 who was frustrated that she was not treated like a competent person in the doctor-patient relationship said during a "Toastmasters" group that she felt very uncomfortable disclosing her condition:

> *I did not go to my reunion … school … high school because I have to tell everyone about aphasia. My good friends, they know, but that's all. Reunion would be too much people.*

At the same time, I observed Justin saying to those affected many times that those with aphasia should not feel like they have to hide their condition or feel ashamed of it. He stressed that in some ways there is a dignity to "just letting it out" for some people.

Many persons with aphasia felt blamed for their condition and as if they did not receive enough sympathy. Contrary to Parson's "sick role," a lot of individuals with aphasia do not enter a role of "sanctioned deviance" (1951). Because improvement is slow moving and tedious, people with aphasia who do not have normative health are constantly reminded of their otherness (Varul, 2010). Accordingly, they have a physical and moral responsibility to constantly engage

in rehabilitation. However, even those who do try and get treatment and make their health a priority are still deemed responsible for their condition. They feel that a lack of empathy and understanding regarding their disability contributes to their stigmatization. One woman in her 30s with aphasia as a result of a TBI experienced felt stigma:

> *There is a big fear factor and not knowing about us. They are angry, like, 'How dare you be broken?'*

She felt shame, devalued, and "not as good" because of her condition. She mentioned that she had a difficult relationship with her mother and sister because of her aphasia. Some individuals with aphasia felt that people simply did not understand what they were going through. A white man in his 60s who was confined to a wheelchair said,

> *You have no idea what it's like to walk in my shoes. You can't know until you're there. It is sudden and quick.*

The apparent lack of empathy many individuals with aphasia perceived from social others demonstrates to them how few lay persons, family members, or health professionals are able to accept disabled people on their own grounds (Kleinman, 1988, p.168). However, unless an individual does not speak, it is nearly impossible to cover up a language impairment in social contexts, preventing people with aphasia from "passing" as a nondisabled person.

Important Social Relations

Despite these "negative" interactions reported above, some people with CDs find environments that promote positive relationships. Support groups, for example, provide the opportunity to rebuild confidence with talking, interacting, public speaking, and sharing ideas. In this environment people with CDs can find what Goffman referred to as "sympathetic others" (1963, p. 19). These sympathetic others may or may not share the same stigma, yet can provide moral support, comfort, and acceptance as a person. The Aphasia Weekly Groups were places to

talk about shared experiences and solve everyday problems (e.g., how to tie your shoes with one hand, how to ride a bike with a leg brace, how to order food at a restaurant, etc.). Aphasia Weekly Groups allowed persons with aphasia to speak freely and not worry about how their speech sounds. They did not have to apologize for their language, and they had more freedom in their interactions, movement, and speech. They could act on potential conversations and activities. Their being-in-the-world was more engaged with others. Allie said that they had the ability to share stories and ideas with someone other than family or a doctor and this helped them feel that they are not alone with their hardships. Support groups created social solidarity and a collective conscience for people with aphasia. During the Toastmasters group, one male would fist bump anyone who had an especially good speech, and they generally gave each other positive feedback no matter how someone's speech went. A white woman in her 50s who acquired aphasia through a traumatic brain injury came to Aphasia Community Chorus and Aphasia Book Club because they help bring meaning and purpose to her life:

> *The people here at these groups … they are my family. They give me a reason to get up in the morning. It is helpful to know the other people with aphasia.*

Allie has observed support groups for people with chronic illnesses other than aphasia and saw similar, positive results:

> *I think support groups are definitely helpful. I went to a Parksinson's support group recently and that was really enlightening on my end and also you can tell the people that go there have these really intense friendships, and they confide in each other they tell stories about vacations and experiences with doctors who don't understand what they're going through. And the simple things like buttoning up their shirts they share tips on how to you know get dressed more easily and to kind of cope with their fine motor skills diminishing. I think support groups are probably, from what I've seen, the most helpful things.*

Justin, who facilitates Aphasia Community Group and attends Aphasia Weekly Groups, agrees with Allie that support groups create what sociologists call "social solidarity" for individuals with CDs and combat social isolation too:

> *I think groups and resources like the aphasia resource center the aphasia community group can be very helpful in kind of breaking that isolation. And just going to a session and meeting other people with the same affliction, I can't tell you how many times people, either family member or the person with the disorder themselves, has indicated to me "I never knew anyone else had this". And it's a huge, like weight lifted off of them when they just started to be in the company of other people that are struggling and they feel that they see that they're not alone, that there's a community.*

Posts from *Daily Strength Aphasia Support Group* forum also demonstrate the value of support groups. One SLP posted in the section specifically for professionals that groups are helpful for both people with CDs and SLPs in order to improve treatment strategies:

> *The peer groups are an extremely valuable asset to the district and provide onward support and allow for adjustment to the community after the "rehabilitation" has ceased. Members give new and old members ideas. They share real life frustrations and solutions - many of which I would never have looked at. As they are the people who live with aphasia they have taught me a great deal about what is a good approach and what isn't. I have reflected much on my own practise from these groups and changed much of my outlook.*
> *(http://www.dailystrength.org/c/Aphasia/forum/6676050-need-find-acceptance-rgmoms)*

Beyond the individual therapy people with aphasia receive, support groups provide additional outlets for hope and improvement. Overall, the people with aphasia in Aphasia Weekly Groups repeated consistently that these groups helped them improve their speech in addition to their speech therapy. One white male in his 60s who attends Aphasia Community Chorus said:

> *Two years ago, couldn't speak. Five years post stroke, this has helped.*

A white woman in her 30s with two young children was a physical therapist (PT) and had a stroke during a hospital shift. She is currently working towards getting her PT license back, and mentioned that her language has improved significantly since participating in Toastmasters.

> *When I first came here I couldn't talk. But today I'm writing bullet points and speaking more natural.*

In Toastmasters this woman was working on her public speaking skills. However, she also felt that she improved her reading through spending time with her children. Her four-year-old son reads *Goodnight Moon* to her every night, and it is the same book her mother read to her when she was little. She and her son are teaching each other language and working on their reading skills together. Maintaining close bonds with family, friends, and caregivers is crucial to people with CDs.

Aphasia forum websites provide ways for people with aphasia and caregivers to virtually connect with each other. On the *Aphasia Hope Foundation* forum, an SLP posted on the topic thread for people with aphasia that she was looking for a pen pal for one of her patients. Two people with aphasia expressed interest and would appreciate having a pen pal (as of 4/18/16). Thus, forums create opportunities for people to communicate with online communities at large as well as build relationships on a more personal level.

As for children with CDs, the SLPs that worked with them highlighted instances when they saw positive peer relationships between children with and without CDs. Integration helps all children's social competence, confidence, development, and learning. It also creates acceptance among peers and can reduce stigma. If children become friends with peers who have a CD, then it is not seen as abnormal or foreign. Jackie believed that integration can reduce the stigmatization of children with CDs:

> *I've seen really nice mentorships; I use the word loosely, older students working with younger students that have communication disabilities. Again it is adult initiated but I think that helps with the overall picture of acceptance, and maybe not a stigma for it.*

Likewise, Sarah found that it is important for children to become friends with peers who may have a CD:

To have peers that also have special needs might be a good thing … He [a boy] had a friend in kindergarten … he's still here … he had a little friend in kindergarten last year who just loved him. "I just want to sit next to him, and he's my best friend." And you could tell it was sincere. He wasn't the class pet. … So making those true social connections I think is important for them to be with people they'll feel comfortable being around.

Positive perceptions of quality of life for young adults with CDs are largely linked to strong social support from family, friends, and other individuals (Johnson, Beitchman, & Brownlie, 2010). However, the SLPs I interviewed disagreed on the prevalence of these positive, mixed relationships. Jackie believed that in general there was acceptance of peers with CDs:

I'd like to think that people are more accepting and diversity of more expected. Certainly in a school setting, in an elementary school setting, I mean from day one everyone is different so I think kids are certainly exposed to all sorts of different communication abilities. And there is a level of acceptance, I think that's good.

Yet, Sarah was more concerned about peer acceptance, and saw many true relationships fall apart. According to her, finding genuine mixed friendships are rare.

When I think of fears I think most of those cognitively intact, low communication skill kids who really had the potential to have a very full life … The little girl who I ran into the street with cerebral palsy, when she left here … her mother said, "I know she's happy right now, but it's not going to be long before she realizes she's not like the other kids, and she's going to be isolated, and she's not going to have a peer group." And she ended up, she went to a patent school for a couple of years but then she ended up at an out of district place where there were other kids with cerebral palsy because, you know, you hear some nice stories here and there and everywhere, but I worry they're not going to be asked to the prom, I worry that they're not going to have true friends.

While true relationships between children can be hard to find, Sarah believed that children with CDs are at higher risk of social isolation than children without CDs. She said that when she saw positive relationships between a speech impaired and "typical" child, she worried that they may not last through adolescence.

Suggestions for Practice

The SLPs I interviewed brought up various ways to improve treatment of CDs and reduce

the stigmas associated with CDs. They all emphasized that medical professionals should treat

their clients with dignity, respect, and awareness for their strengths and weaknesses. Allie

mentioned that as an undergraduate she had to learn how to not insult her clients' intelligence:

> *I was like "can you just tell me whether or not you know them" and he just had to say*
> *"yes, yes, yes". And I was like, "Great job, excellent." And he just looked at me and*
> *rolled his eyes and he said, well obviously he didn't express himself very well but I was*
> *like "crap I should not have said 'great job.' Obviously you're a very intelligent man and*
> *you know how to point and say 'yes.'" So it's those very delicate situations that as a*
> *student you're not really going to know automatically. So I found that to be very kind of*
> *awakening like I need to watch myself basically because this person is probably a lot*
> *smarter than I am.*

This idea that SLPs can treat their patients as inferior, even if by accident, was corroborated in

online forums. One caretaker of her husband who posted on the *Aphasia Hope Foundation* forum

said,

> *My husband did not like the clinical approach of the speech therapist. He was intelligent*
> *and very much aware of his limitations and felt frustrated that he could not tell her to*
> *stop talking down to him and to give him more time to find the right words or to*
> *understand an instruction.*
> *(http://www.aphasiahope.org/forums/?wpforumaction=viewtopic&t=40511.0)*

Justin's philosophy as an SLP is that meaning is more important than grammar, and SLPs

should be aware of their clients' ability to convey ideas and stories regardless of their grammar:

> *Quite frankly I don't care about the grammar and the syntax. To me it's the essence of*
> *sharing information and so to me I think helping people find successful ways and creative*
> *ways of sharing narratives, stories, and anecdotes about their day and their moods and*
> *their feelings and their desires and their frustration and the whole range of a human*
> *experience is key, it makes the person who is sort of with the CDs locked in by their*
> *language affliction feel more connected and breaks through that isolation. I think it's*
> *essential to go in that direction. Not as the expense of the more academic resource*
> *oriented laboratory based research, but in addition to it.*

The Weekly Aphasia Weekly Groups that I visited were a space where individuals with aphasia could take risks (e.g., learn to sing, present a poem, etc.) and boost their confidence in speaking. SLPs and persons with aphasia agreed that it is easier for people with aphasia to talk about things that they were passionate about. Many times during my participant observations, individuals with aphasia tried to read from notes or talked about irrelevant topics and their speech worsened. They were able to convey ideas better when they engaged in spontaneous, natural, and purposeful language. Grammar was rarely corrected by the SLPs because the Aphasia Weekly Groups were places to have fun and engage with language material (i.e., songs, speeches, and novels). The belief was that when they engage with language more, they became more independent and confident in their social lives. Participants on the *Aphasia Hope Foundation* forum supported the importance of encouraging people with aphasia to communicate, even if it is not perfect. One person replied to a post from a mother living in Nairobi, Kenya whose 18-year-old son suffered a TBI from football:

> *Remember that sometimes aphasia can involve understanding problems as well as speaking, reading and writing problems. To make sure he understands, keep things simple. He should not be frustrated in his communication and should not be over tired. You may find that he is better in his home language than in English so that can be encouraged. Even if he mixes up his languages it does not matter. The important thing is that he is able to express himself in any way possible. Even if he has a difficulty with his hand, he may be able to express himself in writing or drawing. (http://www.aphasiahope.org/forums/?wpforumaction=viewtopic&t=40289.0)*

This post shows how the act of expressing language trumps the quality of language, especially for people with aphasia. Justin and online forums suggest that this can help with long-term language improvement.

However, the misconception that individuals with aphasia eventually stop improving during treatment prevents them from regaining their independence. Unfortunately, health insurance companies use the concept of a "plateau" to terminate treatment coverage, which in the

end prevents people with aphasia from further improvement and reinforces the notion of a

"ceiling effect." However, recent research has shown that the idea of a plateau is a myth, and

people can continue to make gains when they are provided with the proper type of therapy

(Korner-Bitensky, 2013). Allie mentioned that because aphasia and CDs in general are so

variable and complex, there is no straightforward way to treat a given disorder:

> *Unfortunately it's your health insurance that's going to decide when you're all better,*
> *when you're not better, and of course they've probably never taken a speech class in*
> *their entire lives. So they wouldn't know. But you stop receiving sessions you stop being*
> *eligible to see a speech-language pathologist and that means you in a way you end up*
> *reaching a plateau because you don't have access to resources. So that's why people*
> *come to universities like UMass because we're desperate to have people participate in*
> *our research and that's how they get help but I think it's because people just think you*
> *can't go any further, you're done, so they stop offering new help. So if you could get rid*
> *of that concept of the plateau, you could probably make so many more gains.*

One African American male in his 50s who was a car salesman before his stroke believed that

even though he made small gains, he still had a lot of improvement left.

> *I know that I'm going up, but there's a lot to go on the mountain.*

This quote gives no indication that the man had reached some kind of "plateau." As with many

modern medical ailments, generalizing every person with aphasia to one prognosis and treatment

course is not reasonable. CDs affect everyone differently and can be hard to treat, but insurance

companies can pose barriers to accessing quality care. Unfortunately, most people with aphasia

find that their insurance coverage runs out before they are done with therapy (Cameron &

Wright, 2009). But, these quotes mentioned above suggest that SLPs and individuals with

aphasia understand that despite the slow moving course of treatment, gains can be made with

enough time and dedication.

All four SLPs that I interviewed explained that some clients, parents, and medical

professionals do not understand enough about what their job entails. They explained how even

some teachers and healthcare professionals do not understand the scope of their practice or what

qualifies someone for speech therapy. Many of the stigmas and misconceptions around CDs

could be mitigated if others knew how treatable CDs were and the value of SLPs as a resource.

Allie had some experience working with medical professionals outside of speech-language

pathology:

> *One of the biggest problems with this field is that a lot of people don't understand what a speech pathologist does. Even if you go into a hospital or go to a physical therapist, they don't fully understand like the scope of practice with an SLP. And I think if more people were educated about the purpose of the field it would kind of take away some of the mysteries surrounding communication disorders and what can be done for communication disorders.*

Likewise, Jackie felt that generally people do not understand the scope of work SLPs can do:

> *There is still definitely not an understanding of what my job is. I don't know if people think that communication disabilities or disorders are all treatable or not.*

This suggests that a lack of awareness about their practice reflects and reinforces misconceptions

about CDs. The public does not have enough information about how and when CDs are treated.

Jackie and Sarah felt a lack of awareness prevalent in the school systems. Parents did not always

understand what qualified their children for SLP services, and this could create conflict between

teachers, parents, and SLPs.

Even though there was sometimes a lack of communication between SLPs and parents,

many SLPs noted that parents' knowledge about their children was necessary in treatment. SLPs

granted that they see a narrow view of children and within a limited context and may even have

their own cultural biases and beliefs about conversations and interactions which can affect how

they give treatment. Therefore, it is important to have a give and take relationship where the

parents are on board with and can provide feedback about therapy. When Allie was an

undergraduate she worked with children. Even though she only worked with pediatric patients

for a brief period of time, she also saw the importance of involving parents in treatment programs.

> *One of the interesting things I've discovered trying to figure out why I am interviewing this person is that parents in particular know their kids better than anyone. They see their kids speak in multiple contexts. And that's not something a teacher or a clinician would necessarily notice. So they kind of have this holistic perception of what their kid can and cannot do and they're constantly around other children who are from a similar cultural or socio-economic background and so they have an idea of how their kid should be performing, especially if they're from a culture that is different than our own.*

These SLPs have an awareness of their clinical limitations and see the importance of involving family members in treatment. Families who take an active role in their child's therapy can make a big difference. One post on *Aphasia Hope Foundation* forum substantiates this notion of familial involvement:

> *To finding out what my family had gone through and still had there own side effects (they are victims also),and to see the love and faith they had in the ezpessions of there fasces when I woke up, I realized how lucky to have them and how presious life is ... Just being here I know they are going to be okay-and that has helped me get better. (http://www.aphasiahope.org/forums/?wpforumaction=viewtopic&t=141.0)*

This post also recognizes that it is no easy task for families to become involved in their loved-one's treatment. Western medicine assumes that people should take responsibility for their health, however, when they can no longer independently care for themselves, it is expected that their family becomes accountable for their health. Even Jackie and Allie suggested that parents or guardians should take personal responsibility in the health of their child, which is a Neoliberal value of Western medicine and society.

Overall, the SLPs I interviewed were optimistic for people with CDs. They hoped that their clients found a setting or "niche" that allowed them to grow socially and linguistically. While CDs are challenging, SLPs want people to understand that they are not a death sentence.

Of course, people with CDs still have strengths and abilities that can allow them to become

integrated into society. As Jackie stated,

> *I try to stay positive and think you know what I don't care you're not going to be a rocket scientist, it's fine if you're not a rocket scientist, we need people of all abilities and all levels of communication in society. You just hope that they learn enough that they can have a functioning job some day you know maybe a family, that's probably it.*

Sarah remembered seeing a play that integrated children with and without disabilities, and she

found this program to be a great way for children with disabilities to grow socially:

> *I was just floored. And I shouldn't been, you know? I mean all that to say I wasn't expecting that kind of a conversation out of a 21 year old just because he had Down syndrome. I mean he really was fabulous. It was so entertaining and it was so great to see. You know so programs like that. And I think it's important, again based on what that mom* [whose daughter had cerebral palsy] *had said, you know she's going to come here she's going to realize she's different … And then I think it's got to get though for these kids. And to have peers that also have special needs might be a good thing. You know unless it's a true friendship, and sometimes that happens too.*

People with aphasia also mentioned the idea of hope and found positives in having aphasia.

Many believed they were stronger and more determined individuals because of their experiences.

They have also met compassionate and understanding caretakers and clinicians. The young

woman mentioned earlier who was getting her PhD in chemistry before acquiring aphasia said,

> *I am now more sure of myself and my confidence. I am empowered. I have self-worth.*

One white woman in her 60s who developed aphasia as a result of a TBI has been going to

speech therapy for over 10 years and showed tenacity and resilience:

> *I have much determination and I am trying to defy the odds.*

Jackie mentioned that improved technology provides hope for decreasing stigmas because they

can reduce the visibility of speech, hearing, and physical impairments:

> *Probably with all the technological changes there's probably less of a stigma for people who need physical devices because everything has become so much smaller. Think of the same thing as hearing impairments which is another big section of CDs, and not talking deaf people as it's own subgroup but anyone who may need auditory equipment. Hearing*

aids are much tinier, you don't need a big strap on auditory trainers which is kind of old school. Everyone has tablets and are using their phones. Texting is completely mainstream, whereas deaf population they were the first ones to have text messaging that were able to use it that way. So I think there's definitely changes in that part of society that probably lessened the stigma.

However, there still needs to be more awareness and visibility of what constitutes CDs themselves. Many persons with aphasia said how their condition by its very nature silences them. That is, their speech impairment sometimes "discourages any group formation whatsoever" (Goffman, 1963, p. 22). Since they are limited in how they can advocate for themselves, it is also hard for them to gain access to treatment resources without caretakers or support systems that can help them navigate the social world. Justin specifically mentioned that there are certain demographics and social groups that need to be targeted and are underrepresented in treatment centers.

One of the ongoing goals of this aphasia resource center has been to do more community outreach ... to have some more in the community. I know that we have a disproportionate number of for instance ethnic minority groups ... I mean the reality is the percentages of stroke and aphasia in Latino, African American, and other minorities cultures and we are not a majority minority culture country ... A couple of years ago the demographics shifted so that as a nation we're comprised more of what we used to call minority ethnicities than let's say European white Anglo Saxon, so it's like 60% minority cultures and 40% and that's a big shift ... but we don't see that reflected in the people that come to for instance the aphasia resource center and other aphasia resource groups.

As these narratives suggest, individuals with CDs face stigma regardless of the invisibility of their language impairment. However, they also felt that age, obtrusiveness, and knowledge shape experiences of stigma. Older age, having multiple other physical and mental impairments, and being in situations where others do not know the symptoms of CDs placed people with CDs at a higher risk of experiencing stigma. There is a clear need to increase public awareness of aphasia as reveled in the responses of other people to aphasia (i.e., enacted stigma). However, social support groups provide sites for ameliorating the shame and isolation of

stigmatization associated with CDs. The findings from this chapter suggest that there is a gap in the understandings of people with aphasia and the understandings of the general public, including medical professionals. It also appears that the role of SLPs is widely misunderstood, which may contribute to stigmas of CDs and the treatability of language impairments. SLPs play an important role is debunking myths and stereotypes about those with CDs and can provide a voice for them. However, SLPs also have to be wary of the biases they bring to treatment approaches and the contexts in which they see clients. In conclusion, the social construction of aphasia and other CDs demands more critical examination through the frame of reference of people with CDs themselves. Whether one is talking to a child with cerebral palsy or an elderly person with aphasia, CDs challenge normative expectations of interlocutors and the ideological construct of Western thinking about agency in language (Ferguson, 2014). People with CDs cannot always uphold the normative role of speakership, too often eliciting prejudices from those around them. Normally, in speech interactions interlocutors fill in the blanks when someone forgets a word or pauses too long. Ideally, people talking to someone with a CD should aim for the delicate balance between collaborating in extracting meaning from conversations while trying to preserve the speaker's autonomy. However, there is something about CDs, possibly the social construction of the disorder, which makes others less likely to help and be sympathetic to their language impairment. This implies a power differential between people with CDs and those without CDs. The ability to use language and express ideas are a significant source of power in society. People with CDs who lack functional independence not only are assumed to be biologically inferior, but they are also exposed to a stigma that depicts them as "not quite human" (Goffman, 1963, p. 5). While helping each other to communicate may seem like a

common and humane thing to do during interactions, stigma prevents people from acting as sympathetic interlocutors for those with chronic communication impairments.

Chapter 6

Discussion and Conclusion

The experience of living with aphasia is complex, and in order to fully understand it we need to look beyond the biological perspective. This study used a phenomenological lens to examine four realms of lived experience (i.e., spatiality, corporeality, temporality, and relationality) and to explain how persons with CDs think about their disorder, the barriers they encounter in everyday life, how they cope with the disorder, and in the case of aphasia the experience of a dramatic loss of language through the onset of a stroke or the occurrence of a traumatic brain injury. Illness narratives are personal accounts that describe the subjective experience of living with an illness, disorder, or other condition (Kleinman, 1988). Personal narratives allow patients to tell their stories, and researchers can re-tell these stories in order to give these patients a voice. While we can track improvement through the objective evaluations of professionals over the various phases of recovery, we also need the perspective of the individual's cognitive and affective experience. Negating subjective experiences assumes that the disability is rooted solely in biology (Fine & Ash, 1988). However, as previous research has shown, communication is also embedded in social processes and contexts (Gallagher, 1993). Illness narratives allow researchers and healthcare professionals to think about illnesses and disorders in a more comprehensive and compassionate way and to create treatment options that are meaningful to their patients.

My thesis brings to light the importance of illness narratives in the rehabilitation of CDs. It is challenging enough for people with CDs to explain that they have a language impairment, let alone express what it means for them as human beings. The inability to use language normatively hinders people from showing themselves as thinking and acting individuals in

everyday life (Hjelmblink et al., 2007). For people with acquired aphasia, it is hard to describe to others how they changed after the stroke or traumatic brain injury and their current thoughts in a manner unaffected others can easily understand. This paper corroborates past research that focuses on physical impairment and how individuals with disabilities are forced to be excluded from spaces (Butler & Parr, 1999; Chouinard, Hall, & Wilton, 2010; Dorn, 1999; Golledge, 1993). People with aphasia feel invisible and their movement through the world is limited. Spaces are currently organized to keep disabled people "in their place" and "written" to convey to the disabled people that they are "out of place" (Kitchin, 1998). This paper mentions segregated schools for children with language disabilities and the lack of wheelchair accessible spaces for adults who had a stroke. Social relationships – which are already threated by their ailments – are also challenging for people with CDs because of limited spatial freedom. Communication is a constant, purposeful, and cooperative activity, and people with CDs can find it challenging to navigate the physical and social spaces of society (McCann & Higgins, 1992).

Communication is an embodied activity; however, people with CDs cannot use language to demonstrate their presence or body in typical ways. Freedom and intentionality of the body is limited for people with concurrent physical impairments. People's sense of corporeality changed after their stroke and they experienced a change in their self-concept because they could not maintain their past social roles. Previous research has also found that stroke survivors report a negative sense of self, reduced social activity, psychological morbidity, and settle for a restricted future because of their expectations of life with a disability (Ellis-Hills & Horn, 2000). People with aphasia demonstrated during my participant observations and on aphasia forum websites that the meaning of living with aphasia includes the temporal relation between the present and their stroke or TBI event. Even though they may not be able to express correctly or easily the

exact time since their stroke or TBI, their attempt to talk about it when they introduced

themselves to me shows its importance. Their concept of time can also be jumbled up and

confused because of their language impairment and possible concurrent memory problems. My

thesis expands on previous research by examining the experience of CDs, such as aphasia,

through spatial, corporeal, temporal, and relational frames. Past research has focused on

phenomenology in relation to stroke and the experience of physical impairment, medical care,

loss of self, loss of connection with others (Anderson & Whitfield, 2012; Burton, 2000;

Kaufman, 1988; Secrest & Thomas, 1999), and the development of depression (Robinson &

Starkstein, 1990). However, the current paper is organized around a phenomenological typology

that allows a better understanding of how stroke or TBI influences people's sense of space, the

body, time, and relations explicitly. It also is focused around aphasia, not just stroke. As Justin

mentioned in Chapter 5, the word "aphasia" is not widely used in public discourse, and survey

research has demonstrated that public awareness and knowledge of aphasia is limited (Flynn,

Cumberland, & Marshall, 2009; Simmons-Mackie, Code, Armstrong, Stiegler, & Elman, 2002).

Understanding the lived experience of aphasia, and not simply just stroke, targets the importance

of language loss across multiple medical problems and addresses the assumptions made about

people with aphasia.

The majority of my thesis aimed to understand how relationality shapes the lived

experience of CDs. Stigma is not an isolated phenomenon, but instead a central process in the

constitution of social orders (Parker & Anggleton, 2003). Stigma reinforces the role of "health"

of dominant groups, creates hierarchies between groups, and legitimates that ranking by

convincing the inferior groups to accept existing hierarchies. Sickness is viewed as a form of

deviant behavior (Williams, 2005). Parsons sick role viewed health as a functional prerequisite

of society, making illness dysfunctional and a form of social deviance that needs to be policed by the medical system (Segall, 1976). The sick role is a mechanism of social control. However, the sick role assumes that illness is a temporary form of deviance and people will return to their previously healthy state. Chronic illnesses, such as aphasia, are by definition not temporary. Applying the expectations and responsibilities of acute illness to people with chronic illness is inappropriate. Persons with aphasia are adjusting to a permanent condition, not striving to overcome a temporary one. In my paper, SLPs and people with aphasia reported that CDs are stigmatizing conditions. In particular, people with aphasia are assumed to be deaf, mentally ill, and cognitively impaired. In accordance with Goffman (1963), in our society language is deemed to be related to intelligence, and the stigma of aphasia can be socially debilitating as a result. Sarah and Jackie mentioned that children with CDs are assumed to be immature, which can impact their intellectual development and learning. Past research has also found that children with CDs are subject to being perceived as less competent then their peers without CDs (Davis, Howell, and Cooke, 2002; Gallagher, 1993, 1999). Both Sarah and Jackie touched upon the problems associated with children who have CDs in school, such as forming peer relationships.

The introduction and maintenance of language-impaired students into mainstream schooling is contested. Young children are exposed to social others in schools settings where they may be teased for possessing a stigmatizing threat (Goffman, 1963). At the same time, integrating stigmatized with non-stigmatized classmates and engaging in self-disclosure (i.e., sharing intimate information) can predict more positive friendships, empathy, and intergroup trust (Turner, Hewstone, & Voci, 2007). Further research should study the long-term effects and developmental outcomes of integration across a variety of childhood CDs.

In the current study there were some indications of courtesy stigma. Jackie and Sarah said how some parents are over-concerned about their child's communication abilities and want SLPs to immediately fix what they perceive to be a problem. Modern American culture assumes children as essentially "good" but lacking agency, and intensive parenting models are based on "children's fragility and the constant dangers they face" (Francis, 2015, p. 84). Thus, the stigma of bad parenting increases when parents are held responsible for the perceived "poor behavior" of their kids. Of course, parental association with a child with a disability is assumed because of parents' responsibilities as child raisers and carers (Gray, 1993). My research suggests that parents may feel blamed or responsible for their child's communication impairments. Sarah mentioned this was especially true for more affluent families, and constructions of "normality," "disability," and "deviance" can be different for middle-class families than families of lower socio-economic status (Francis, 2015).

Many CDs are chronic conditions that do not elicit much sympathy from others. People expect disabled people to try and "cover," "pass," or normalize their status (Goffman 1963; Kleinman, 1988). While everyone engages in impression management all the time, according to Goffman, "passing" can be a strategy used by people with undesirable traits in order to "pass" in public as someone "normal" (i.e., without the discrediting attribute; Goffman, 1963). The current study corroborates past research that suggests that concern over social interaction among people with language, speech, or hearing impairments leads them to avoid social situations and minimize communication (Van Riper, 1987). People who stutter employ passing strategies such as avoiding verbal interaction, substituting words that are easier to say, giving short answers, and not speaking unless absolutely necessary (Acton & Hird, 2004). Thus, those with invisible chronic CDs try and appear to be "normal," showing how one's virtual identity reflects back to

the idea of the body being normal and healthy and how "passing" as normal, when possible, is often desirable.

Having a concealable stigma poses distinctive problems. One of the only ways to cover or hide a CD is to not talk, which is problematic in social contexts and exacerbates isolation. If the individual with a CD speaks, the disability is revealed. If he or she does not speak, then social connections cannot be fostered with others. Research has shown that the mere act of hiding information about a stigma can be shameful by nature (Kelly, 2002). University students who possess a concealable stigma reported lower social confidence, higher anxiety, higher depression, and lower self-esteem than did visibly stigmatized and nonstigmatized students (Frable, Platt, & Hoey, 1998). Past research and the current study both suggest that concealability moderates the link between possessing a stigma and experiencing negative emotions.

In my research, many factors mediated the influence of stigma on social interactions. Stigma was seen as less of an issue between young children, less obtrusive CDs, and when people had knowledge or previous experience with CDs. My interviews, participant observations, and forums also revealed that certain activities promoted positive interactions. Support groups and positive mixed peer relationships and mentorships helped people with CDs gain confidence speaking, empowered their sense of self, and created an environment where they did not have to worry about being stigmatized for their language impairments. It is also important to note the emotional strain of being a caretaker of someone with a CD. Support systems need to be in place for both people with CDs and their caretakers.

Finally, my research has implications for clinicians and medical professionals. Clinicians should involve people with aphasia in dialogues about prognosis and treatment in a way that

regards them as thinking and acting human beings. Rehabilitation should involve the goals of the individuals with aphasia, such as the words and activities they want to do and the spaces they want to be able to occupy (e.g., job, leisure activities, playing with children, etc.). Because communication is a dynamic phenomenon rooted in biological, cognitive, and social processes, the body should be thought of as a tool for accessing space and human relations, not simply a biologically damaged tool. Personally, after conducting my research I now understand that aphasia is more than language impairment; it is a loss of a kind of being-in-the-world.

When people understand what it is like to have a CD, we can only hope that they are less likely to express prejudice and discrimination. Ignorance and overgeneralization of populations with CDs silences a group of people who struggle to have a voice in the first place. Educating insurance companies about CDs, such as aphasia, can help eliminate the concept of a "plateau" in treatment and can show the complexity of CDs. This could reduce the assumptions insurance companies make about people's quality of life with CDs and the benchmarks they reach in treatment. Furthermore, clinicians need to be aware of the role of SLPs and the scope of their practice. This could decrease assumptions that CDs are untreatable or unworthy of medical support.

CDs are troubling disorders beyond the fact that we cannot always "see" them. People with CDs have lost the ability to engage in the world with others in a fundamental way: communication. The largest barriers to a good life, it seems, show us that CDs are deeply social. Therefore, CDs are more than biological and neurological problems that cause language impairments. Merleau-Ponty (1974) refutes the simplicity of explaining aphasia in terms of cause and effect processes by saying that,

> If speech presupposed thought, if talking were primarily a matter of meeting the object through a cognitive intention or through a representation, we could not understand why thought tends towards expression as towards its completion (p. 206).

Clinicians should think about or explain CDs in terms of communication and being-in-the-world, not just the mechanistic production or comprehension of language.

Because a CD can be stigmatizing and devalue one's identity, further research should explore activities and treatment options that empower people with CDs. In Toastmasters, everyone clapped at the end of speeches and always complemented critical feedback with positive feedback. Positive reinforcement is better than negative. During Book Club, using humor and engaging in debates about the plot of a novel seemed to excite and empower individuals. Lastly, in Chorus people used song to express emotional language and theatrical body movements. While people with CDs have physical and linguistic limitations, they can still feel empowered in the right environment.

Clinicians should also be aware of how they recognize the presence of their patients. Medical professionals are not just treating a language disorder; they should also be assessing their patient's being-in-the-world and embodied experience of CDs. Communication and the body should not be seen as separate problems. Physical therapy should be attentive to the ways body movement enhances communication, such as through nonverbal gestures.

As Kathy Charmaz (1991) explained in her novel *Good Days, Bad Days*, chronic illnesses can dominate people's lives. Those with severe and debilitating diseases are enveloped by them, and CDs also dominate the lives of sufferers and call forth continual efforts at adaption. People may enjoy the taken-for-grated assumption that their bodies and minds will not interfere with the requirements of everyday life (Karp, 1996). However, covering is almost impossible in social interactions for those with CDs. Researching the lived experience of CDs is also challenging because illness narratives tend to rely on the expression of language. Unfortunately,

the powerful stories of those deeply stigmatized are silenced by the very nature of CDs. Speech pathologists, family members, and caretakers are the closest outlet to accessing these stories, and can even help us understand subjective experiences of CDs. Further research should target the lived experience of people with severe CDs using possible alternative methods of communication (e.g., nonverbal, ASL, etc.). People with disabilities, such as CDs, are rendered powerless, and the power relationships between able-bodied and disabled people marginalizes and excludes the disabled politically, socially, and economically (Young, 1990). More research that examines the landscapes of power and exclusion as it relates to people with CDs could find ways to promote sympathetic interlocutors, knowledge about CDs, and awareness of discrimination towards those with CDs.

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Appendix A: Interview Guide

Broad/Opening Questions
- How is your overall health currently?
- Any recent changes in your overall health?
- Any significant events that have happened or activities you've been doing?

Specific Questions About Disorder
- Tell me about your role as a parent/caregiver of someone with a communication disorder or a clinician/researcher of communication disorders and sciences?
    - Probe: Explain the disorder that person has or the typical disorder you work with.
- If a parent/caregiver, when did you start caring for someone with a communication disorder? If a clinician/researcher, how long have you been in this role and why did you choose this career path?
- Are you currently helping someone with/administering any kind of treatment or therapy?
- Do you engage in group activities that include people with communication disorders? (E.g., group therapy, group meetings, family therapy, online forums)

Impact on Life
- How has caring for/researching someone with this type of condition changed the way you live?
    - Probe: Specific changes to daily living?
- How has caring for/researching someone with this type of condition changed the way you think or feel about that person?
- Do others look at someone with a communication disorder differently? Do others look at you differently?
- Do you think there are stigmas associated with communication disorders in general?
    - Probe: Has that person or you personally experience stigmatization?
- What are some misconceptions about communication disorders?
    - Probe: What do you wish people knew about your loved one/client/participant?
- What do you fear most about the people you care for/treat?
- What have you seen that has helped people with communication disorders live their lives despite their condition?
- How have friends, family, religious practice, or your spiritual life helped you and the people you know with communication disorders?
- Is there anything else you would like to add?

Impact of Illness Narratives
- What types of resources have you used to gain more information about the condition your loved on/client/participants has? (E.g., personal stories, medical/biological texts, doctors and clinicians, etc.)
- How to do feel about research that focuses on narratives and stories instead of experiments and surveys in order to learn more about disorders?
- Any other comments about anything we've talked about